



# **JOURNAL OF HEALTHCARE, SCIENCE, AND THE HUMANITIES**

**SPECIAL ISSUE ON HIV/AIDS AND THE BLACK COMMUNITY**

National Center for Bioethics  
in Research and Health Care



*Looking Back to Move Forward*



TUSKEGEE

UNIVERSITY

---

# **Journal of Healthcare, Science and the Humanities**

**Published by the National Center for Bioethics in Research and Health Care located at Tuskegee University.  
The National Center publishes the Journal in friendship with the Smithsonian Institution.**

# The Journal of Healthcare, Science and the Humanities

## General Information

The *Journal of Healthcare, Science and the Humanities* is published by the National Center for Bioethics in Research and Health Care at Tuskegee University. The *Journal* is published in friendship with the Smithsonian Institution Office of Sponsored Projects. The *Journal* was first published in 2009 by the former Navy Medicine Institute for the Healthcare Humanities and Research Leadership. The *Journal* was transferred to the new publisher in 2012 as a private publication. The publisher today continues the mission of the *Journal* to benefit international academic and professional development regarding health, healthcare, the humanities, the sciences and social justice. ISSN (print): 2159-8880. ISSN (online): 2159-8819.

## Correspondence

Manuscripts are to be submitted to the Senior Associate Editor. Submission of a manuscript is considered to be a representation that is not copyrighted, previously published, or concurrently under consideration for publishing by any other entity in print or electronic form. Contact JHSH for specific information for author, templates, and new material. The preferred communication is through email at [dhodge@tuskegee.edu](mailto:dhodge@tuskegee.edu) or via voice at + 1 (334) 724-4554.

## Subscriptions

The *Journal of Healthcare, Science, and the Humanities* is a PubMed journal. Thus, access to our intellectual and research work is now global. Also, a pdf version of the journal is available at <https://www.tuskegee.edu/about-us/centers-of-excellence/bioethics-center>. Hard copies of the journal are available for purchase by emailing the Senior Associate Editor at [dhodge@tuskegee.edu](mailto:dhodge@tuskegee.edu), or contact the National Center for Bioethics in Research and Health Care at Tuskegee University: 1 (334) 724-4554.

## Copyright Information

As a private sector publication, authors retain copyright for their articles; but grant to the *Journal* an irrevocable, paid-up, worldwide license to sue for any purpose, reproduce, distribute, or modify their articles in their entirety or portions thereof. Articles prepared by employees of the U. S. Government as part of their official duties are not copyrighted and are in the public domain. The *Journal* retains the right to grant permission to third party non-usage to others. Etc. Third party usage must give credit to the *Journal* and to the author (s.). Opinions expressed in the *Journal* represent the opinions of the authors and do not reflect official policy of the institutions they may serve. Opinions in the *Journal* also do not reflect the opinions of the publishers or the institutions served by members of the Journal Editorial Board.



---

# Table of Contents

<b>Journal Editorial Board</b> .....	3
--------------------------------------	---

<b>From the Editor's Desk</b> .....	7
-------------------------------------	---

*Rueben C. Warren,*

*Director of the National Center for Bioethics in Research and Health Care*

## Special Commentaries:

### **The White House**

Forty Years of Questions and Answers: What Will It Take to End the  
HIV Epidemic.....

13

*Harold J. Philips*

### **Guest Editor**

Let's Get Serious: Reducing Health Disparities in HIV.....

17

*Vivian L. Carter*

## Literature Review

HIV and AIDS Inequity in the Black Community: Proximal Solutions  
to Distal Determinants.....

25

*Alicia L. Best, Anastasia Wynn, Chukwuemeka Emmanuel Ogbu, & Stefani Nixon*

## Articles

### **Science**

The Relation of Age on HIV-Positive women's Cluster of Differentiation 4,  
Antiretroviral Therapy, Papanicolaou test, Human Papillomavirus test  
and Visual Inspection with Acetic Acid.....

37

*Atiya Shahid, Ehsan Abdalla*

African American Women's Current Knowledge, Perceptions, and  
Willingness of PrEP use for HIV prevention in the South.....

51

*Jamie Troutman, Lucy Annang Ingram, Bambi Gaddist, Alyssa Robillard, Shan Qiao*

Conspiracy Beliefs About HIV/AIDS Among HIV-Positive African American  
Men and Women in Alabama's Black Belt: A Mixed-Method Analysis.....

73

*Andrew D. Zekeri*

Utilizing Policy and Electronic Health Record (EHR) System Modifications  
to Implement and Sustain Routine HIV Screening and Linkage-to-Care.....

84

*Alexis K Fields, Pamela Kirlew, Haroon Zafar, Zoraima Douglas,*

*Tenisha Gillett-Smith, Jessica E Yager*

## Table of Contents

Routine Opt-Out Screening is Key to Understanding and Identifying HIV/HCV Incidence.....	101
<i>Cordella Lyon</i>	
<b>Social</b>	
The (Contrasted) Ethics of Covid-19 and HIV: Will the Favor be Returned? .....	107
<i>Hope Campbell, Jacinda C. Abdul-Mutakabbir, David Augustin Hodge, Sr.</i>	
From Policy to Funding: A Case Study of Inequitable Funding Towards Chicago, Illinois' Black-led HIV/AIDS Service Providers .....	122
<i>Yaa Simpson</i>	
The Evolution of Dignity: An Intervention Model to Engage and Retain HIV-Positive Black Women in Care .....	134
<i>Ivy Turnbull, Deane Taylor, Alicia Beatty, June Trimble, Elizabeth Cabrera</i>	
HIV Testing and Associated Characteristics Among Black Cisgender and Transgender Women in the United States.....	149
<i>Jaleah D. Rutledge, Kaston Anderson-Carpenter, Jae Puckett</i>	
Leveraging Public and Private Funding to Expand “Opt-Out” HIV Screening Programs in Select Urban Academic and Rural Community Emergency Departments in South Carolina Discovered a High Rate of Human Immunodeficiency Virus (HIV) Infection in Black Patients .....	163
<i>Phillip Moschella, Smith Heavner, Susan Cordero Romero, Jess Knapp, Prerana Roth, and Alain H Litwin</i>	
We the People: A Black Strategy to End the HIV Epidemic in the United States of America .....	173
<i>Tenesha Lewis and Maximillian Boykin</i>	
Health Care Reform: Exploring Health-Related Quality of Life of HIV/AIDS Patients in Baltimore Post Implementation of the Affordable Care Act.....	193
<i>Francesca Weeks</i>	
Wisdom Matters: Honoring the Wisdom and Assessing the Health Literacy of Black Women Living with HIV .....	204
<i>Nathanaelle Ibeziako</i>	
The Increased Risk for HIV and Other Sexually Transmitted Infections Among Substance-Using and Depressed Women in the Legal System.....	225
<i>Johnson K., Pretz, A., Chu, W., West, C.I., Chang, M., Anand, A., Chapman, B.P., Goddard-Eckrich D., Hunt T., Wu, E., Gilbert, L., and El-Bassel N.</i>	
Health Communication, HIV/AIDS, and Black Women.....	251
<i>Gwendolyn West</i>	

---

## Table of Contents

### Theological/Spiritual

Influence of Spirituality, HIV Stigma and Education on HIV Knowledge in Rural African American Congregants in the Deep South: Additional Findings From Project FAITHH.....	259
<i>Shameka Cody, Raheem J. Paxton, Hannah Woodard, Pamela Payne-Foster</i>	

People, Pulpits and Non-Profits Outlining a Model for Collaboration Near the Origins of the HIV Epidemic.....	275
<i>Victoria Revelle, Ruth Gilliam Phillips</i>	


### Commentary

HIV, Stigma and Me: One Woman's Story .....	287
<i>Lynn Jones Benson</i>	

Author Requirements .....	297
---------------------------	-----



Prepared by Graphic Arts and Publishing Services  
at The Henry M. Jackson Foundation  
for the Advancement of Military Medicine, Inc.

The background of the entire page is a light gray abstract design. It features several overlapping spheres of varying sizes. The spheres have a textured surface, with some showing concentric circles and others showing a more irregular, organic pattern. Small, stylized leaves or petals are scattered around the spheres, some appearing to grow from them. The overall effect is a sense of depth and organic complexity.

# JOURNAL EDITORIAL BOARD



## **Executive Director**

Rueben C. Warren, DDS, MPH, DrPH, MDiv.

## **The Board of Governors**

Tuskegee University Council of Deans

## **Editor**

Rueben C. Warren, DDS, MPH, DrPH, MDiv.

## **Senior Associate Editor**

David Augustin Hodge, Sr., Ph.D, D.Min, MTS, M.Ed.

## **Assistant Senior Associate Editor**

A. Delores Alexander, PhD., MS.

---

## **Associate Editors**

Moni McIntyre, PhD  
Moral Theology  
Duquesne University

Brendan Ozawa-de Silva, PhD, MPhil, MTS  
Modern History, Philosophy,  
Theological Studies  
Emory University

Theirmo Thiam, PhD, MA  
Political Science, International Relations,  
Comparative Politics, Culture  
Tuskegee University

Andrew A. Zekeri, PhD  
Sociology  
Tuskegee University

---

## **Academic Review Committee Chair**

Darryl Scriven Ph.D.  
Dean of Arts & Sciences  
School of Arts & Sciences  
Clarkson University

Mill Etienne, MD  
Neurology  
Bon Secours Charity Health System  
New York Medical College

## **Academic Review Committee Members**

David Anderson, DDS, MDS, MA  
Oral Health, Ethics & Health Policy  
Pennsylvania Dental Association

Frank Franklin, PhD, JD, MPH  
Director, Division of Treatment & Prevention  
Services, Epidemiology Division, OHSU-PSU  
Public Health, Volunteers of America Oregon  
Portland, Oregon

Manju Bhat, M.V.Sc., Ph.D.  
Chair and Associate Professor of Physiology  
Department of Biological Sciences  
Winston-Salem State University

Sylvester Johnson, PhD  
Associate Professor of African American Studies  
& Religious Studies  
Department of Religion & African American Studies  
Northwestern University

David Baines, MD  
Family Medicine, American Indian and  
Alaska Native Health, Spirituality and Culture  
Anchorage Neighborhood Health Center  
University of Washington

Torhonda Lee, PhD, MCHES  
Associate Professor of Public Health  
Institute of Public Health  
Florida A&M University

Beverly A. Ebo, Ed.D., M.Ed.  
Public/Private School Liaison  
Orientation Instructor  
Tuskegee University

Adrienne R. Lotson, JD, MDiv  
Cultural Anthropologist

Frederick Luthardt, MA, MA  
Bioethics Research Ethics, Human Research  
Ethics, Human Research Protections  
John Hopkins University

(cont.)

# Journal Editorial Board

---

## Academic Review Committee Members *(cont.)*

George Nasinyama, BVM, MS, PhD  
Epidemiology, Food Safety, Ecosystem Health  
Makerec University

Michael Owen, PhD  
History, Education, Human Research Ethics,  
Research Integrity  
University of Ontario Institute of Technology

Paulette Reneau, PhD  
Assistant Professor of Genomics &  
Molecular Phylogenetics  
Department of Biology  
Florida A&M University

Mesia Steed, Ph.D.  
Associate Professor of Biology  
Department of Biological Sciences  
Winston-Salem State University

Tracy A. Thomas, PT, PhD  
Associate Professor  
Department of Physical Therapy  
Florida A&M University

Roland Thorpe, PhD  
Associate Professor of Health, Behavior, & Society  
Bloomberg School of Public Health &  
School of Medicine  
Johns Hopkins University

Tanganyika Wilder, PhD  
Assistant Professor of Cardiovascular Physiology  
Department of Biology  
Florida A&M University

Richard Wilkerson, PhD  
Entomology  
Smithsonian Institution



The background of the entire page is a light gray abstract design. It features several large, semi-transparent spheres of varying sizes. These spheres are covered in a pattern of small, circular indentations, resembling a textured surface like a virus or a planet. Interspersed among these spheres are numerous small, stylized leaves or petals, some of which are attached to thin stems. The overall effect is a complex, organic, and somewhat futuristic aesthetic.

## FROM THE EDITOR'S DESK



## Message from the Editor

**Rueben C. Warren, DDS, MPH, Dr. P.H. MDiv**

Professor of Bioethics & Director

The National Center for Bioethics in Research and Health Care

John A. Kenney Hall 44-107

Tuskegee University

Tuskegee, AL 36088

Tel: 334-7252314

Email: [rwarren@tuskegee.edu](mailto:rwarren@tuskegee.edu)

In late 2019-early 2020, Dr. Vivian Carter, Chairperson of the Department of Sociology and Psychology, Tuskegee University, approached me about co-hosting a conference on HIV/AIDS and the Black Community at Tuskegee University. As Director of the National Center for Bioethics in Research and Health Care (National Bioethics Center), I agreed. We invited a trans-disciplinary group of non-government agencies and organizations, community advocates, faith leaders, academicians, researchers, graduate and undergraduate students from historically Black colleges and universities (HBCUs), predominately-white institutions (PWIs), and people living with HIV/AIDS to the historic campus of Tuskegee University. They needed a trusted space and place to discuss the continuing rampage of HIV/AIDS and its disproportionate burden in the Black population. The infamous legacy of the United States Public Health Service Syphilis Study at Tuskegee made Tuskegee University and specifically the National Bioethics Center the optimal place to have this dialogue.

The conference extended beyond the traditional topics of biomedical and behavioral research advancements and challenges in eliminating HIV/AIDS in the U.S. To have the greatest impact in the Black community, the conference needed to address additional issues. Thus, the title reflects the depth and breadth of HIV/AIDS in the Black Community and considers the legacy of Tuskegee University in addressing matters of health and healthcare in the Black population. The agreed upon title was, *Lifting the Veil of HIV: Addressing the Implications of Medical Mistrust and Racism on Black Communities Impacted by HIV*. Consistent with Black History Month, February 27- 28, 2020 was selected for the conference. This conference also to commemorated National Black HIV/AIDS Awareness Day.

The conference was well attended and the presentations, deliberations, individual and group engagements were extraordinary. Rather than share the salient deliberations from the conference in a proceeding document, as is usually done, Gilead Science Inc. proposed publishing a Special Issue of HIV/AIDS and the Black Community in the *Journal of Healthcare, Science, and the Humanities* (JHSH). The JHSH is a peer review, PubMed journal, owned by the National Bioethics Center. This Special Issue addresses the plethora of challenges and opportunities, including public policy development, particularly related HIV/AIDS, and the Black Community.

In each edition of the JHSH, a summary of its contents is included in a section entitled, "From the Desk of the Editor." The section summarizes the content of each article published in the

## From the Editor's Desk

---

specific edition. However, the emphasis of this Special Issue is not only on the content of the scholarly works included, but also on the importance of ethical partnerships between institutions and individuals to impact public policy related to HIV/AIDS and the Black Community. The Special Issue is a continuation of the February 27-28 conference, and a bridge to advance public policy that will end the disproportionate burden of HIV/AIDS in the Black Community.

Harold J. Phillips MRP, Director White House Office of National AIDS Policy, provides an extraordinary Commentary entitled, *Forty Years of Questions and Answers – What Will It Take to End the HIV Epidemic*. The salient matters that he addresses set the tone the other materials included in this Issue. He stresses the importance of building trustworthy relationships between individuals within and outside of organizations, institutions, and agencies. For example, from the onset, Pema McGuinness, Director and Aquarius D. Gimmer, Associate Director, Corporate Policy and Alliances, Government Affairs Gilead Sciences, Inc., have been overwhelming in their support for this Special Issue. Along with the Tuskegee University team, they initially met bimonthly and more recently weekly, to discuss content and logistical matters related to the Special Issue. Their connection with the HIV/AIDS advocacy community is exemplary. The Tuskegee University team included, Dr. Vivian Cater, Chairperson of the Department of Sociology and Psychology and Guest Editor for this Special Issue, Dr. David A. Hodge, Senior Associate Editor for the *Journal of Healthcare, Science and the Humanities* and Associate Director of Education at the National Bioethics Center and Dr. Delores Alexander, Assistant Editor of the *Journal of Healthcare, Science and the Humanities* and Director of the Integrative Biosciences PhD Program, Dr. Darryl Scriven Dean, School of Arts and Sciences, Clarkson University, and Dr. Jasmine D. Ward, Assistant Professor, Texas Women University. Additionally, Dr. Beverley Ebo and Dr. Barry Williams assisted Dr. Hodge with logistical and editorial support. Dr. Davis Banks, served as computer software consultant in developing webinar support. Dr. Alicia Best, Assistant Professor, School of Public Health, University of South Florida, completed a literature review of HIV/AIDS and the Black Community.

Since 2012, the JHSH is published biannual editions in the Fall and the Spring, consistent with two important events: the Annual Commemoration of the 1997 Presidential Apology for the United States Public Health Service Syphilis Study at Tuskegee which includes, the Public Health Ethics Intensive Course, and the Public Health Ethics Forum co-sponsored with the Centers for Disease Control and Prevention. This Special Issue of HIV/AIDS and the Black Community required an additional series of tasks and special assignments. Dr. David Hodge provided the overall leadership for this Special Issue. He coordinated the Call for Papers, solicited and encouraged manuscript submissions from a broad array of potential authors. He also facilitated the peer review process between the manuscript submissions from the authors and Dr. Scriven, organized timelines and updates for the overall publication effort, and confirmed deadlines for completion and distribution of electronic and hard copies of the Special Issue. Dr. Scriven managed the peer review process by soliciting a broad array of peer reviewers and assuring that the reviews were completed and submitted in a timely manner. There were approximately 28 abstracts submitted resulting in 26 being approved for full manuscript submission. Twenty manuscripts were approved for publication after a rigorous review process.

The editorial staff makes every effort to assure the authors can publish their work. New, as well as more seasoned authors are encouraged to publish their work in the JHSH.

As you read the peer-reviewed article, commentaries, and other material in this Special Issue, three themes emerge, theology, science, and sociology. From my perspective, theology is the study of GOD, known by many names. At the National Center for Bioethics in Research and Health Care, we synergize the sacred and the secular to enhance the well-being of the individuals, groups, and communities within their physical and social environment. For example, for the last 5 years, the National Bioethics Center has implemented the Tuskegee University & Macon County Bridge Builders Program to support and promote the wealth and well-being of 50 Macon County High School students. The Lilly Endowment Inc. funds the Program. The program expanded last year to include middle school students and will eventually become a permanent part of the National Bioethics Center education and community engagement activities. Science also is the focus of several articles, while acknowledging the importance of various forms of science they also stress the limitation of science in eliminating HIV/AIDS in the Black community. Science simply means and strives "to know." However, when one knows better, they must do better. There is enough science to eliminate the health disparity between the Black population and the other racial and ethnic groups, related to the disproportionate suffering, sickness, and premature death from HIV/AIDS. One of the foci of JHSH, is science. We extend invitations to transdisciplinary scientists to publish their scholarship in the JHSH, to maximize what is known, to address the plethora of challenges and opportunities to improve individual and population health. The last theme, social, is foundational to address HIV/AIDS in the Black Community. This disease is grounded in social engagement and in my view, will be resolved by social engagement to assure the well-being of individuals, groups, and communities, regardless of demographic differences. I hope that this Special Issues will further advance what we know and what we do to create and advance public policy related to HIV/AIDS in the Black Community. Please enjoy this Special Issue.

Regards,

Rueben C. Warren



The background of the entire page is a light gray abstract design. It features several large, semi-transparent spheres of varying sizes. These spheres are covered in a pattern of small, circular indentations, resembling a textured surface like a virus or a planet. Interspersed among these spheres are numerous small, stylized leaves or petals, some of which are attached to thin stems. The overall effect is a complex, organic, and futuristic aesthetic.

## SPECIAL COMMENTARIES





## Special Commentary: The White House Forty Years of Questions and Answers: What Will It Take to End the HIV Epidemic

**Harold J. Phillips, MRP**

Director, White House Office of National AIDS Policy

“Of all the forms of inequality, injustice in health care is the most shocking and inhumane”  
- Martin Luther King, Jr.

“There are years that ask questions and years that answer”  
- Zora Neale Hurston

The National Center of Bioethics in Research and Health Care at Tuskegee University has developed this Special Edition of the *J* and asked me to include a commentary. Tuskegee is known as the place where extraordinary intellectual thought and leadership, is nurtured and brought to light. It is also known as the place where the struggle for righteousness, equality and justice has taken root and grown across the nation and the world. The Special Edition adds to this extraordinary legacy. The focus of the Special Edition are the factors that drive the disproportionate and adverse impact of HIV on Black communities and the public policy recommendations to eliminate this disparity.

As Director of the White House Office of National AIDS Policy, I am spearheading the development of a new National HIV AIDS Strategy that acknowledges racism as a public health threat and uses data to illustrate the adverse impact on the Black community. This new strategy acknowledges the ability to end the HIV epidemic by the year 2030 using the scientific tools, and innovative work to engage the community and implement services. A key to our nation's success will be our ability to address the inequities and systemic factors that place members of the Black community at risk for HIV infection. These include the poverty, access to quality health care, access to stable housing, racism, homophobia, transphobia, medical mistrust and medical misinformation, incarceration, stigma and discrimination including stigma and discrimination against those who misuse drugs. All of these intersecting factors impact the health and resiliency of our community as illustrated by the data.

On June 5, 2021, the world marked 40 years since the first five cases of what later became known as AIDS were officially reported. As part of this commemoration, the world honored the more than 32 million people globally including the more than 700,000 individuals in the United States who have died from AIDS-related illness since 1981. There are over 38 million people worldwide, including approximately 1.2 million Americans living with HIV.

The nation's annual new HIV infections have declined from their peak in the mid-1980s, and people with HIV in care and treatment are living longer, healthier lives. In 2019, the estimated number of new HIV infections was 34,800. Despite this progress, disparities

## Special Commentary

---

still exist. Black, Latino and White gay and bisexual men and Black heterosexual women bore the greatest burden of new HIV infections between 2015 and 2019. Black and Latino gay and bisexual men had the highest burden, while the rate of new HIV infections among Black women was 13 times that of white women from 2015-2019. It is estimated in 2019 that more than half of the new HIV infections occurred in the South.

In 2019 African-Americans represented 13% of the US population, but 40% of people with HIV and 43% of the HIV-related deaths.<sup>i</sup>

President Biden called for accelerated efforts to end the HIV epidemic in the United States by the year 2030. The Ending the HIV Epidemic in the United States Initiative (EHE) leverages the scientific advances in HIV prevention, diagnosis, treatment and out-break response. Additional federal resources and community engagement are combining to help reduce the number of new HIV infections by 75% by 2025, and by at least 90% by the year 2030. President Biden's fiscal year 2022 budget requested \$670 million for this effort reflecting his commitment to address this issue.

Nearly 11 months into the EHE Initiative, COVID-19 began its disruptive and devastating march through communities of color. Viruses attack vulnerabilities. They do not discriminate but they do take advantage of the outputs produced by years of structural and systemic racism. Income inequality, lack of access to quality health care, food insecurity, unstable housing and lack of access to transportation, depression, anxiety and discrimination intersect creating a nexus for infectious diseases to flourish. In this way, the impact of infectious diseases such as COVID-19, HIV and even chronic diseases among certain communities is not equal. The numbers of African-Americans living with chronic diseases such as diabetes, obesity, hypertension, cardiovascular diseases, those with jobs where telework or social distancing was not an option and those experiencing incarceration resulted in large rates of COVID-19 infection, hospitalization and death within the Black community. It is these conditions rooted in both slavery and emancipation that have created a system of medical apartheid that produces the health inequities we as African-Americans experience today. As I write this in mid-October over 700,000 people have died in the United States. As of October 6, 2021, around 15 percent of COVID-19 deaths in the U.S. have been among non-Hispanic Black or African Americans.

Last year, trapped at home due to the COVID pandemic, we saw the murders of George Floyd and Breanna Taylor on television. We were socially distant, but angry, sad and grieving, but willing to stand up and demand the promise of America – liberty and justice for All. Yet, to build a better nation, we must do the work to implement policy and systemic changes that will enable African-Americans to achieve their full potential for health and well-being. We must address the generational injustices that perpetuate racial health inequities. Our march toward equality must include improving access to both health care and health information.<sup>ii</sup>

---

<sup>i</sup><https://www.kff.org/hiv/aids/fact-sheet/the-hiv-aids-epidemic-in-the-united-states-the-basics/>

<sup>ii</sup><https://www.statista.com/statistics/1122369/covid-deaths-distribution-by-race-us/>

Increasing access to comprehensive health care through expansion of Medicaid programs, counseling about private insurance through the Affordable Care Act and the American Rescue Plan, and implementing programs to support maintaining insurance such as co-pay and premium assistance are important steps forward. These changes to health policy and programs will help address the HIV disparities by increasing access to HIV testing, prevention and care.

The new National HIV AIDS Strategy calls for innovative models and culturally appropriate approaches that expand access to and availability of HIV testing in various settings such as routine opt-out testing in clinical settings, testing in retail pharmacies, self-testing, testing in correctional facilities, mobile testing, and self-testing offered via social networks are required. Early detection coupled with prompt linkage to care and immediate initiation of treatment is also critical and can lead to improved individual and community health outcomes.

President Biden's Administration continues to support strengthening public health and improving access to health care services in the African-American community. Many of the investments have been historic. We must also work to improve health insurance literacy in the African-American community. Health insurance literacy is defined as "a person's ability to seek, obtain, and understand health insurance plans, and once enrolled use their insurance to seek appropriate health care services". Health insurance literacy is often considered a subset of health literacy. With expanded access to health care, more health education to help the community understand the financial and health implications of insurance plans is needed to help close the health disparities gaps. Health insurance literacy is not taught in school, so we must expand access to this kind of information in places where we work, play and worship. We must also engage the community to ensure appropriate messages are delivered from trusted sources.

At all levels, further effort is needed to construct organizations, institutions, systems, and a workforce that embrace and implement the concepts and principles of health literacy. Efforts to create more health-literate public and private health systems at the federal, state, tribal, territorial, and local levels will help patients understand the health care system and the importance of HIV prevention, care, and treatment, and the benefits of viral suppression. Patient education is a necessary aspect of people-centered care, but it requires systems and providers to end the use of jargon, take the time to educate and explain in plain language, alter websites and brochures, proactively counter medical misinformation, use social media differently, and consider other culturally appropriate ways to deliver key information. Understanding HIV, the importance of treatment, the various HIV prevention options and the risks of transmission to others can also lead to less stigma and shame, which in turn can lead to increased interactions with the health system and positive health outcomes. Efforts to increase health literacy can also aid in addressing the mistrust of the medical system prevalent among many minority groups because of the historical systemic racism in many health care settings.

Another important tool to help address health disparities includes building a diverse healthcare workforce. Diversity, inclusion, and community representation are key to achieving creative problem-solving perspectives, and to ensuring the comprehensive cultural spectrum

## Special Commentary

---

necessary to understand epidemic dynamics. The development of a diverse health workforce, research that effectively reduces and eliminates health disparities in HIV will require the participation of all sectors of the community. Inclusion of all sectors is fundamental to better understand current needs and develop effective actions to mitigate existing gaps in HIV research and service delivery.

The articles in this special issue will provide additional insights into the issues I have mentioned as part of this commentary. Their research and scholarship contribute to a deeper understanding of how race, gender, stigma, discrimination, and homophobia and the social determinants of health influence HIV health outcomes for the African-American community. The authors shine a light on these realities by raising questions and in some cases providing answers. Nearly 400 years of medical apartheid and the resulting health disparities must be addressed to achieve justice for all. Forty years into the HIV epidemic, we have the necessary tools and answers to the question of how to end the HIV epidemic. Two years into the COVID-19 pandemic and we see what happens when equity is not in the center of our response. The health history of African-Americans includes stories of resilience. Let's use that resilience to create a more equitable health care system free from racism, stigma and discrimination. Let this be the year we answer the call to end the HIV epidemic and we continue to march on until the battle for health equity and justice is won.

## Special Commentary: Guest Editor

### Let's Get Serious: Reducing Health Disparities in HIV

**Vivian L. Carter, PhD, Department Head,**  
Department of Psychology and Sociology  
Tuskegee University  
vcarter@tuskegee.edu  
Kenney Hall, Rm. 44-302  
Phone: 334-727-8737

The general themes of the articles presented in the special edition of the Journal of Health Care, Science and Humanities centers around two major bioethical principles, Autonomy and Justice.

The bioethical principle of “Autonomy” rests on the notion that there must be a respect for the will of the individual. Individuals have the right to self-determination and that must be respected. This principle is often referred to as the principle of human dignity. Respecting autonomy is meant to be an empowerment to the individual with the understanding that one is competent to make such a decision. Competency is the first step in informed consent. Thus, in the articles presented in this special edition the subject of competency is addressed as a major barrier to detection and adherence to treatment health protocols within the African American community. Whether we are addressing the social stigmas attached to HIV/AIDs or the lack of knowledge regarding the terminology surrounding the diagnosis and treatment modalities or just the blatant misinformation, the competency of the populations must be clearly determined and addressed in a manner that provides the individual and not the clinician or researchers interpretation. This type of clarification involves a targeted community specific approach that is not obtained from merely reviewing data from aggregated reporting sources. A community based participatory approach is a necessity to achieving any levels of competency within those communities considered hard to reach and disadvantaged.

It is often stated, “once people know better they do better.” A partnership between community, health care researchers and providers can produce result in better health outcomes with the community. A Community Based Participatory Research (CBPR) model is designed to engage the community as a partner in the research process from the inception. CBPR weaves into the study the language and social nuances of the target population and garners the approval of the community. The core value of CBPR is reciprocity, which stipulates that community members and academic partners design, implement, analyze, and interpret results collaboratively—to the mutual benefit of both partners (*Figure 3*). Inherent to CBPR is the philosophy that states “if the problem is in the community, then so are the solutions” (Foad, Wynn, Martin, and Partridge 2010). In CBPR the community's voice and expertise are essential. Undergirded by cornerstones such as trust and communication, CBPR has been used to examine HIV disparities among various populations. CBPR is a useful philosophical framework for assessing HIV screening knowledge and behaviors, promoting HIV screening, developing

culturally relevant interventions and instrumentation, and discovering new areas for scientific inquiry, all of which can contribute to reducing HIV disparities within the African American community and other vulnerable populations (Berkley-Patton , et al. 2010; Light et al. 2014).

The second major component relates to the principle of “Justice”. As a bioethical principle, the issue of justice is interpreted as the fair, equitable, and appropriate treatment of persons. This definition of justice refers to what is known as ‘distributive justice”, which refers to the fair and equitable distribution of health resources as determined by the justified norms that structure the terms of social cooperation (Fleishacker, S 2005). While much funding and focus on HIV AIDS has increased since the 1990’s and more health clinics and agencies have added HIV/AIDS treatment to their list of services provided, we still see the same health inequities along the color line.

At the heart of the HIV/AIDS health crisis is the need for attention to the disparities within the health care system itself and the disproportionate number of African Americans affected by the disease. Both issues are paramount to ever achieving any success in eradicating HIV AIDS and ending the disproportionate impact it has on the African American Community. The 1990s witnessed the passage of one of the most progressive legislative acts to actively support and fund HIV/AIDS, the Comprehensive AIDS Resources Emergency Act (currently known as Health Resources and Services Administration (HRSA) Ryan White HIV/ AIDS Program (RWHAP)). The legislation outlines categories (A-D, F) to improve HIV/ AIDS health outcomes along the five stages of the HIV/AIDS care continuum. The HIV/ AIDS care continuum includes HIV diagnosis, linkage to care, retention in care, antiretroviral use, and viral suppression.



Figure 1.

Along the continuum are specific allocations of funding which is where the disproportionate allocations of funds first arises. Part A of the act distributes funding to metropolitan municipalities with high incidences of HIV/AIDS while Part B allocates funding to states and territories. While Part C requires Planning Commissions and Planning Boards to prioritize for allowable services and allocations. In addition, HHS also collaborates with federal agencies such as Centers for Disease Control (CDC), Health Resource and Services

Administration (HRSA), National Institutes of Health (NIH), and the Secretary of Health, Substance Abuse and Mental Health Services Administration (SAMHSA). Yet we still see persistence in the racial disparities in treatment, access, and health outcomes. According to the CDC, there were 36,801 persons diagnosed with HIV/AIDS in 2019. Of those persons, the majority were of African American/Black ancestry (42%). Black men have the highest HIV infection rate among men in general, and black men who are gay and bi-sexual account the largest population of men diagnosed with HIV (37%). In addition, black women have the highest rates among females diagnosed with HIV/AIDS (55%).

Table 1.

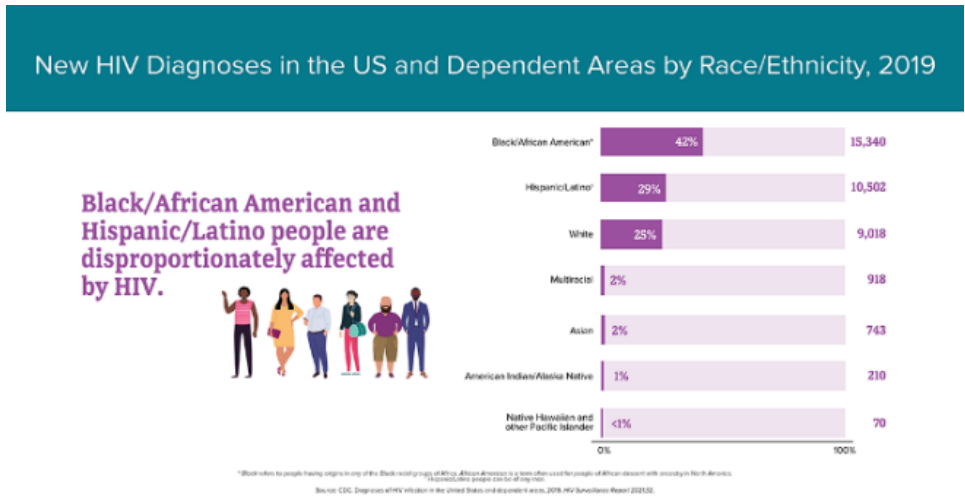
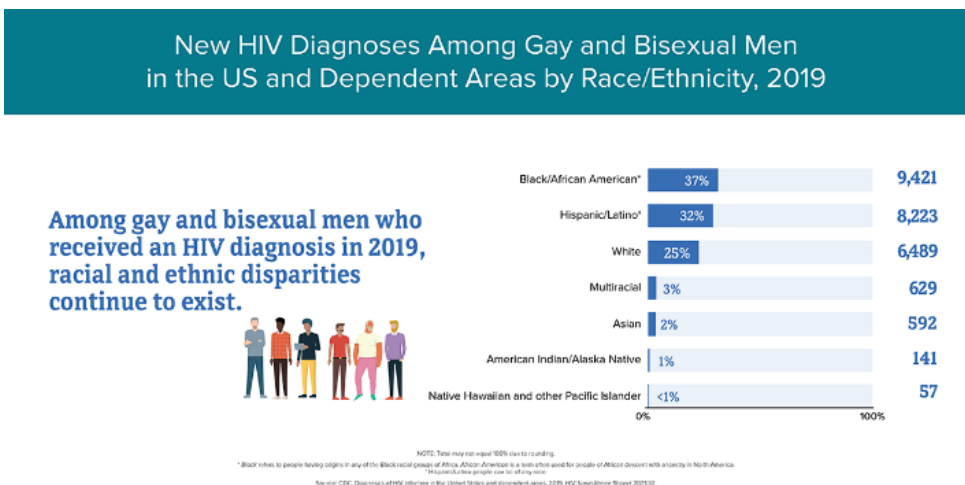


Table 2.



I provide this background to illustrate the discrepancy between the amount of funding opportunities available and actual distribution focus. The funds are being disproportionately distributed because the structural entities by which they are administered continue to bypass the very communities that are in need of the most assistance. Let us take, for instance, the amount of funding afforded Historically Black Institutions and Colleges to address HIV/AIDS in their communities. We know that 90% of all HBCUs are located in predominantly minority communities, yet the finding for research and program development allocated for such studies is often provided to Predominantly White Institutions (PWIs). Infrastructure grants are graciously bestowed on PWIs, while HBCUs are vigorously scrutinized, and questioned before even given consideration to address the health care needs of their communities. Despite the staggering over-representation of the African American community in the number of persons diagnosed and at risk of HIV/AIDs, their communities do not experience the same investment and support as their white counterparts. When funding is made available, it is usually in conjunction with the supervision of a PWI. I generally describe this as healthcare sharecropping; as PWIs reap all the benefits from the labor of HBCUs, while the HBCUs continue to labor without the benefit of the maximum reward. HBCU researchers and students have long been exploited and overlooked for the contributions they continue to make despite the glaring lack of funding and professional recognition they so justly deserve for the scholarly and civic sacrifices they make for the good of their communities.

A more serious and direct approach would be to invest in HBCUs at the same level as PWIs with purposive programs to strategically support and fund collaborations on an equal basis, recognizing the strength of the HBCU and the communities they serve as vital to the successful health outcome in those communities with the greatest need.



### References

- M. Fouad, T. Wynn, M. Martin, E. Partridge, Patient navigation pilot project: results from the Community Health Advisors in Action Program (CHAAP), *Ethn Dis* 20(2) (2010) 155-61.
- Berkley-Patton, J., Bowe-Thompson, C., Bradley-Ewing, A., Hawes, S., Moore, E., Williams, E., et al. (2010). Taking it to the pews: A CBPR-guided HIV awareness and screening project with black churches. *AIDS Education and Prevention*, 22(3), 218–237.
- Lightfoot, A.F., Taggart, T., Woods-Jaeger, B.A. *et al.* Where is the Faith? Using a CBPR Approach to Propose Adaptations to an Evidence-Based HIV Prevention Intervention for Adolescents in African American Faith Settings. *J Relig Health* 53, 1223–1235 (2014). <https://doi.org/10.1007/s10943-014-9846-y>
- CDC. Diagnoses of HIV infection in the United States and dependent areas, 2019. *HIV Surveillance Report* 2021;32.
- Varkey B: Principles of Clinical Ethics and Their Application to Practice. *Med Princ Pract* 2021;30:17-28. doi: 10.1159/000509119
- Fleishacker S. A short history of distributive justice. Cambridge (MA): Harvard University Press; 2005



The background of the entire page is a complex, layered composition. It features several large, semi-transparent spheres of varying sizes. These spheres are covered in a dense pattern of small, circular, textured protrusions, resembling a microscopic view of a cell or a complex molecular structure. Interspersed among these spheres are numerous small, stylized leaves or petals, some of which are attached to thin, curved stems. The overall color palette is muted, consisting of various shades of gray, beige, and a deep, dark brown that forms a horizontal band across the upper middle of the page. The lighting is soft and diffused, creating a sense of depth and texture throughout the composition.

# LITERATURE REVIEW



# Improve the Quality of Life Related to HIV and the Black Community

## HIV and AIDS Inequity in the Black Community: Proximal Solutions to Distal Determinants

Alicia L. Best, Anastasia Wynn, Chukwuemeka Emmanuel Ogbu, & Stefani Nixon

### Abstract

This literature review describes the historical impact of HIV and AIDS among Black populations in United States (US), as well as the misalignment between root causes of HIV-related inequities and HIV prevention efforts. Specifically, we describe how distal factors (including structural racism) contribute to the disproportionate rates of HIV infection within Black communities. Further, we highlight consequences of focusing primarily on proximal determinants of acquiring HIV. Finally, we share some brief conclusions and recommendations to help move towards eliminating HIV and AIDS inequities among Black populations.

*Keywords:* HIV/AIDS disparities/inequities; Black/African American communities; social determinants of health; distal and proximal determinants, structural racism

### Introduction

The United States (US) Census defines Black/African American populations as persons “having origin in any of the Black racial groups of Africa” (U.S. Census Bureau, 2021). While individuals racialized as Black/African American (hereafter, Black) represent approximately 13% of the total US population, Black populations account for the majority of human immunodeficiency virus (HIV) diagnoses and acquired immunodeficiency syndrome (AIDS) deaths in the US, annually (Centers for Disease Control and Prevention [CDC], 2019). Importantly, the disproportionate incidence of HIV among Black populations cannot be explained by individual-level factors such as genetics/ancestry or differences in sexual behavior (Millett, Flores, Peterson, & Bakeman, 2007; Buot, et al., 2014). In fact, literature indicates that HIV and AIDS inequities in the US are primarily driven by social rather than biomedical or behavioral factors (Zeglin & Stein, 2015).

The overarching goal of this literature review is to describe the historical impact of HIV and AIDS among Black populations in the US, along with the misalignment between root causes of HIV-related inequities and HIV prevention efforts. We describe how systemic factors, including structural racism, contribute to disproportionate rates of HIV infection within Black communities. Further, we describe how most evidence-based interventions focus primarily on addressing proximal determinants of HIV-related inequities. Finally, we share some brief conclusions and recommendations to help move towards eliminating HIV and AIDS inequities among Black populations across the US.

### Evolution of HIV Inequity in the Black Community

AIDS was first recognized in 1981 and HIV was identified as the cause of AIDS in 1983 (Melhuish & Lewthwaite, 2018; Shampo & Kyle, 2002). In the US, non-Hispanic White men represented the primary population initially affected by HIV and AIDS in the early 1980s, and male-to male sex was (and still is) the highest mode of HIV transmission (CDC, 2001). Specifically, from 1981-1987, non-Hispanic White populations accounted for 59.7% of persons living with AIDS, while Black populations accounted for 25.5% (CDC, 2001). However, in 1992, AIDS-related mortality was recorded as the seventh cause of excess deaths among Black populations in the US (Satcher et al., 2005). As time progressed, the percentage of non-Hispanic White populations living with AIDS had decreased to 34%, while this percentage increased to 44.9% among Blacks populations (CDC, 2001). Notably, highly-active antiretroviral therapy was introduced as a treatment for HIV in the mid-1990s and AIDS rates for White populations began to decline, while rates in Black populations increased – a shift that underscores inequities in access to health care and allocation of HIV treatment within Black communities (Gebo et al., 2005).

#### *HIV-Related Outcomes among Black Populations*

When comparing Black and White US populations, respectively, across HIV incidence, prevalence, and AIDS-related mortality, Black Americans experience stark disparities in all categories, including HIV incidence (45.0 vs 5.3 per 100,000), HIV prevalence (1,027.5 vs 153.9 per 100,000), and AIDS-related mortality (16.1 vs 2.5 per 100,000) (CDC, 2019). Among Black people in the US, populations currently most affected by HIV include gay, bisexual, and other men who have sex with men (MSM) and Black women (Tillerson, 2008; CDC, 2019). From 2015 through 2019, Black MSM accounted for more than 36% of new HIV infections diagnosed annually (CDC, 2019). Furthermore, Black MSM have lower rates of being retained in HIV medical care and achieving viral suppression in comparison to other racial/ethnic MSM populations (CDC, 2019), further highlighting disparities along the HIV continuum for Black MSM. In the US, Black women and adolescents make up only 13% of the female population, while accounting for up to 55% of new HIV infections diagnosed between 2015-2019 (CDC, 2019). On the other hand, non-Hispanic White women and adolescents make up 62% of the female population in the US, while only accounting for 22% of new HIV infections (CDC, 2019). Black women and adolescents diagnosed with HIV also die at disproportionately higher rates than their White counterparts (11.6 vs 0.8 per 100,000, respectively) (CDC, 2019). The evolution of HIV as a health issue primarily impacting Black populations mirrors the trajectory of most health inequities in the US and globally – that is, those who are most socioeconomically disadvantaged have disproportionate rates of negative health outcomes.

#### *Distal Determinants of HIV and AIDS Inequities*

The social determinants of health (SDOH) framework posits that “environments in which people are born, live, learn, work, play, worship, and age” significantly impact their health outcomes (US Department of Health and Human Services [DHHS], 2010). As such, social, political, and economic factors greatly influence HIV-related inequities among Black

populations (Braveman, 2014). Another important public health framework, the social ecological model (SEM), uses a systems perspective to help organize determinants of health along a continuum from proximal to distal determinants (Baral, Logie, Grosso, Wirtz, & Beyrer, 2013). Distal determinants can be described as structural factors such as economics, policy, and community infrastructure, which serve as fundamental or root causes of health. Proximal determinants are often described as the most direct (i.e., easily observable) causes of a particular health outcome (Baral et al., 2013). In the context of HIV, proximal determinants may be individual-level factors such as genetics, culture, and sexual behaviors (Baral et al., 2013).

Research suggests that individual behavior, such as condom use and number of sexual partners, does not adequately explain differences in rates of HIV infection (Hallfors, Iritani, Miller, & Bauer, 2007). There is increasing evidence that SDOH play a much larger role, yet surveillance systems do not routinely collect data on many of these distal determinant (Aral, Adimora, & Fenton, 2008; Dean & Fenton, 2010). For example, education and housing are strongly associated with HIV incidence, both of which are inextricably tied to poverty (Zeglin & Stein, 2015). Poverty affects where individuals live, housing quality and stability, access to and quality healthcare, and other important social conditions (Adimora, Schoenbach, & Floris-Moore, 2009). In turn, poverty is at the root of HIV and AIDS inequities (Adimora et al., 2009). One fourth of all those infected with HIV in the US pass through the criminal justice system (Kraut-Becher et al., 2008). As such, disproportionate rates of incarceration also influence HIV-related inequity among Black populations who account for 47% of the prison population (Kraut-Becher et al., 2008). Additionally, high rates of incarceration among Black men reduces the male-to-female ratio in many Black communities, impacting risk for HIV infection (Kraut-Becher et al., 2008).

Structural racism is an important social determinant that undergirds racial health inequity in general, and HIV-related inequities in particular. Structural racism operates in the US as the complex interaction of macro-level systems, policies, and institutional practices resulting in the unfair advantage of non-Hispanic White populations and the simultaneous disadvantage Black populations (Powell, 2007). Structural racism, like the SEM, is best understood from a systems perspective which focuses on relationships among multiple intersecting processes rather than singular linear causes (Powell, 2007). Structural racism impacts housing, educational and employment opportunities, access to health care, safety, and social networks, which all influence risk for HIV infection (Aral et al., 2008; Zeglin & Stein, 2015). Structural racism is an important, if not the most important, distal determinant of HIV-related inequities. For example, neighborhood segregation, which is rooted in structural racism (e.g., Redlining), helps facilitate unfair policing practices within Black communities and disproportionate incarceration rates, in turn, increasing risk for acquiring HIV (Kraut-Becher et al., 2008).

### *Proximal Solutions to Distal Determinants of HIV-Related Inequity*

Despite evidence that SDOH (including structural racism) are at the root of HIV-related inequities (Dean & Fenton, 2010), most interventions are not focused on

## Literature Review

---

addressing these distal determinants (Crepaz et al., 2007; Rotheram-Borus, Swendeman, & Chovnick, 2009; Adimora & Auerbach, 2010; Sipe et al., 2017; Jeffries & Henny, 2019; Williams, Lawrence, & Davis, 2019). Most evidence-based HIV interventions developed and implemented among Black populations focus on proximal determinants including knowledge, awareness, attitudes, sexual behavior, and substance abuse (Jemmott, Jemmott, & Fong, 1992; Diallo et al., 2010; Kogan et al., 2012; Zellner et al., 2016; Prado, Lightfoot, & Brown, 2013). For example, the *Color It Real* program is a culturally-tailored intervention designed to decrease risky sexual behavior, substance abuse, and perceived stress among African American heterosexual men and women, aged 18–24 (Zellner et al., 2016). While some interventions address factors at the family and community levels (e.g., *Strong African American Families*), strategies focus mainly on enhancing HIV knowledge and modifying related behaviors (Prado et al., 2013).

### Recommendations to Advance HIV-Related Inequity Research and Practice

Given that HIV-related inequities are rooted in SDOH, failure to address these distal determinants violates principles of public health ethics such as social justice and beneficence, as well as negatively shape public perceptions about populations most affected by HIV (e.g., perpetuating stereotypes). Furthermore, ignoring SDOH in HIV prevention efforts wastes valuable resources by developing and implementing interventions that are ineffective at reducing HIV-related inequities. The following sections provide recommendations to enhance public health efforts to eliminate HIV-related inequities by addressing structural racism and other SDOH.

#### *Engage and Empower Black Communities in HIV/AIDS Research and Practice*

It is essential that power imbalance is addressed at all levels, and within all phases, of HIV prevention research and practice. Not only is it important to engage Black communities in HIV prevention efforts, but it is equally important that Black scholars are centered in HIV inequity research (Best, Fletcher, Kadono, & Warren, 2021). As many Black scholars experience marginalization in ways that mirror the communities most impacted by HIV, these perspectives are invaluable for understanding and appropriately addressing HIV inequities. The CDC provides funding to support Black and Hispanic early career investigators to conduct HIV epidemiologic and prevention research aimed at reducing racial/ethnic inequity in the US (Prado et al., 2013). These and other efforts are necessary to address structural racism within the research process, and to enhance HIV inequity research itself.

#### *Reframe HIV and AIDS Inequity Language*

Over three decades ago, the US DHHS noted that racial/ethnic minority populations in the US “have not benefited fully or equitably” from systems responsible for ensuing health (US DHHS, 1985). As such, HIV-related inequities are unnecessary, avoidable, and unjust (Braveman, 2014); and HIV prevention efforts that do not explicitly address SDOH only serve to perpetuate these inequities. For example, race is commonly listed as a risk factor for HIV-related and other health inequities (Crear-Perry, Maybank, Keeys, Mitchell, & Godbolt,



2020). Framing race, rather than racism, as a risk factor for acquiring or transmitting HIV is problematic and functions to further stigmatize already marginalized populations (Crooks, Donenberg, & Matthews, 2021). Similarly, framing HIV-related inequities based on proximal risk factors such as sexual behavior (e.g., men who have sex with men [MSM]) further stigmatizes and dehumanizes priority populations, which is especially relevant for populations most affected by HIV (Crooks et al., 2021; Fletcher, Jiang, & Best, 2021).

### *Develop and Implement Multi-Level Interventions to Address HIV and AIDS Inequity*

Inaccurate framing of HIV and AIDS inequities can also contribute to development and implementation of ineffective public health interventions – that is, most interventions to date have largely focused on individual-level factors. Thomas and colleagues (2011) propose a fourth generation of health inequity research that is grounded in critical race praxis and utilizes multi-level, structural interventions to address racism and other SDOH. HIV prevention researchers and practitioners should integrate biomedical, behavioral, and social/structural factors in their approaches to effectively reduce and eliminate HIV-related inequities. Currently, there are limited strategies that address SDOH, especially structural racism. The Expanded Syringe Access Program (ESAP) is one example of a multi-level intervention which provides health education, referral to community resources, and it permits pharmacy syringe sales without a prescription within inner-city communities in Harlem, NY (Fuller et al., 2007). This program leverages existing resources and builds community capacity through interdisciplinary partnerships with organizations that explicitly address relevant social and structural determinants (e.g., drug treatment, housing, and job placement). Existing evidence-based interventions could be enhanced by collecting/utilizing data and incorporating strategies focused specifically on SDOH and structural racism to adequately address a wider range of HIV-related risk factors (Carter & Jeffries, 2019).

## Conclusion

This literature review highlights the misalignment between root causes of HIV and AIDS inequities and public health efforts to address these inequities in the Black community. In March 2021, the National Institutes of Health (NIH) launched the UNITE initiative “to address structural racism and promote racial equity and inclusion at NIH and within the larger biomedical research enterprise” (NIH, 2021). One of five primary objectives of UNITE involves addressing racial health inequities in the US through enhanced support of health equity research (NIH, 2021). To meet this objective, SDOH and structural racism must be at the forefront of efforts to address HIV-related and other health inequities which disproportionately impact Black communities. This involves meaningful engagement and empowerment of Black community members and scholars; reframing stigmatizing language used to describe HIV and AIDS inequities; and implementing HIV-prevention interventions that comprehensively address multiple socio-ecological levels to enhance effectiveness.

## References

- Adimora, A. A., & Auerbach, J. D. (2010). Structural interventions for HIV prevention in the United States. *Journal of acquired immune deficiency syndromes (1999)*, 55(0 2), S132.
- Adimora, A. A., Schoenbach, V. J., & Floris-Moore, M. A. (2009). Ending the epidemic of heterosexual HIV transmission among African Americans. *American journal of preventive medicine*, 37(5), 468-471.
- Aral, S. O., Adimora, A. A., & Fenton, K. A. (2008). Understanding and responding to disparities in HIV and other sexually transmitted infections in African Americans. *The Lancet*, 372(9635), 337-340.
- Baral, S., Logie, C. H., Grosso, A., Wirtz, A. L., & Beyrer, C. (2013). Modified social ecological model: a tool to guide the assessment of the risks and risk contexts of HIV epidemics. *BMC public health*, 13(1), 1-8.
- Best, A. L., Fletcher, F. E., Kadono, M., & Warren, R. C. (2021). Institutional Distrust among African Americans and Building Trustworthiness in the COVID-19 Response: Implications for Ethical Public Health Practice. *Journal of Health Care for the Poor and Underserved*, 32(1), 90-98. <https://www.muse.jhu.edu/article/783096>
- Braveman, P. (2014). What are health disparities and health equity? We need to be clear. *Public health reports*, 129(1\_suppl2), 5-8.
- Buot, M.-L. G., Docena, J. P., Ratemo, B. K., Bittner, M. J., Burlew, J. T., Nuritdinov, A. R., & Robbins, J. R. (2014). Beyond Race and Place: Distal Sociological Determinants of HIV Disparities. *PLOS ONE*, 9(4), e91711. <https://doi.org/10.1371/journal.pone.0091711>
- Carter, J. W., & Flores, S. A. (2019). Improving the HIV prevention landscape to reduce disparities for Black MSM in the South. *AIDS and Behavior*, 23(3), 331-339.
- Centers for Disease Control and Prevention (CDC) (2001). HIV and AIDS--United States, 1981-2000. *MMWR. Morbidity and mortality weekly report*, 50(21), 430-434
- Centers for Disease Control and Prevention. *HIV Surveillance Report, 2019*; vol.32. <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Published May 2021. Accessed [November 6, 2021].
- Crear-Perry, J., Maybank, A., Keeys, M., Mitchell, N., & Godbolt, D. (2020). Moving towards anti-racist praxis in medicine. *The Lancet*, 396(10249), 451-453.

- Crepaz, N., Horn, A. K., Rama, S. M., Griffin, T., Deluca, J. B., Mullins, M. M., ... & HIV/AIDS Prevention Research Synthesis Team. (2007). The efficacy of behavioral interventions in reducing HIV risk sex behaviors and incident sexually transmitted disease in black and Hispanic sexually transmitted disease clinic patients in the United States: a meta-analytic review. *Sexually transmitted diseases*, 34(6), 319-332.
- Crooks, N., Donenberg, G., & Matthews, A. (2021). Ethics of research at the intersection of COVID-19 and black lives matter: a call to action. *Journal of Medical Ethics*, 47(4), 205-207.
- Dean, H. D., & Fenton, K. A. (2010). Addressing social determinants of health in the prevention and control of HIV/AIDS, viral hepatitis, sexually transmitted infections, and tuberculosis.
- Diallo, D. D., Moore, T. W., Ngalame, P. M., White, L. D., Herbst, J. H., & Painter, T. M. (2010). Efficacy of a single-session HIV prevention intervention for black women: a group randomized controlled trial. *AIDS and Behavior*, 14(3), 518-529.
- Fletcher, F. E., Jiang, W., & Best, A. L. (2021). Antiracist Praxis in Public Health: A Call for Ethical Reflections. *Hastings Center Report*. doi.org/10.1002/hast.1240
- Fuller, C. M., Galea, S., Caceres, W., Blaney, S., Sisco, S., & Vlahov, D. (2007). Multilevel community-based intervention to increase access to sterile syringes among injection drug users through pharmacy sales in New York City. *American journal of public health*, 97(1), 117-124.
- Gebo, K. A., Fleishman, J. A., Conviser, R., Reilly, E. D., Korthuis, P. T., Moore, R. D., ... & HIV Research Network. (2005). Racial and gender disparities in receipt of highly active antiretroviral therapy persist in a multistate sample of HIV patients in 2001. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 38(1), 96-103.
- Hallfors, D. D., Iritani, B. J., Miller, W. C., & Bauer, D. J. (2007). Sexual and drug behavior patterns and HIV and STD racial disparities: the need for new directions. *American journal of public health*, 97(1), 125-132.
- Jeffries, W. L., & Henny, K. D. (2019). From epidemiology to action: the case for addressing social determinants of health to end HIV in the Southern United States. *AIDS and Behavior*, 23(3), 340-346.
- Jemmott 3rd, J. B., Jemmott, L. S., & Fong, G. T. (1992). Reductions in HIV risk-associated sexual behaviors among black male adolescents: effects of an AIDS prevention intervention. *American journal of public health*, 82(3), 372-377.

## Literature Review

---

- Kogan, S. M., Yu, T., Brody, G. H., Chen, Y. F., DiClemente, R. J., Wingood, G. M., & Corso, P. S. (2012). Integrating condom skills into family-centered prevention: Efficacy of the Strong African American Families–Teen program. *Journal of Adolescent Health, 51*(2), 164-170.
- Kraut-Becher, J., Eisenberg, M., Voytek, C., Brown, T., Metzger, D. S., & Aral, S. (2008). Examining racial disparities in HIV: lessons from sexually transmitted infections research. *JAIDS Journal of Acquired Immune Deficiency Syndromes, 47*, S20-S27.
- Melhuish, A., & Lewthwaite, P. (2018). Natural history of HIV and AIDS. *Medicine, 46*(6), 356-361. <https://doi.org/https://doi.org/10.1016/j.jmpmed.2018.03.010>
- Millett, G. A., Flores, S. A., Peterson, J. L., & Bakeman, R. (2007). Explaining disparities in HIV infection among black and white men who have sex with men: a meta-analysis of HIV risk behaviors. *Aids, 21*(15), 2083-2091.
- National Institutes of Health. Ending Structural Racism. Available at: Ending Structural Racism | National Institutes of Health (NIH). Accessed August 12, 2021.
- Powell, J. A. (2007). Structural racism: Building upon the insights of John Calmore. *NCL Rev., 86*, 791.
- Prado, G., Lightfoot, M., & Brown, C. H. (2013). Macro-level approaches to HIV prevention among ethnic minority youth: state of the science, opportunities, and challenges. *American Psychologist, 68*(4), 286.
- Borus, M. J., Swendeman, D., & Chovnick, G. (2009). The past, present, and future of HIV prevention: integrating behavioral, biomedical, and structural intervention strategies for the next generation of HIV prevention. *Annual review of clinical psychology, 5*, 143-167.
- Satcher, D., Fryer Jr, G. E., McCann, J., Troutman, A., Woolf, S. H., & Rust, G. (2005). What if we were equal? A comparison of the black-white mortality gap in 1960 and 2000. *Health affairs, 24*(2), 459-464.
- Shampo, M. A., & Kyle, R. A. (2002). Luc Montagnier—Discoverer of the AIDS Virus. *Mayo Clinic Proceedings, 77*(6), 506. <https://doi.org/10.4065/77.6.506>
- Sipe, T. A., Barham, T. L., Johnson, W. D., Joseph, H. A., Tungol-Ashmon, M. L., & O'Leary, A. (2017). Structural interventions in HIV prevention: a taxonomy and descriptive systematic review. *AIDS and Behavior, 21*(12), 3366-3430.

- Thomas, S. B., Quinn, S. C., Butler, J., Fryer, C. S., & Garza, M. A. (2011). Toward a fourth generation of disparities research to achieve health equity. *Annual review of public health*, 32, 399-416.
- Tillerson, K. (2008). Explaining racial disparities in HIV/AIDS incidence among women in the US: A systematic review. *Statistics in medicine*, 27(20), 4132-4143.
- U.S. Census Bureau. (2021). About Race. Retrieved from <https://www.census.gov/topics/population/race/about.html>
- US Department of Health and Human Services. Healthy People 2020: An opportunity to address societal determinants of health in the United States. In Secretary's Advisory Committee on Health Promotion and Disease Prevention Objectives for 2020. Available at: <https://www.healthypeople.gov/2010/hp2020/advisory/SocietalDeterminantsHealth.htm>. Accessed August 15, 2020.
- US Department of Health and Human Services. Report of the secretary's task force on black and minority health (Volume 1). Washington, DC: US Government Printing Office. 1985.
- Williams, D. R., Lawrence, J. A., & Davis, B. A. (2019). Racism and health: evidence and needed research. *Annual review of public health*, 40, 105-125.
- Zeglin, R. J., & Stein, J. P. (2015). Social determinants of health predict state incidence of HIV and AIDS: A short report. *AIDS care*, 27(2), 255-259.
- Zellner, T., Trotter, J., Lenoir, S., Walston, K., Henry-Akintobi, T., & Miller, A. (2016). Color it real: A program to increase condom use and reduce substance abuse and perceived stress. *International Journal of Environmental Research and Public Health*, 13(1), 51.



The background of the entire page is a complex, layered abstract design. It features several large, semi-transparent spheres of varying sizes. These spheres are covered in a dense pattern of small, circular, textured protrusions, resembling a microscopic view of a cell or a virus. Interspersed among these spheres are numerous small, stylized leaves or petals, some of which are attached to thin, curved stems. The overall color palette is muted, consisting of various shades of gray, beige, and a deep, dark brown that forms a horizontal band across the upper middle of the page. The lighting is soft and diffused, creating a sense of depth and texture throughout the composition.

## ARTICLES





## **The Relation of Age on HIV-Positive Women's Cluster of Differentiation 4, Antiretroviral Therapy, Papanicolaou Test, Human Papillomavirus Test and Visual Inspection with Acetic Acid**

**Atiya Shahid, MS, MPH & Interdisciplinary Pathobiology (IDPB) PhD Fellow**

Department of Graduate Public Health

College of Veterinary Medicine

Tuskegee University

Phone: (314) 913-2107

Email: ashahid9106@tuskegee.edu

**Ehsan Abdalla, DVM, MSc (Hons) (Vet Path), MSc and PhD  
(Epidemiology and Risk Analysis)**

Assistant Professor/Director of Analytics

Department of Graduate Public Health

College of Veterinary Medicine

Tuskegee University

Phone: 334-727-8042

Email: eabdalla@tuskegee.edu

### **Authors' Note**

The authors would like to acknowledge the Tuskegee University College of Veterinary Medicine, the Tuskegee University Department of Graduate Public Health, and the Tuskegee University Center for Biomedical Research Program. This work was funded by the Tuskegee University Center for Biomedical Research/Research Centers in Minority Institutions (TU CBR/RCMI) Program at the National Institute of Health (NIH). The CBR/ RCMI U54 grant number MD007585.

### **Abstract**

Despite increased life expectancy, mortality rates among women infected with HIV are 3-15 times higher than those in the overall population, HIV-infected women are also excessively affected by HPV and have increased risks of HPV-associated developments. This study's objective is to examine the relation between the ART treatment, CD4 levels, Pap, HPV and VIA tests with p16 detection among HIV-infected women. The data used in this study was collected by survey questionnaire instruments in 2009 in Kenya. Descriptive and explanatory statistics using frequency and chi-square/fisher's exact tests were performed for analysis using SAS-software. The data was stratified by age groups (30-39, 40-49, and 50 years and older). 75.28% of single HIV-positive women between the ages 30-39 participated significantly in the study, with a *p-value* of <0.0001. 52.24% of HIV-positive women 30-39 years old were

most likely to receive ART treatment for less than two years by a margin of 11.2% compared to those who received the treatment for more than two years and those who were off treatment by a margin of 2.24% (*p-value* of 0.03). The HIV-positive women 30-39 years old had lower CD4 counts of less than 350 cells/ $\mu$ l (44%) and higher CD4 counts of 500 cells/ $\mu$ l or higher (46.64%). 45.3% of the HIV-positive women 30-39 years old were more likely to have positive VIA tests with a *p-value* of 0.05. 65.87% of HIV-positive women 30-39 years old were most likely to have positive VIA tests with a *p-value* of <0.05. HIV-positive women 30-39 years old were most likely to have high-risk HPV compared to their older counterparts. This study shows that incorporating screening strategies (Pap tests, VIA tests and HPV genotyping) in conjunction with ART treatment were more effective in preventing cervical cancer in HIV-positive young women 30-39 years old.

*Keywords:* Cervical cancer, HIV, HPV, VIA, Kenya

### Introduction

Since the first reported cases of the Human Immunodeficiency Virus (HIV) in 1981, millions of more cases have been reported. HIV is a sexually transmitted disease that in its inception affected gay white men primarily, it is now highly associated with its impact and prevalence in developing countries. The management, reduction, and prevention of the virus is a public health issue that is being attacked from various angles. Cervical cancer is the most common cancer among women living with HIV, and according to UNAIDS (2019), the likelihood of a woman developing invasive cervical cancer is up to five times higher as opposed to a woman who is not HIV infected. Both diseases are fully preventable, yet both are causing astronomical instances of mortality in women who reside in low-income, low-resourced, and developing countries.

In sub-Saharan Africa, HIV predominately affects adolescent girls and young women. Nearly 68% of people living with HIV/AIDS are women, according to Ruger (2004), nine out of every ten women living with cervical cancer in low and middle-income countries succumb to the disease. According to Cancer.net (2020), cervical cancer is most often diagnosed between the ages of 35 to 44. Invasive cervical cancer can take 10-15 years to develop after infection, therefore screening and preventative methods are integral to limit and eliminate the progression of cancer according to Melnikow (1998).

Three effective screening methods that have decreased the rates of cervical cancer are Papanicolaou (Pap) smear testing, Human papillomavirus (HPV) testing, and Visual inspection with acetic acid (VIA) testing. To reduce HIV-related morbidity and mortality, Antiretroviral therapy (ART) treatment is used, the WHO recommends the use of ART in all HIV-infected individuals with CD4 cell counts of 500 cells/ $\mu$ l or less, the CD4 cell counts are used to indicate response to treatment (Ayele et al., 2019). The use of p16 immunohistochemistry expression in HIV-infected women is limited but has been used to differentiate mild cervical intraepithelial neoplasm (CIN1) from moderate to severe cervical intraepithelial neoplasm (CIN2/3) (McGrath et al. 2017). The implementation of preventative methods in more developed

countries has resulted in decreased mortality rates attributable to cervical cancer by more than 70%, in addition, screening women every three to five years has also shown risk reductions of 80-90% of overall lifetime risks according to Eddy (1990).

The goal of this study was to examine the relation between the ART treatment, CD4 levels, Pap, HPV, and VIA tests among HIV-infected women. It was hypothesized that women 30-39 years old would be most impacted due to their increased risk of developing cervical cancer.

## Methods

Data used in this study was collected by Chung et al (2013). In the original study, 500 HIV-infected women were recruited from a medical center between June 2009 and December 2009 (McGrath 2017). Eligibility for participation was based on the women: 1). Being between the ages of 18 and 55, 2). Having an intact cervix, 3). Not previously received treatment for cancerous or precancerous cervical lesions. The women participated in four types of testing, a Papanicolaou (Pap) smear, Human papillomavirus (HPV) test, Visual inspection with acetic acid (VIA), and a Colposcopy-directed biopsy, which is considered the disease gold standard in Kenya. The performance and use of p16 immunohistochemistry was used to assess the HPV-associated cervical intraepithelial neoplasia, via use of the pap smears. A standardized questionnaire was used to obtain demographic and clinical information, the participants underwent a pelvic examination, and their CD4 cell count information was collected.

The original study used “sensitivity, specificity, positive predictive value (PPV), and area under the receiver operating characteristic curve (AUC) of p16 to detect CIN2/3 on histology and the impact of immunosuppression and ART was assessed. Comparisons of sensitivity and specificity were stratified by CD4 count ( $\leq 350$  and  $>350$  cells/ $\mu$ l), ART (none,  $<2$  years and  $\geq 2$  years), and age ( $<40$  and  $\geq 40$  years) and compared using chi-square tests. Statistical analyses were performed using STATA 13 (Stata Corporation, College Station, Texas, USA).” (McGrath 2017)

The data in this secondary analysis was collected from the questionnaire instruments used in the preliminary study. Descriptive and explanatory statistics using frequency distributions, chi-square, and Fisher’s exact tests were performed for analysis using SAS-software to examine association. The data was stratified by age groups (30-39, 40-49, and 50 years and older). All  $p$ -values were two-sided with a significance of  $P < 0.05$ . Calculated statistics were obtained and presented in Microsoft Word tables and bar graphs using Excel functions.

## Results

The detailed results of this study are presented in Figures 1-7 and Table 1. The analysis was comprised of 500 cervical sample cases collected from HIV-positive women, of which 331 cases were the final sample size used for analysis. The results show subsequent analysis of the association between selected demographic and clinical information stratified by age groups of HIV-positive Kenyan women in 2009.

## Demographics

### Marital Status

Single women less than 40 were more likely to have cervical lesions with p16 detection, with a p value of <0.0001. There was not a significant difference between the age groups of women with CD4 levels of less than or equal to 350 cells/ul. There was not a significant difference between the age groups of women with CD4 levels of less than 350 cells/ul or more than or equal to 500 cells/ul. Women younger than 40 who were on ART for less than 2 years were more likely to have cervical lesions with p16 detection with a p value of 0.03. There was not a significant difference between the age groups of women with the use of p16 detection and a Pap smear test. Women younger than 40 years old were more likely to have a positive VIA test with p16 detection, with a p value of 0.05. There was not a significant difference between the age groups of women with p16 detection and an HPV test.

As seen in Figure 1, single women between the ages 30-39 comprised 75.28% of the study. Single women ages 40-49 comprised 21.35% of the study. Single women aged 50 years and older comprised 3.37% of the study. Married women between the ages 30-39 comprised 66.18% of the study. Married women between the ages 40-49 comprised 30.88% of the study. Married women aged 50 years or older comprised 2.94% of the study. Divorced/separated women between the ages 30-39 comprised 28.57% of the study. Divorced/separated women between the ages 40-49 comprised 67.35% of the population. Divorced/separated women aged 50 years or older comprised 4.08% of the study. Widowed women between the ages 30-39 comprised 38.60%. Widowed women between the ages 40-49 comprised 38.60%. Widowed women aged 50 years or older comprised 22.81% of the study.

### CD4 Count ( $\leq 350$ cells/ $\mu$ l and $>350$ CD4 cells/ $\mu$ l)

As shown in Figure 2, 56% of women between the ages 30-39 had a CD4 count of less than or equal to 350 cells/ $\mu$ l. 36.67% of women between the ages 40-49 had a CD4 count of less than or equal to 350 cells/ $\mu$ l. 7.33% of women aged 50 years or older had a CD4 count of less than or equal to 350 cells/ $\mu$ l. 60.22% of women between the ages 30-39 had a CD4 count of greater 350 cells/ $\mu$ l. 33.70% of women between the ages 40-49 had a CD4 count of greater 350 cells/ $\mu$ l. 6.08% of aged 50 years or older had a CD4 count of greater 350 cells/ $\mu$ l.

### CD4 Count ( $\leq 500$ cells/ $\mu$ l and $>500$ cells/ $\mu$ l)

As illustrated in Figure 3, 57.33% of women between the ages 30-39 had a CD4 count of less than 500 cells/ $\mu$ l. 34.91% of women between the ages 40-49 had a CD4 count of less than 500 cells/ $\mu$ l. 7.76% of women aged 50 years or older had a CD4 count of less than 500 cells/ $\mu$ l. 60.61% of women between the ages 30-39 had a CD4 count equal to or more than 500 cells/ $\mu$ l. 35.35% of women between the ages 40-49 had a CD4 count equal to or more than 500 cells/ $\mu$ l. 4.04% of women aged 50 years or older had a CD4 count equal to or more than 500 cells/ $\mu$ l.

### *Antiretroviral Therapy Treatment*

As shown in Figure 4, 64.18% of women 30-39 were on Antiretroviral therapy (ART) for less than two years. 51.45% of women 40-49 were on Antiretroviral therapy (ART) for less than two years. 67.78% of women 30-39 were on Antiretroviral therapy (ART) for less than two years. 26.87% of women 30-39 were on Antiretroviral therapy (ART) for more than or equal to two years. 42.77% of women 40-49 were on Antiretroviral therapy (ART) for more than or equal to two years. 25.56% of women aged 50 years or older were on Antiretroviral therapy (ART) for more than or equal to two years. 8.96% of women 30-39 were not on Antiretroviral therapy (ART). 5.78% of women 40-49 were not on Antiretroviral therapy (ART). 6.77% of women aged 50 years or older were not on Antiretroviral therapy (ART).

### *Papanicolaou (Pap) Smear Test*

As seen in Figure 5, 58.27% of women 30-39 received a negative Papanicolaou (Pap) smear test. 35.25% of women 40-49 received a negative Papanicolaou (Pap) smear test. 6.47% of women aged 50 years or older received a negative Papanicolaou (Pap) smear test. 58.33% of women 30-39 received a positive Papanicolaou (Pap) smear test. 34.90% of women 40-49 received a positive Papanicolaou (Pap) smear test. 6.77% of women aged 50 years or older received a positive Papanicolaou (Pap) smear test.

### *Visual Inspection with Acetic Acid (VIA) Test*

As seen in Figure 6, 54.23% of women 30-39 received a negative Visual inspection with Acetic Acid (VIA) test. 37.81% of women 40-49 received a negative Visual inspection with Acetic Acid (VIA) test. 7.91% of women aged 50 years or older received a negative Visual inspection with Acetic Acid (VIA) test. 65.87% of women 30-39 received a positive Visual inspection with Acetic Acid (VIA) test. 30.95% of women 40-49 received a positive Visual inspection with Acetic Acid (VIA) test. 3.17% of women aged 50 years or older received a positive Visual inspection with Acetic Acid (VIA) test.

### *Human Papillomavirus (HPV) Test*

As shown in Figure 7, 53.55% of women 30-39 received a negative Human papillomavirus (HPV) test. 36.77% of women 40-49 received a negative Human papillomavirus (HPV) test. 9.68% of women aged 50 years or older received a negative Human papillomavirus (HPV) test. 62.50% of women 30-39 received a positive Human papillomavirus (HPV) test. 33.52% of women 40-49 received a positive Human papillomavirus (HPV) test. 3.98% of women aged 50 years or older received a negative Human papillomavirus (HPV) test.

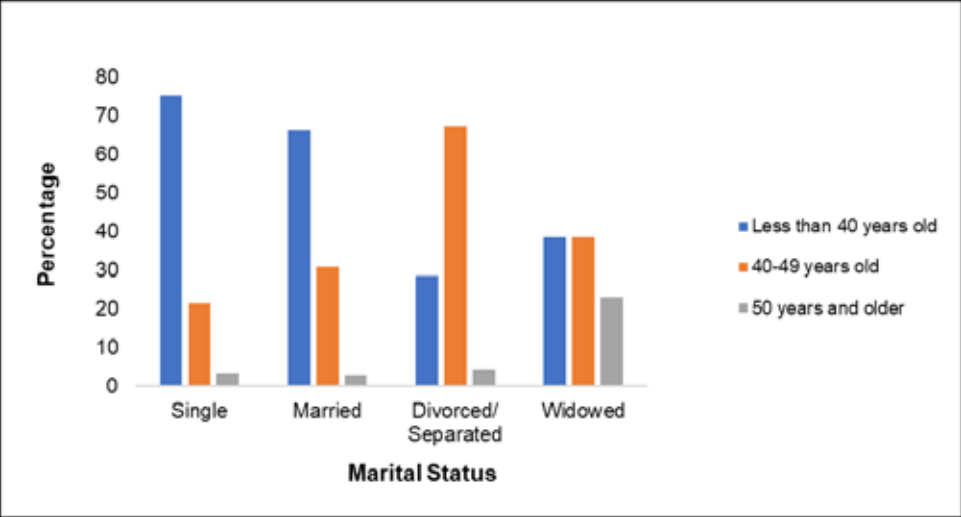


Figure 1: Frequency distributions of marital status among HIV-infected women stratified by age groups

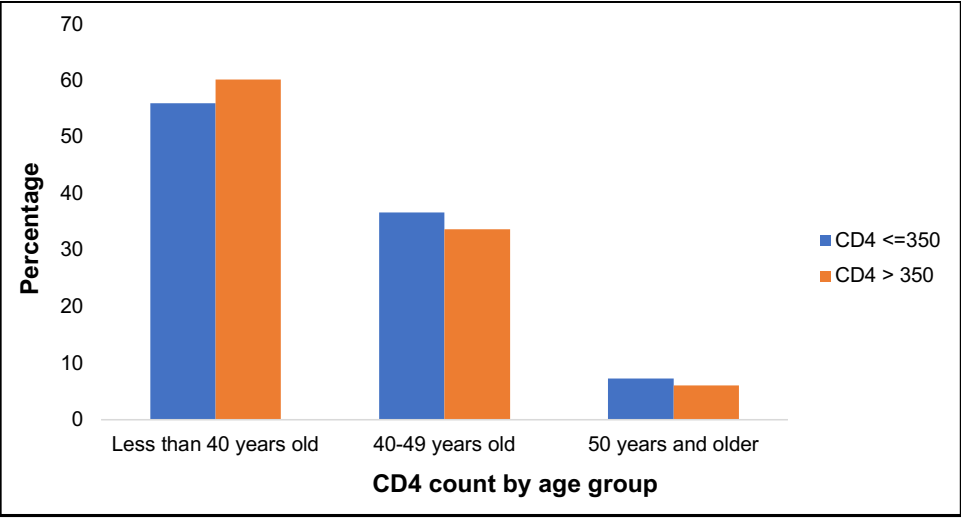


Figure 2: Frequency distributions among HIV-infected women with CD4 cell counts of less than 350 cells/ul stratified by age groups

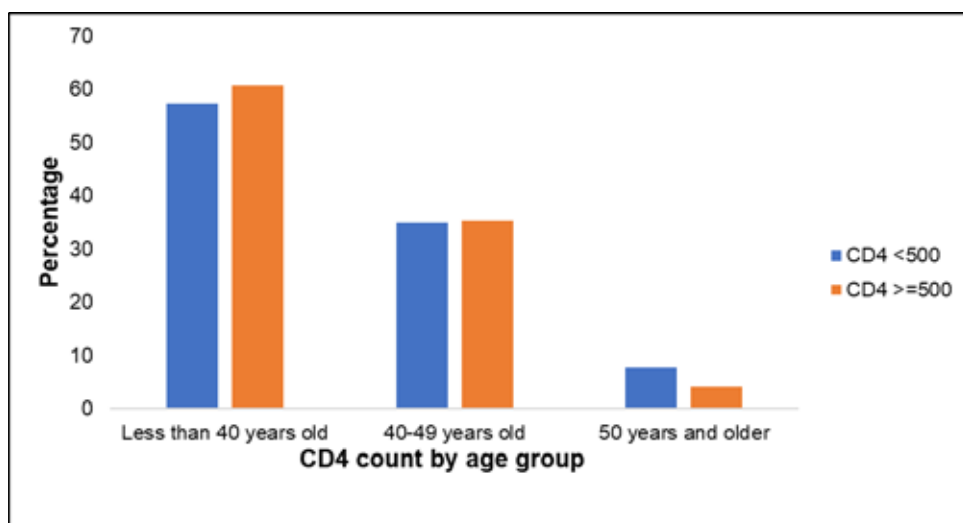


Figure 3: Frequency distributions among HIV-infected women with CD4 cell counts of more than 350 cells/ul stratified by age groups

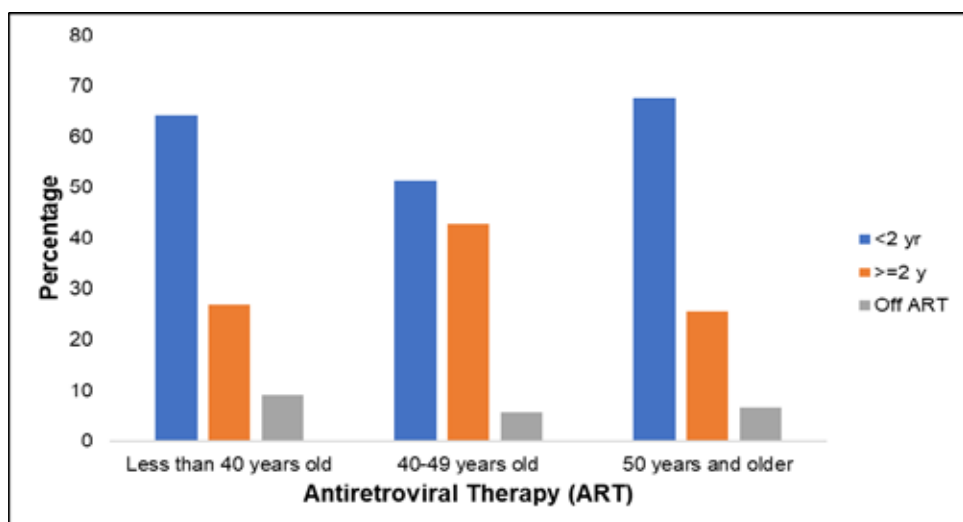


Figure 4: Frequency distributions of Antiretroviral therapy (ART) use among HIV-infected women stratified by age groups

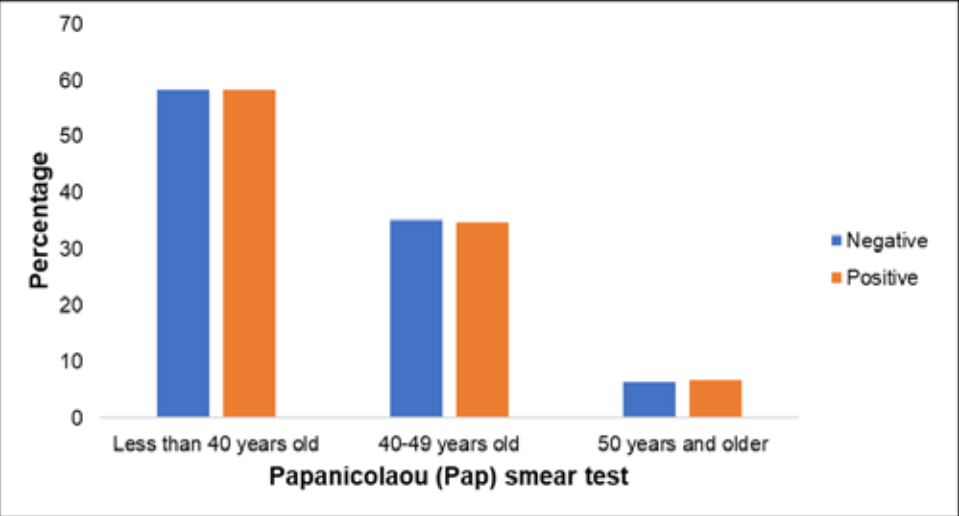


Figure 5: Frequency distributions of Papanicolaou (Pap) smear test results in HIV-infected women stratified by age groups

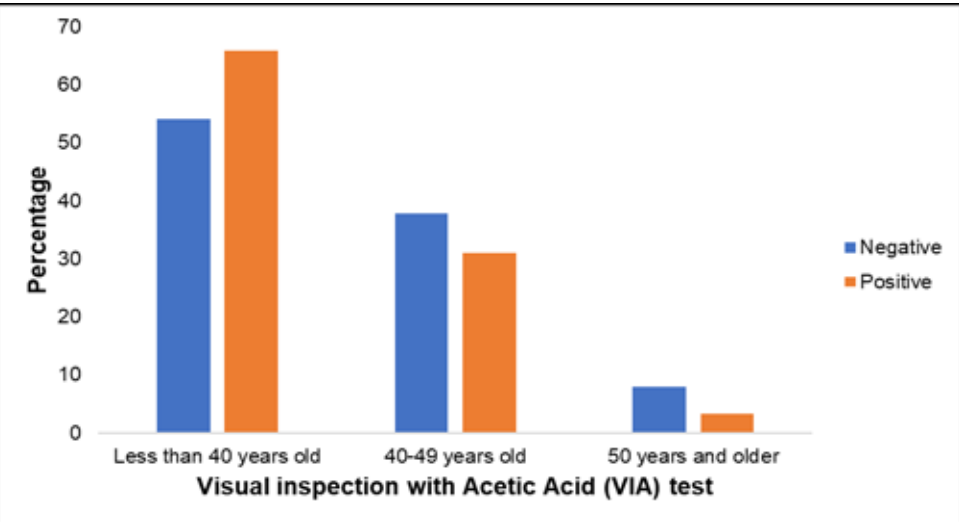
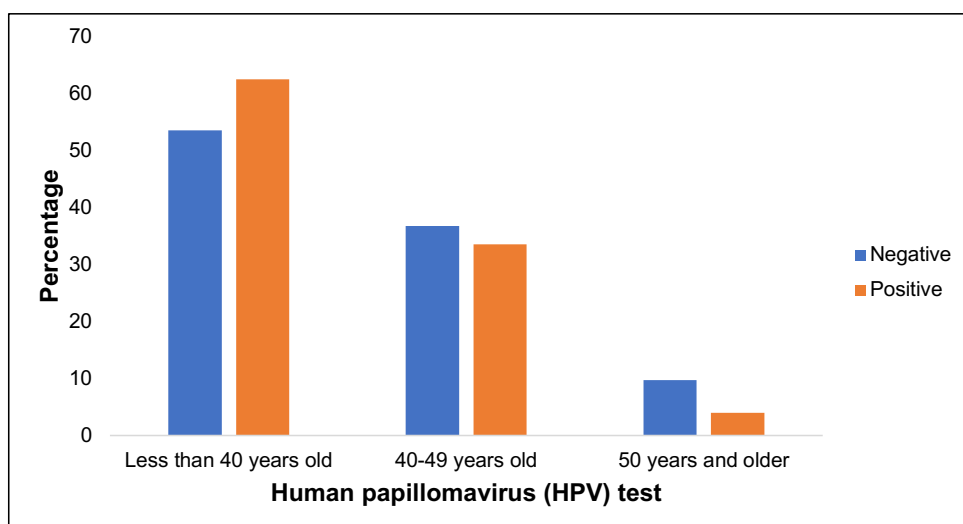


Figure 6: Frequency distributions of Visual inspection with acetic acid (VIA) test results in HIV-infected women stratified by age groups





*Figure 7: Frequency distributions of Human papillomavirus (HPV) test results in HIV-infected women stratified by age groups*

Table 1. Selected Demographic characteristics and Cervical Cancer Screening Information of HIV positive Kenyan women in 2009.

Variables	Age groups			p-value
	Less than 40 years old (%)	40-49 years old (%)	50 years and older (%)	
<b>Marital status</b>				
Single	75.28	21.35	3.37	* <b>&lt;.0001</b>
Married	66.18	30.88	2.94	
Divorced/ Separated	28.57	67.35	4.08	
Widowed	38.60	38.60	22.81	
<b>CD4 count &lt;=350 cells/µl and &gt;350 CD4 cells/µl</b>				
CD4 <=350	56.00	36.67	7.33	0.8000
CD4 > 350	60.22	33.70	6.08	
<b>CD4 count (CD4LT500) &lt;=500 cells/µl and &gt;500 cells/µl</b>				
CD4 <500	57.33	34.91	7.76	0.5000
CD4 >=500	60.61	35.35	4.04	
<b>Antiretroviral therapy (ART)</b>				
<2 yr	64.18	51.45	67.78	0.0300
>=2 y	26.87	42.77	25.56	
Off ART	8.96	5.78	6.67	
<b>Papanicolaou (Pap) smear</b>				
Negative	58.27	35.25	6.47	1.000
Positive	58.33	34.90	6.77	
<b>Visual inspection with acetic acid (VIA)</b>				
Negative	54.23	37.81	7.96	0.0500
Positive	65.87	30.95	3.17	
<b>Human papillomavirus (HPV) test</b>				
Negative	53.55	36.77	9.68	0.0700
Positive	62.50	33.52	3.98	

P\* statistically significant difference (chi-square and Fisher Exact tests P-value <0.05).

## Discussion/Conclusion

HIV-positive women 30-39 years old were most likely to have high-risk HPV compared to their older counterparts. This study shows that incorporating screening strategies (Pap tests, VIA tests and HPV testing) with p16 detection and ART treatment was more effective in preventing cervical cancer in HIV-positive women 30-39 years old. This is crucial due to invasive cervical cancer having a delayed presentation of 10-15 years after infection (Melnikow 1998). In a French study, researchers found that HIV testing in their general population led to “decreases in the delay from HIV infection to diagnosis, increases in mean CD4 count at diagnosis, improves survival among HIV-infected patients, reduces secondary infections at ten years, and achieves cost-effectiveness ratios” (Yazdanpanah 2010). According to Chambuso (2018), HIV as a co-infection of HPV can have a significant impact on the development of cervical cancer outcomes in women who are HIV-positive. Chambuso (2018) stated that “HIV positive women are also more likely to have concurrent infections of single or multiple strains of oncogenic HPV, compared to HIV negative women. Furthermore, published data clearly shows that, persistent oncogenic HPV and HIV co-infections, contribute to rapidly progressing cervical carcinogenesis when compared to HIV negative women with a single, multiple, or no HPV infection.”

In the original study, the use of p16 immunohistochemistry detection to detect CIN2/3 provided a higher specificity of 72.4% and lower specificity of 54.1% in comparison with the PAP, VIA, and HPV tests for HIV-infected women (McGrath 2017). This study explored the relation between ART and testing methods (Pap, HPV, and VIA) when used with the p16 immunohistochemistry detection. It was hypothesized that women between 30-39 years old would be affected the most due to developmental mechanism of cervical cancer and HPV.

One limitation of the original study was the lack of socioeconomic information provided. Information such as income, employment, and education are pertinent in establishing prevention and treatment strategies. Other studies have found that lower education and higher poverty resulted in increased cervical cancer incidence rates (Benard 2008). Studies have shown that lower socioeconomic resources can be attributed to more dangerous health behaviors that result in issues such as poverty, increased substance use, and food insufficiency. According to the American Psychological Association (2010), people infected with HIV tend to have a damaging result on the overall socioeconomic status of a community due to their decreased capacity to work and earn income as well as afford treatment options.

The use of the effects of p16 testing with HIV-infected women is still novel and more research needs be completed to further understand its role, despite this fact, there has been a significant association found between p16 expression and increased disease-free survival (RR 0.60; 95% CI 0.44-0.82;  $p=0.001$ ) (DARE 2014). Based on the results of this analysis, in the future p16 should be used in conjunction VIA testing in HIV-infected women between the ages 30-39 to further assess its value.

This type of research is important because the burden affecting women infected with HIV in rural communities in Kenya are similar to those affecting African American women

living with cervical cancer in rural communities in the United States. Cervical cancer is the fourth most frequent cancer in women, killing 4,000 women in the United States annually (ADPH 2020). African American women living with cervical cancer are burdened with extraordinarily high rates of prevalence, morbidity, and mortality, with Alabama exhibiting the highest rates of mortality as a result of cervical cancer. Due to the lack of preventative measures, African American women in Alabama are dying at a rate of 5.2 per 100,000, which is double the rate of white women (Green 2018).

Due to the length of time since the original study, it is recommended that the preliminary study be completed again due to various advancements, including screening methods, access, treatment options, education, and research efforts. Another recommendation would be to conduct a similar study within the United States, to compare and observe the impact in a less developed country as opposed to a developed country.

### Author Contributions

**Atiya Shahid, MS, MPH & Interdisciplinary Pathobiology (IDPB) PhD Fellow:** Is the first author and major conceiver and designer of the manuscript. Participated and made major contributions to the analysis, interpretation of the data, and writing of the manuscript. Critically reviewed the manuscript and approved the final version.

**Ehsan Abdalla, DVM, MSc (Hons) (Vet Path), MSc and PhD (Epidemiology and Risk Analysis):** Is the corresponding author, participated in the conceiving and designing of the manuscript. Made major contributions to analysis, interpretation of the data and writing of the manuscript and approved the final version.

### References

- Access to health services.* Access to Health Services | Healthy People 2020. (n.d.). Retrieved November 15, 2021, from <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/access-to-health>.
- American Psychological Association. (n.d.). *HIV/AIDS and socioeconomic status.* American Psychological Association. Retrieved November 15, 2021, from <https://www.apa.org/pi/ses/resources/publications/hiv-aids>.
- Ayele, T. A., Worku, A., Kebede, Y., Zuma, K., Kasim, A., & Shkedy, Z. (n.d.). *Model-based prediction of CD4 cells counts in HIV-infected adults on antiretroviral therapy in northwest Ethiopia: A flexible mixed effects approach.* PLOS ONE. Retrieved November 15, 2021, from <https://doi.org/10.1371/journal.pone.0218514>.

- Benard, V. B., Johnson, C. J., Thompson, T. D., Roland, K. B., Lai, S. M., Cokkinides, V., Tangka, F., Hawkins, N. A., Lawson, H., & Weir, H. K. (2008). Examining the association between socioeconomic status and potential human papillomavirus-associated cancers. *Cancer*, 113(S10), 2910–2918. <https://doi.org/10.1002/cncr.23742>
- Cervical cancer - statistics*. Cancer.Net. (2021, February 8). Retrieved November 15, 2021, from <https://www.cancer.net/cancer-types/cervical-cancer/statistics>.
- Cervical cancer death rates alarmingly high among black women in Alabama*. Cancer Health. (2018, December 21). Retrieved November 15, 2021, from <https://www.cancerhealth.com/article/cervical-cancer-death-rates-alarmingly-high-among-black-women-alabama>.
- Chambuso, R., Gray, C. M., Kaambo, E., Rebello, G., & Ramesar, R. (2018). Impact of host molecular genetic variations and HIV/HPV co-infection on cervical cancer progression: A systematic review. *Oncomedicine*, 3, 82–93. <https://doi.org/10.7150/oncm.25573>
- Chung, M. H., McKenzie, K. P., De Vuyst, H., Richardson, B. A., Rana, F., Pamnani, R., Njoroge, J. W., Nyongesa-Malava, E., Sakr, S. R., John-Stewart, G. C., & Mugo, N. R. (2013, November 28). *Comparing papanicolau smear, visual inspection with acetic acid and human papillomavirus cervical cancer screening methods among HIV-positive women by immune status and antiretroviral therapy*. AIDS (London, England). Retrieved November 15, 2021, from <http://www.ncbi.nlm.nih.gov/pubmed/23842133/>.
- DM, E. (n.d.). *Screening for cervical cancer*. Annals of internal medicine. Retrieved November 15, 2021, from <https://pubmed.ncbi.nlm.nih.gov/2115753/>.
- Huang, K., Li, L.-A., Meng, Y.-G., & Fu, X. Y. (2014, October 24). *P16 expression in patients with cervical cancer and its prognostic significance: Meta-analysis of published literature*. European Journal of Obstetrics & Gynecology and Reproductive Biology. Retrieved November 15, 2021, from <https://www.sciencedirect.com/science/article/pii/S0301211514005405?via%3Dihub>.
- Kalichman, S. C., Pellowski, J., Kalichman, M. O., Cherry, C., Detorio, M., Caliendo, A. M., & Schinazi, R. F. (2011). Food insufficiency and medication adherence among people living with HIV/AIDS in urban and peri-urban settings. *Prevention Science*, 12(3), 324–332. <https://doi.org/10.1007/s11121-011-0222-9>
- Macroeconomics and health: Investing in health for ...* (n.d.). Retrieved November 15, 2021, from <http://apps.who.int/iris/bitstream/handle/10665/42435/924154550X.pdf;sequence=1>.

- McGrath, C. J., Garcia, R., Trinh, T. T., Richardson, B. A., John-Stewart, G. C., Nyongesa-Malava, E., Mugo, N. R., Glynn, E. H., Sakr, S. R., Vuyst, H. D., & Chung, M. H. (n.d.). *Role of p16 testing in cervical cancer screening among HIV-infected women*. PLOS ONE. Retrieved November 15, 2021, from <https://doi.org/10.1371/journal.pone.0185597>.
- Melnikow, J., Nuovo, J., Willan, A. R., Chan, B. K. S., & Howell, L. P. (2004, January 17). *Natural history of cervical squamous intraepithelial lesions: A meta-analysis*. Obstetrics & Gynecology. Retrieved November 15, 2021, from <https://www.sciencedirect.com/science/article/pii/S0029784498002452?via%3Dihub>.
- Pellowski, J. A., Kalichman, S. C., Matthews, K. A., & Adler, N. (2013). A pandemic of the poor: Social disadvantage and the U.S. HIV epidemic. *American Psychologist*, 68(4), 197–209. <https://doi.org/10.1037/a0032694>
- Riley, E. D., Gandhi, M., Bradley Hare, C., Cohen, J., & Hwang, S. W. (2007). Poverty, unstable housing, and HIV infection among women living in the United States. *Current HIV/AIDS Reports*, 4(4), 181–186. <https://doi.org/10.1007/s11904-007-0026-5>
- Ruger, J. P. (2004). Combating HIV/AIDS in developing countries. *BMJ*, 329(7458), 121–122. <https://doi.org/10.1136/bmj.329.7458.121>
- Unaid.org. (2019, May 31). *The little-known links between cervical cancer and HIV*. UNAIDS. Retrieved November 15, 2021, from [https://www.unaids.org/en/resources/presscentre/featurestories/2019/may/20190531\\_cervical-cancer-hiv](https://www.unaids.org/en/resources/presscentre/featurestories/2019/may/20190531_cervical-cancer-hiv).
- Yazdanpanah, Y., Sloan, C. E., Charlois-Ou, C., Vu, S. L., Semaille, C., Costagliola, D., Pillonel, J., Poullié, A.-I., Scemama, O., Deuffic-Burban, S., Losina, E., Walensky, R. P., Freedberg, K. A., & Paltiel, A. D. (n.d.). *Routine HIV screening in France: Clinical impact and cost-effectiveness*. PLOS ONE. Retrieved November 15, 2021, from <https://journals.plos.org/plosone/article?id=10.1371%2Fjournal.pone.0013132>.

## **African American Women's Current Knowledge, Perceptions, and Willingness of PrEP Use for HIV Prevention in the South**

**Jamie Troutman, PhD (Corresponding Author)**

Arnold School of Public Health, University of South Carolina  
Department of Health Promotion, Education, and Behavior  
Discovery I, 915 Greene Street, Columbia, SC 29208  
Phone: 704-605-0354 Fax: 803-254-2209  
Email: [Jamie.l.troutman@gmail.com](mailto:Jamie.l.troutman@gmail.com)

**Lucy Annang Ingram, PhD**

Arnold School of Public Health, University of South Carolina  
Department of Health Promotion, Education, and Behavior  
Discovery I, 915 Greene Street, Columbia, SC 29208  
Phone: 803-777-4389 Fax: 803-777-6290  
Email: [lannang@mailbox.sc.edu](mailto:lannang@mailbox.sc.edu)

**Bambi Gaddist, DrPH**

South Carolina HIV Council dba Wright Wellness Center  
1022 Calhoun Street, Columbia, SC 29201  
Phone: 803 254-6644 Fax: 803-254-2209  
Email: [dr.gaddist@wright-wellness.org](mailto:dr.gaddist@wright-wellness.org)

**Alyssa Robillard, PhD**

Institute for Families in Society, University of South Carolina  
1600 Hampton Street, Suite 507, Columbia, SC 29208  
Phone: 803-777-8462 Fax: 803-777-6290  
Email: [AROBILLA@mailbox.sc.edu](mailto:AROBILLA@mailbox.sc.edu)

**Shan Qiao, PhD**

Arnold School of Public Health, University of South Carolina  
Department of Health Promotion, Education, and Behavior  
Discovery I, 915 Greene Street, Columbia, SC 29208  
Phone: 803-777-6844 Fax: 803-777-6290  
Email: [shanqiao@mailbox.sc.edu](mailto:shanqiao@mailbox.sc.edu)

### **Authors' Note**

**Funding:** Partial financial support was received from The University of South Carolina.

**Conflicts of interest/Competing interests:** The authors have no relevant financial or non-financial interests to disclose.

**Ethics approval:** This study received ethical approval by the Institutional Review Board at the University of South Carolina.

**Consent to participate:** Informed consent was obtained from all individual participants included in the study.

**Consent for publication:** Patients signed informed consent regarding publishing their data.

**Availability of data and material:** All data and materials comply with field standards.

**Code availability:** Not applicable.

**Authors' contributions:** All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Jamie Troutman, Lucy Ingram, Bambi Gaddist, Alyssa Robillard, and Shan Qiao. The first draft of the manuscript was written by Jamie Troutman and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

**Acknowledgements:** The authors would like to thank the South Carolina HIV Council dba Wright Wellness Center for their support and contributions.

### Abstract

African American women accounted for approximately 60% of new HIV diagnoses among women in the United States, with the greatest burden occurring in the South. Past efforts to prevent HIV focused on behavioral interventions aimed at reducing sexual risk behavior. More recent HIV prevention methods have included oral pre-exposure prophylaxis (PrEP) with antiretroviral drugs. Although PrEP has been designated as an effective HIV prevention method since 2012, awareness and uptake of PrEP remains low among African American women. Our study explored African American women's knowledge, perceptions, and willingness of PrEP use. Four focus groups were held in April 2019, consisting of 27 women, who identified as African American and resided in South Carolina. Focus group topics focused on participants' awareness, perceptions, and potential use of PrEP. The majority of women had heard of PrEP; however, over half of the participants were in the HIV or health field. Overall, participants believed that the "lay woman" would be unaware of PrEP. Participants' perceptions of PrEP included stigma of PrEP use, benefits to non-monogamous couples, and experiences with PrEP clients. The majority of women were willing to use PrEP, but major concerns around short and long-term side effects were expressed. Participants provided recommendations to improve PrEP uptake among African American women that included targeted campaigns and spokespersons.

African American women are interested and supportive of PrEP use for HIV prevention in the South, where HIV rates remain highest. Past PrEP implementation efforts have not been relatable to African American women; therefore, awareness and uptake rates remain low. Future efforts to increase PrEP awareness and uptake among African American women should be relevant, and should provide comprehensive information on potential side effects, purpose of use, and eligibility criteria.

*Keywords:* PrEP, HIV prevention, African American women, HIV in the South



## Introduction

Within the United States, there are over 1.1 million people living with HIV and an average of 40,000 new HIV diagnoses annually (Centers for Disease Control and Prevention [CDC], 2019). Women represent 19% of new HIV diagnoses in the United States, with African American women accounting for 60% of new cases (CDC, 2018). HIV/AIDS related illnesses continue to be among the top-leading causes of death among African American women between the ages of 20-54 years (CDC, 2015). The distribution of HIV in the United States varies geographically, with the South accounting for nearly 52% of people living with HIV (CDC, 2018). Of the new HIV diagnoses among women, 54% of diagnoses were among women residing in the Southern United States (CDC, 2017). In the South, the rate of new HIV diagnoses among African American women per 100,000 (26.8) was 11 times the rate of non-Hispanic white women (5.8) and 5 times the rate of Hispanic women (2.4) (CDC, 2017).

Unknown HIV status, sexual risk behaviors (i.e., unprotected sex and multiple sexual partners), previous sexually transmitted infections (STIs), sexual assault, and alcohol and other drug use are influential factors that increase HIV risk among African American women (Aral et al., 2008). In addition, the high prevalence of HIV within their sexual networks increases their risk of HIV, regardless of their relationship status (Aral et al., 2008). Sexual partner sharing and difficulty with condom negotiation with their primary partner creates additional HIV risk for African American women. Therefore, actual risk can vary across reported risk behaviors and perceived risk, and thus HIV prevention efforts should be measured and considered across all risk groups (no-, low-, medium-, and high-risk) among African American women.

Current efforts to reduce HIV risk and transmission among African American women include tailored behavioral interventions that aim to increase safer sexual behaviors and practices (i.e., routine HIV and other STI testing, condom use, and reduced number of sexual partners), reduce HIV-related stigma, and improve treatment services and retention rates among HIV-positive individuals (CDC, 2017). Due to reported barriers to HIV testing and condom access, and continued high rates of HIV among African American women, further HIV prevention efforts are needed.

Pre-exposure prophylaxis (PrEP) has been shown to be highly effective (92%-99%) at preventing HIV when taken consistently and as prescribed (CDC, 2019). PrEP has been recommended for men who have sex with men (MSM), transgender individuals, injection drug users (IDU), and heterosexual men and women who report one or more of the following risk factors: inconsistent condom use, having multiple sexual partners, having an HIV-positive sex partner, having a recent STI, having an HIV-positive IDU partner, sharing of injection equipment, involvement in commercial sex work, and use of post-exposure prophylaxis (PEP) for HIV prevention in the past 12 months (CDC, 2019).

Past research studies around PrEP have focused on MSM, injection drugs users, and high-risk international and heterosexual men and women (Brooks et al., 2011; Eisingerich et al., 2012; Flash et al., 2014; Galea et al., 2011; Guest et al., 2010; Heffron et al., 2012; Khawcharoenporn et al., 2012; Krakower et al., 2012; Smith et al., 2012; Towe et al., 2020;

Walters et al., 2020). One study found PrEP awareness to be lowest among heterosexual persons (7%), compared to MSM (85%) and injection drug users (26%) (Jones et al., 2021). Understanding knowledge, attitudes, perceptions, and interest in PrEP use among populations who continue to experience high rates of HIV is essential, however there are limited studies that examine African American women's knowledge, perceptions, and willingness of PrEP use in the United States. A recent qualitative study consisting of Black women found the majority of women to be interested in PrEP, despite having never heard of PrEP, and reported numerous structural barriers (e.g., poor access to transportation, childcare and social services) and systematic barriers (e.g., intimate partner violence, substance use, and community violence) that prevented PrEP adoption (Nydegger et al., 2021; Nydegger et al., 2020). However, most PrEP studies involving African American women in the United States have taken place in predominantly urban cities, have included mixed-race and mixed-gender participants, included women who experienced substance use and violence, and were single method studies (Auerbach et al., 2012; Auerbach et al., 2015; Bond & Gunn, 2016; Flash et al., 2014; Khawcharoenporn et al., 2012; Kwakwa et al., 2016; Nydegger et al., 2021; Nydegger et al., 2020; Smith et al., 2012; Whiteside et al., 2011; Wingood et al., 2013). Given the consistently high rates of HIV experienced in the Southern United States, specifically among African American women, continued research focusing on HIV prevention in the South is needed. Our study aimed to fill these gaps, using qualitative research, by exploring the awareness, knowledge, perceptions, and willingness of PrEP use among African American women in the South.

### Methods

The data for our study was derived from a mixed-methods study focusing on sexual behaviors and PrEP awareness, perceptions, and potential use among African American women. Focus group participants were recruited from the quantitative survey sample (N=413). A total of 27 women participated in the focus groups. The study will only report findings from the qualitative data collected.

### Procedures

Surveys were collected between May 2018 and March 2019. Multiple channels were used to invite participants to take the online survey. This included emails and social media advertisements, as well as face-to-face recruitment. Emails and social media posts provided the link to the survey and eligibility requirements. Face-to-face recruitment for the online survey involved handing out cards with the survey link and information about the survey and eligibility criteria. In addition to the online survey, participants were also given the chance to take the survey in-person at a local non-profit organization and various community events, which included The Black Women's Expo, community health fairs, and targeted testing events in Columbia, South Carolina.

Eligibility criteria for survey participation included women who (1) self-identify as African American or Black, (2) are 18 years of age or older, (3) self-report as HIV-negative,

and (4) reside in the Southeastern United States (South Carolina, North Carolina, Georgia, Alabama, or Florida). A total of 413 participants completed a quantitative survey that assessed their demographic information, sexual risk behaviors, perceived HIV risk, dynamics of their sexual relationships, and basic PrEP knowledge and perceptions.

Participants who completed the survey were entered into a drawing for the chance to win one of two \$50 VISA gift cards. At the completion of the survey, participants were asked if they would be interested in participating in a focus group to discuss the survey topics further, sometime at a later date. If interested, participants were asked to provide their email and/or phone number so that they could be contacted at a later date to invite them to a focus group. Only women who completed the survey were eligible for focus group participation.

Participants who were interested in the focus group were contacted between February 2019 and March 2019 to invite them to the upcoming focus groups. A total of four focus groups were conducted in April 2019. A total of 27 women participated in the focus groups. All participants received a \$25 VISA gift card upon completion of the focus group session.

A topical guide was developed to guide focus group discussions and to ensure all focus groups covered the same overall topics. The moderator and note taker used the topical guide to lead the focus group and to ensure the focus group stayed within the intended time frame. Each focus group lasted approximately 90 minutes. At the beginning of each focus group, participants signed an informed consent form, where they were provided information about potential risks or harms of participating in this study, and completed a demographic questionnaire. Participants were asked questions about 1) knowledge, awareness and understanding of PrEP; 2) attitudes about PrEP usage for themselves and others; 3) perceptions of PrEP's impact on future sexual behaviors (i.e., condom use); 4) stigma related to PrEP use; 5) willingness to use PrEP; 6) likelihood of recommending PrEP to their sexual partners; 7) likelihood of PrEP uptake and adherence, given the behavioral requirements and financial obligations; 8) current relationship with their provider, focusing on patient-provider discussions around sexual history and behaviors, and provider recommendations of PrEP use; 9) past and recent sexual activity behaviors; and 10) experiences and composition of sexual relationships. All procedures for this study were approved by the Institutional Review Board at the University of South Carolina.

### *Data Analysis*

Focus groups were recorded, transcribed, and analyzed using NVivo 12 Pro. A codebook was developed to guide data analysis and to further analyze identified themes. The transcripts were reviewed, coded, and discussed by three researchers. All four transcripts were double coded. Researchers met post coding to discuss and compare similarities and differences between themes from each focus group. Analysis indicated consistency of themes across all four focus groups.

### Results

A total of 27 women participated in the focus groups. All participants resided in South Carolina. The average age was 39.15 years among participants, with participants' age ranging from 20-67 years. Among the 27 participants, 59.3% reported they were interested in PrEP prior to the focus group through the sexual behavior survey. Table 1 includes the demographic data for the participants.

Focus group discussions were categorized under the following themes: PrEP knowledge and awareness, perceptions of PrEP, willingness to use PrEP, concerns about PrEP, and recommendation to increase PrEP uptake among African American women. Major findings from each emergent theme are presented below.

#### *PrEP Knowledge and Awareness*

The majority of participants had heard of PrEP prior to the focus group. Participants reported hearing of PrEP through various channels such as commercials on television, television shows, magazines, and at their place of employment. The majority of participants reported working in the health care field and contributed their awareness of PrEP to their occupation. One woman stated, "If I wasn't working here, I know I probably would never have heard of PrEP. When I worked at [health insurance company], I knew HIV, but I didn't know HIV." Several women said they had heard of PrEP from relevant television shows featuring a predominantly African American cast. One participant had heard of PrEP through a family member who was a MSM and had started taking PrEP.

#### *PrEP Not Targeting African American Women*

All groups expressed that although they had heard of PrEP, the advertisements and promotions for PrEP targeted mainly MSMs, and were therefore not relatable to African American women. Several women believed this was a reason why many African American women are still unaware of PrEP. One participant commented, "PrEP should be marketed to anyone who is having sex." Some participants mentioned that more recent advertisements for PrEP have started to include women and African American women, but they only make a small appearance, so the advertisements still do not feel targeted towards African American women. One participant said, "There has been more focus on getting PrEP and PrEP information into the MSM community. The same has not been on women and African American women who are at high risk for HIV."

#### *Providers Not Promoting PrEP*

No participants had heard of PrEP through their provider. Some participants felt that their provider was only concerned about birth control and preventing pregnancy. Several women mentioned that they would have been interested in PrEP if their provider would have recommended it. One participant shared, "If I would have known, and my provider would have shared this information, I probably would have known about PrEP, and probably would have

at least used it before to know what it's like. But guess that's why I'm here." Some women also felt that providers target their PrEP recommendations to MSM and fail to consider women and others who may be eligible for PrEP. One woman hesitantly said, "And it seems like providers mainly, and this is, I mean it's bad, but mainly they're told to talk about PrEP with MSM. They don't really talk about promoting it with other like heterosexuals."

### *Poor Marketing*

All participants agreed that the African American community had very little awareness or knowledge of PrEP. One participant argued that PrEP hasn't infiltrated the "urban market" strong enough yet to know that there is a product that can help those who are HIV negative. Another participant commented, "I think it should be marketed more to African Americans because we are the highest risk of people becoming newly infected with HIV. So I think it's a great thing, but we are unaware of it. A lot of people don't know a lot about it."

Overall, general knowledge of PrEP was high among participants — however, the majority of participants worked in the HIV or health field. For the participants who did not work in the field and still had heard of PrEP, they still did not know about the side effects, the timeframe for the drug to go into effect, and the guidelines and criteria for taking PrEP (e.g., routine HIV screenings, routine STI screenings, and routine provider visits to assess kidney function). Several participants questioned how long the drug had to be taken to be effective and to continue preventing HIV. The majority of participants working in the field felt that most African American women do not know about PrEP, but are aware of the HIV risk and epidemic in the African American community.

Outside of women working in this field, and not all of them working in this field because every agency is not as thorough as ours [HIV/AIDS service organization], I don't know anybody I could walk up to now, if I'm just going to go do outreach, and I asked any woman, any black woman, how many days it takes before PrEP is it effective in your body? Nobody is gonna tell me twenty-one days. That's how inadequate the education, the rollout, and exposure of PrEP is in our community.

### *Perceptions of PrEP*

#### *Stigma*

The majority of participants believed there was a stigma associated with PrEP. Many participants felt that taking PrEP was associated with "unfaithfulness" and "cheating." Some participants believed that research and clinical trials do not accurately represent what would happen in real life situations with couples who try to take PrEP; emphasizing that the majority of couples would have an issue with their partner taking PrEP.

Participant: What comes out of research and clinical trials is not what happens in real life. The first thing that African American says is 'you must not only be fucking me.'

Participant: That's right. Yeah. It's that stigma.

Several participants mentioned that they would doubt or question their partner if they started to take PrEP; however, if their partner was taking PrEP before they started dating then they would be more accepting of them taking PrEP. One woman commented:

I would be a little bit, um, I think I would be a little bit offended because I know myself and it probably would make me start to wonder 'okay, so are you doing something that I need to know about?' It would probably bring that into my mind a little bit, but if it were a scenario where we just met and the person was on it, I think it would be fine.

Several participants believed that people who take PrEP are more promiscuous and tend to have more sexual partners. One participant responded, "Yeah, they love to have sex with everybody."

### *Sex Practices on PrEP*

The majority of participants believed that their sex practices on PrEP would either remain the same or become riskier than their current sex practices; reporting that they most likely would not use a condom on PrEP. One participant compared PrEP to the birth control pill, saying that it would give them more of a reason not to use a condom and that the combination of birth control and PrEP together may result in people feeling "invincible." A minority of participants said they would "try" to use a condom still if they were on PrEP, particularly if they doubted the monogamy of their relationship. One woman stated:

I would say, if I could like absolutely, 100% trust somebody, that I probably, to be honest, probably would engage in just not using a condom. Because I'm trusting that we're in a monogamous relationship and we're not going to step out on each other. But I guess just being realistic, at least from my situation... I'd probably stay strapped up [use a condom] and use PrEP too.

Several participants questioned how PrEP was better or any different from using a condom, given that they still should use a condom consistently when on PrEP.

Participant: And so one of my issues, my personal issue with PrEP, is that they say use PrEP in conjunction with the condom. So what is the PrEP doing that the condom is not doing?

Participant: STDs.

Participant: No, the condom is going to prevent that [STDs] and HIV as well. That's what I'm saying. The condom works. The condom works.

Some participants felt that PrEP could help promote regular testing among couples who decided to take PrEP either together or singularly. One participant, that routinely received HIV screenings with her partner, felt that it would make the conversation around getting tested every three months easier so that she wouldn't have to ask her partner every three months. She stated, "If I said 'hey there's a pill out, let's start taking it because we get tested every few months anyways'...I think that it can help me get him to get tested without the every 3-month discussion that we have to have about it."

### *Beneficial for Women in Non-Monogamous Relationships*

All participants felt PrEP would be an effective HIV prevention strategy for African American women who are in relationships with a partner that has other sexual partners. Several participants mentioned that PrEP is for any woman who feels like they may be at risk, with one woman commenting, "Even if you're not high risk, you still want her to take it [PrEP] because you may be monogamous, but your partner may not be; because you got a lot of men that like to do that...undercover." The majority of participants expressed that they believe most relationships are no longer monogamous and PrEP could be used to "protect" women who may have "concerns" about their partner, or who may be aware of their partner's additional sexual partners —especially when they decide to stay with this partner. One woman said:

Some women know they partners cheating, but they still want that person. So they go along with it when they should be using PrEP or using condoms, but they want to keep that person and they know that they're not sleeping with just them. Maybe they're a good provider, so they gonna over look."

Several participants acknowledged the physical benefit PrEP could provide to women who are experiencing a partner who is sexually active with others, but participants also mentioned the potential emotional and psychological impact PrEP may have on these women. Participants discussed how PrEP could provide a positive sense of empowerment and protection to women. One woman shared, "I would see it like, as me like, taking my power back. Like you going to sleep with such-and-such, well I'm going to take this pill, and I'm not going to tell you I'm taking it, but I know that I'm protecting myself." Some participants mentioned the potential negative effects PrEP may have by serving as a daily reminder that their partner is "unfaithful" and were concerned about the toll it may take on them mentally; however, participants agreed that the benefits outweighed the potential negative effect. One participant explained:

I think physically it's great for her for the obvious reason. I just think that there's an emotional or psychological component that comes with that. Like, every day that she puts that pill in her mouth, she's kind of being reminded of why she's doing it. Because I think, for any of us that have had that suspicion or concern, it can kind of nag at you. And just to put that pill in your mouth every day because of that concern, I think that would be something different. Especially if it wasn't something that I communicated to my partner, like 'oh

I'm going to start taking this just because I want to protect myself;' but if I'm doing it and not having that conversation because I know or I think you're doing something...it would eat me up.

All participants agreed that PrEP gives women who may be in an abusive relationship or forced to have sex with their partner who is “stepping out” a chance to be “proactive” and to protect themselves. One woman said, “You gotta protect yourself. If you're not worried about the other person, at least be worried about yourself.” These participants also felt that PrEP was a good option for women who are at high risk of HIV or in a relationship with someone who is HIV positive. One participant commented, “If I was dating somebody or having sex with somebody that I know is HIV positive, then I'd want to protect myself of course with condoms; but if PrEP is going to help, I'd remember to take that pill everyday then.”

### *Disclosure of PrEP Use*

The majority of participants felt that PrEP would protect their sexual health and would allow them to take their health into their “own hands,” given the epidemic in the area. The majority of participants reported that they wouldn't let their partner know that they are taking PrEP because it might make their partner think that they are trying to cheat or might make their partner think they can go engage in riskier behaviors. Participants felt that the decision to take PrEP, was a personal choice and strategy to take care of themselves, and also could be taken discreetly without their husband or partner knowing. Two of the participants commented:

Participant: And that's like personal health. That's not...well it is sexual related, but it's not like pregnancy where if you know you're expecting to have a child and then you withdrew from birth control, or you added yourself on birth control, and you didn't talk to your husband about it... maybe that could be an issue. But this is, I think it's more of like, just personal for you. It's strictly just taking care of yourself.

Participant: Yeah, a choice you're making.

Participant: It's like a vitamin for HIV prevention.

Participant: Mmhmm, that's right. I agree with that. Nine out of ten, if he already in another relationship, he's not paying that much attention to what you taking anyway. Like you said, it can be a vitamin. That's right.

However, several participants reported that they would feel comfortable bringing up PrEP to their partners, with several participants saying that they were comfortable telling their partner that they need to get tested before they have sex, so bringing up PrEP would not be an issue.



### *Experiences with PrEP Clients*

Several participants actively counsel and test individuals who are currently taking PrEP. Their experiences with PrEP clients have been mixed; however, most mentioned negative experiences and perceptions of the PrEP clients. Several participants believed that clients on PrEP are not provided with a thorough education of PrEP prior to being prescribed the medication. These participants also reported that the majority of PrEP clients do not follow-up every three months for their required testing. Moreover, participants reported that many PrEP clients continue to come back in testing positive for other STIs. Participants believed that their PrEP clients were getting a false sense of protection against more than HIV, or they were no longer worried about getting other STIs because they were curable, unlike HIV. One participant shared “Some people that come in, and they on PrEP, we tell them make sure they use the condoms. And one guy told me ‘Well, I’m young.’ I said, ‘But you leaving here with syphilis.’ You know, he say ‘Well I don’t have HIV. I’m taking my PrEP,’ I’m like, ‘but you still got syphilis.’” Several participants commented:

Participant: But I think PrEP messes up people really bad, because I have a lot of clients that take PrEP, but they still coming in having gonorrhea, chlamydia, and syphilis.

Participant: Because it’s just stopping that [other STDs].

Participant: It’s only preventing HIV. It’s not preventing the other STDs.

Participant: So you still gotta use condoms. I mean, you gotta be smart.

Participant: But they don’t worry about that because you can get treated for chlamydia. You can get treated for gonorrhea. You can get treated for syphilis. So they don’t worry about it. They like, ‘I’m good.’

Participant: They’re just worried about HIV.

### *Willingness to Use PrEP*

#### *Willing to Use PrEP*

Participant’s willingness to use PrEP had mixed responses. Roughly 59% of the participants said they would be interested in using PrEP. Several of these participants said that they would consider using PrEP if it were recommended to them by a provider. One woman said, “I think if I was in a high risk situation, you know, if my doctor would talk to me about PrEP, maybe I would consider it more; but I do worry about the long term effects of everything”. Those who were interested in taking PrEP thought it was a good method to prevent HIV, as long as they used a condom and were not “promiscuous.” Most women said they would start PrEP immediately if it was available and covered by insurance. One participant said, “I’m gonna call my doctor and tell him give me this shit [PrEP]. Gimme my PrEP.”

Willing participants also said that they would want to know more about the research that has been conducted on PrEP before they start taking it. Participants were interested in knowing who the research participants included, the number of participants that contracted HIV while on PrEP, and the percentage of participants that were taking the medication correctly. One participant commented, “I feel like I learned something. I think that it’s very useful because I hadn’t heard about it before, um, and I do want to tell more people about it. And I’m hesitant, but I’m willing and I’m open, you know? So I will be looking more into it when I get home.”

Among the participants willing to use PrEP, there were still concerns around the potential long-term side effects and about how long they would have to take PrEP. One woman commented:

My worry would just be the consistent part. Like when can I stop? Like I shouldn’t have to take this for the rest of my life; I’m even considering like being married, and still having to protect myself. I still have to take PrEP? I don’t want to have to do that. I’d still have to take PrEP, so I’m literally going to have to take PrEP until I die. That’s just my opinion.

### *Not Willing to Use PrEP*

Of the participants that were not willing to use PrEP, several mentioned that they would not take PrEP because they felt it was associated with distrust in the relationship. Some participants were still hesitant to take PrEP because of the “newness” of the drug, the potential side effects, and risk to their kidneys. All of the non-interested participants said that they would still recommend PrEP to women who may be high-risk or eligible, but believed that women in relationships may not be receptive to PrEP.

Participants that considered themselves not very sexually active said they would not be interested in PrEP at the moment, but they would promote PrEP to other women. However, these women stated that if they became more sexually active in the future then they would be very interested in starting PrEP.

### *Concerns about PrEP*

Several concerns about PrEP were discussed among participants. Potential health issues and side effects caused by PrEP were two main concerns among participants. Many participants were concerned about the harshness of the medicine and the potential long-term effects. One participant commented, “We know how harsh HIV medications are. Why take this medication, that has to go through my kidneys, and may potentially affect me 15 to 20 years down the road, versus using the damn condom?” Some participants were particularly concerned with the potential effects PrEP could have on their reproductive system; especially, if they wanted to have children in the future.

The mistrust of the health care system that still exists in the African American community was also a concern. Some participants discussed how one “bad” incident that

someone may experience on PrEP in the Black community may cause complete distrust of the medicine. One woman commented, “It only has to happen to one Black person and all Black people will start saying that PrEP caused kidney disease.” Participants also stated that it is difficult for the African American community to trust new innovations due to the substandard health care they received for over 100 years. One participant mentioned how most African Americans do not participate, “as a rule,” in clinical trials and so new medications were “not made to work on us from the beginning.” Another woman agreed and responded saying, “So new innovations are always harder too. We are not, in public health terms, ‘early adapters’. We’re more laggards. It takes us a little longer.”

Additional concerns about PrEP included potential effects on women’s sex drive, being able to meet the criteria to stay on PrEP, worries that the medication may show up on a drug test for work, and affordability and access among African American women. One woman said, “You can’t pay for the medicine or the doctor. So if you want to start and pick a target population, start where people have jobs, with insurance, that can afford PrEP, without a barrier — or just make PrEP affordable.”

### *Recommendations to Increase PrEP Uptake among African American Women*

Participants were asked for their suggestions and recommendations to improve PrEP awareness and use among African American women in the South. Several key strategies were proposed and discussed, which included targeted campaigns, use of a relatable PrEP spokesperson, increasing support from the African American community, and targeting younger generations. Regardless of what tactic was used to promote and advertise PrEP moving forward, all participants agreed that they need to come together within the African American community to show a concerted effort and support for PrEP.

### *Targeted Campaigns and PrEP Spokesperson(s)*

All participants mentioned and agreed that campaigns moving forward need to target African American women, and not only MSM and transsexuals. Future commercials and marketing tactics should have advertisements that only focus on African American women to ensure women feel relatable to the situation and to increase their interest in PrEP. Participants believed that any campaign moving forward should recruit or hire on a “PrEP spokesperson” that is both relatable and inspirational to African American women. Several women recommended a celebrity that is open about taking PrEP and promotes taking PrEP, to be used as a spokesperson. Through these updated and targeted campaign strategies, participants believed that PrEP could become “normalized” in the African American community.

I also think that part of the rollout, and the uptake of PrEP, is going to have to be to come up with some type of massive campaign that normalizes it. Like they did with birth control; the birth control pill eventually became normal. It

became that you didn't hide that round thing in everybody's pocketbook. They be having lunch and pop it out. And you know you would no longer hide your pills and don't want nobody to know. And until we get there with PrEP, then we're still gonna have an uphill roll. We're not there yet. You know, in the African American community, with African American women across age groups, we have not gotten there yet. And so that's part of the rollout, the normalization of PrEP, a spokesperson, a face — recognizable, famous, what have you.

### *Frequented and Targeted Areas*

Participants discussed target areas in the South where advertisements and campaigns for PrEP need to be targeted such as clubs, churches, and doctor's offices in the African American community. One participant commented, "I mean in the South, what do people do most of the time? They either go to the club or they go to church. And so, if it's being discussed in either of those places, they may be more receptive to it." Another participant mentioned that future efforts may have difficulty getting into churches to promote PrEP given the sensitivity of the topic, and would have to be strategic about who the information comes from in the church. This participant compared her story of trying to teach safe sex practices in the church by sharing:

It depends on the connection within the church, I think. Because for my church, if you, for example went to my pastor's wife and she received it well, then everyone would really get on board with it. Um, if you asked me, like they were upset that I was promoting safe sex to the youth, so like it just depends on who it's coming from. When it was me it was wrong, but when she said it, it was okay. So I think for you to do that, you would have to be very strategic about who you went to and how you presented it.

### *Promote PrEP Earlier*

The majority of participants felt that future tactics needed to start promoting PrEP sooner among younger generations and sooner in the relationship cycle. Participants highly recommended using social media platforms to promote PrEP to the youth using sponsored advertisements. One participant commented, "They're always on social media, for everything." Participants also recommended that PrEP be promoted and targeted at high schools, universities and colleges, in order to reach the younger generations. Most participants mentioned how sexual activity comes sooner than it used to in relationships; now people are having sex before they "really get to know one another or before courting one another." One participant shared:

You had to sit in that living room, you had to talk to them, and now we are using the sex and intimacy to decide whether or not you go court and get to know each other. The sex comes first to decide if you're going to court. So the risk now comes first. So now PrEP has to come first before as a health issue and not as a sexual issue. Because now, getting to know somebody is judged on whether you go out with him again. So because of the shift, we will have to shift our messages

about protection, prevention, and PrEP, and things of that nature. We're gonna have to start sooner.

## Discussion

The participants expressed and emphasized their concerns about the “newness” of PrEP and possible side effects. Although they were informed of the drug's 2012 release date and supportive research demonstrating no-low side effects, women were questionable of the short timeframe and accuracy of the research findings. Evidence of PrEP safeness and effectiveness were not relatable due to the lack of research targeting specifically African American women and PrEP. Continued research involving African American women and PrEP should focus on the clinical outcomes of PrEP for this population to improve acceptance and uptake of PrEP among African American women.

Findings related to PrEP awareness and knowledge were similar to previous studies, (Bradley et al., 2019) demonstrating there is still a lack of information and promotion targeting potential PrEP user groups, specifically African American women. Although overall knowledge and awareness was high among participants, the majority of African American women are still unaware of PrEP as a method of HIV prevention. Additionally, PrEP promotion and advertisement efforts have focused mainly on targeting MSM, which has made PrEP advertisements not relatable to African American women, resulting in no-to-low interest in PrEP use.

Participants were supportive of PrEP when sexual partner sharing and lack of monogamy were of concern. Similar to other studies, women believed PrEP to provide a sense of protection and empowerment (Bond & Gunn, 2016; Smith et al., 2012). Our participants highlighted this advantage by conveying that PrEP provided an opportunity to “take their sexual health into their own hands” and to “take back control.” Other than the female condom, PrEP is the only female-controlled HIV prevention method. For women who may experience concurrent sexual partnerships or abusive situations where they are forced to have sex without consent, PrEP may serve as a practical and discrete option for HIV prevention.

There were no significant differences among focus group participants in regards to awareness, concerns, and recommendations of PrEP. There were several differences around willingness to use PrEP and perceptions of PrEP among participants. Eleven participants were not willing to start using PrEP for HIV prevention; however, the remaining 16 participants were willing to use PrEP, with many stating that they were eager to start taking PrEP immediately if it was available and covered by insurance. Participants who described themselves as low-risk individuals and reported low-risk behavior, had a high willingness to use PrEP. The high willingness to use PrEP could be reflective of their need to engage in continued safer sexual practices (e.g., consistent condom use) or engaging in very little sexual activity. However, not reflective of their current approach to sexual activity, these participants, along with the other participants reported they would be less likely to use a condom if on PrEP — demonstrating

that even women who practice safe and responsible sex can feel a sense of invincibility on PrEP. It is imperative that potential PrEP users receive a proper and thorough education of PrEP and how it works most effectively with condom use prior to uptake.

Our study was unique in that several participants provided testimonies about experiences they have had with their PrEP clients. The majority of these participants only provided negative experiences involving their PrEP clients. For example, many of their PrEP clients do not follow the drug criteria for regular testing and follow-up visits, and many test positive for STIs and become “repeat offenders.” It was believed that PrEP created a false sense of protection against more than HIV and concern about other STIs was lessened given their curable nature. Continuing to witness PrEP clients incorrectly using and abusing the medication could negatively impact both health care professionals’ and African American women’s perception of and promotion of PrEP. Providers must work to improve knowledge of PrEP, requirements for PrEP, and enforcement of PrEP requirements for those who are interested and begin taking PrEP. However, research has found that providers do not envision themselves to be primarily responsible for prescribing PrEP (Krakower et al., 2014). Future efforts to increase PrEP uptake may focus on PrEP promotion, counseling, and prescription recommendations mainly through counselors and other health care workers.

Recommendations to improve PrEP awareness and use among African American women in the South were provided. Similar to previous research, participants identified venues such as doctor’s offices, billboards, social media, schools and peers (Auerbach et al., 2015). Other areas recommended included places that participants considered to be most frequented and prominent in the African American community in the South, which included churches and clubs. Participants felt strongly that future PrEP efforts should involve a targeted campaign for African American women and should include a PrEP spokesperson who is both relatable and a user of PrEP. Comparably, a recent review recommended conducting gain-based stigma-reduction campaigns as an approach to address complex challenges to PrEP implementation in the South (Sullivan et al., 2019). Future PrEP efforts should focus on reaching the youth population and should take into account that sexual activity is occurring sooner in the relationship cycle compared to older generations. These efforts will aid in the normalization of PrEP awareness and use among African American women, and within the African American community.

To our knowledge, our study was one of the first to conduct qualitative focus groups to explore knowledge, perceptions, and willingness of PrEP use among African American women in the rural South. However, there were several limitations to our study. First, the sample size of 27 focus group participants was small and took place in a single community in Columbia, South Carolina. Second, the sample may have been biased due to the majority of participants being health care professionals or directly working in the field of HIV. Conversely, this also allowed us to gather unique insight related to health care workers’ perceptions, support, and potential willingness of PrEP use, that were not specifically medical providers’ opinions as examined in previous research.

## Conclusion

Our study provides findings that are encouraging of potential PrEP interest and use for HIV prevention among African American women in the South. Future PrEP research focused on African American women should examine 1) determinants that influence actual PrEP use and adherence, 2) sexual risk behaviors and STI incidence while using PrEP, 3) outcomes of PrEP use disclosure, 4) stigma and/or acceptability of PrEP use, and 5) short-term and long-term side effects of PrEP use. The findings from our study provide targeted avenues for future research and PrEP implementation efforts for African American women in the South. Data from our study can inform the development of targeted campaigns aimed to increase PrEP awareness, knowledge, and uptake among African American women residing in areas experiencing the greatest burden of HIV.

Table 1. Participants' Demographic Characteristics, PrEP Focus Group Study

	n	%
Education		
9 <sup>th</sup> -12 <sup>th</sup> grade	2	7.4
Some college or university	9	33.3
Bachelor's degree	5	18.5
Higher education	11	40.7
Employment		
Employed	26	96.3
Disabled	1	3.7
Income		
Less than \$5,000	4	14.8
\$5,000-\$20,000	4	14.8
\$21,000-\$40,000	9	33.3
\$41,000-\$60,000	7	25.9
\$61,000	3	11.1
Health Insurance		
Yes	22	81.5
No	5	18.5
Relationship Status		
Single	16	59.3
Married	4	14.8
Partner	2	7.4
Divorced	4	14.8
Widowed	1	3.7
Sexual Orientation		
Heterosexual	25	92.6
Bisexual	2	7.4
Profession		
HIV field	10	37.0
Health field	6	22.2
Other	8	29.6
Student	3	11.1



## References

- Aral, S. O., Adimora, A. A., & Fenton, K. A. (2008). Understanding and responding to disparities in HIV and other sexually transmitted infections in African Americans. *Lancet*, 372(9635), 337-340. [https://doi.org/10.1016/S0140-6736\(08\)61118-6](https://doi.org/10.1016/S0140-6736(08)61118-6)
- Auerbach, J. D., Banyan, A., & Riordan, M. (2012). Will and Should Women in the US Use PrEP? Findings from a Focus Group Study of At-risk HIV-negative Women in Oakland, Memphis, San Diego, and Washington, DC. XIX International AIDS Conference, Washington, DC.
- Auerbach, J. D., Kinsky, S., Brown, G., & Charles, V. (2015). Knowledge, attitudes, and likelihood of pre-exposure prophylaxis (PrEP) use among US women at risk of acquiring HIV. *AIDS Patient Care and STDS*, 29(2), 102-110. <https://doi.org/10.1089/apc.2014.0142>
- Bond, K. T., & Gunn, A. J. (2016). Perceived Advantages and Disadvantages of Using Pre-Exposure Prophylaxis (PrEP) among Sexually Active Black Women: An Exploratory Study. *Journal of Black Sexuality and Relationships*, 3(1), 1-24. <https://doi.org/10.1353/bsr.2016.0019>
- Bradley, E., Forsberg, K., Betts, J. E., DeLuca, J. B., Kamitani, E., Porter, S. E., Sipe, T. A., & Hoover, K. W. (2019). Factors Affecting Pre-Exposure Prophylaxis Implementation for Women in the United States: A Systematic Review. *Journal of Women's Health (Larchmt)*. <https://doi.org/10.1089/jwh.2018.7353>
- Brooks, R. A., Kaplan, R. L., Lieber, E., Landovitz, R. J., Lee, S. J., & Leibowitz, A. A. (2011). Motivators, concerns, and barriers to adoption of preexposure prophylaxis for HIV prevention among gay and bisexual men in HIV-serodiscordant male relationships. *AIDS Care*, 23(9), 1136-1145. <https://doi.org/10.1080/09540121.2011.554528>
- Centers for Disease Control and Prevention. (2018). *Health Equity*. Retrieved June 21, 2019 from <https://www.cdc.gov/women/lcod/2015/black/index.htm>
- Centers for Disease Control and Prevention. (2014). *HIV in the Southern United States*. Retrieved June 21, 2019 from <https://www.cdc.gov/hiv/pdf/policies/cdc-hiv-in-the-south-issue-brief.pdf>
- Centers for Disease Control and Prevention. (2017). *HIV Prevention Works*. Retrieved June 21, 2019 from <https://www.cdc.gov/hiv/policies/hip/works.html>
- Centers for Disease Control and Prevention. (2017). *HIV Surveillance in Women, 2017*. Retrieved June 29, 2019 from <https://www.cdc.gov/hiv/library/slideSets/index.html>

- Centers for Disease Control and Prevention. (2019). *PrEP*. Retrieved June 21, 2019 from <https://www.cdc.gov/hiv/basics/prep.html>
- Centers for Disease Control and Prevention. (2019). *HIV in the United States and Dependent Areas*. Retrieved June 21, 2019 from <https://www.cdc.gov/hiv/statistics/overview/ata glance.html>
- Centers for Disease Control and Prevention. (2018). *HIV Surveillance Report, 2017*. Retrieved June 25, 2019 from <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>.
- Eisingerich, A. B., Wheelock, A., Gomez, G. B., Garnett, G. P., Dybul, M. R., & Piot, P. K. (2012). Attitudes and acceptance of oral and parenteral HIV preexposure prophylaxis among potential user groups: a multinational study. *PLoS One*, 7(1), e28238. <https://doi.org/10.1371/journal.pone.0028238>
- Flash, C. A., Stone, V. E., Mitty, J. A., Mimiaga, M. J., Hall, K. T., Krakower, D., & Mayer, K. H. (2014). Perspectives on HIV prevention among urban black women: a potential role for HIV pre-exposure prophylaxis. *AIDS Patient Care and STDS*, 28(12), 635-642. <https://doi.org/10.1089/apc.2014.0003>
- Galea, J. T., Kinsler, J. J., Salazar, X., Lee, S. J., Giron, M., Sayles, J. N., Cáceres, C., & Cunningham, W. E. (2011). Acceptability of pre-exposure prophylaxis as an HIV prevention strategy: barriers and facilitators to pre-exposure prophylaxis uptake among at-risk Peruvian populations. *International Journal of STD & AIDS*, 22(5), 256-262. <https://doi.org/10.1258/ijsa.2009.009255>
- Guest, G., Shattuck, D., Johnson, L., Akumatey, B., Clarke, E. E., Chen, P. L., & Macqueen, K. M. (2010). Acceptability of PrEP for HIV prevention among women at high risk for HIV. *Journal of Women's Health (Larchmt)*, 19(4), 791-798. <https://doi.org/10.1089/jwh.2009.1576>
- Heffron, R., Ngure, K., Mugo, N., Celum, C., Kurth, A., Curran, K., & Baeten, J. M. (2012). Willingness of Kenyan HIV-1 serodiscordant couples to use antiretroviral-based HIV-1 prevention strategies. *Journal of Acquired Immune Deficiency Syndromes*, 61(1), 116-119. <https://doi.org/10.1097/QAI.0b013e31825da73f>
- Jones, J. T., Smith, D. K., Wiener, J., August, E. M., Finlayson, T., Wejnert, C., & for the National, H. I. V. B. S. S. G. (2021). Assessment of PrEP Awareness, PrEP Discussion with a Provider, and PrEP Use by Transmission Risk Group with an Emphasis on the Southern United States. *AIDS and Behavior*. <https://doi.org/10.1007/s10461-021-03164-5>

- Khawcharoenporn, T., Kendrick, S., & Smith, K. (2012). HIV risk perception and preexposure prophylaxis interest among a heterosexual population visiting a sexually transmitted infection clinic. *AIDS Patient Care and STDs*, 26(4), 222-233. <https://doi.org/10.1089/apc.2011.0202>
- Krakower, D., Ware, N., Mitty, J. A., Maloney, K., & Mayer, K. H. (2014). HIV providers' perceived barriers and facilitators to implementing pre-exposure prophylaxis in care settings: a qualitative study. *AIDS and Behavior*, 18(9), 1712-1721. <https://doi.org/10.1007/s10461-014-0839-3>
- Krakower, D. S., Mimiaga, M. J., Rosenberger, J. G., Novak, D. S., Mitty, J. A., White, J. M., & Mayer, K. H. (2012). Limited Awareness and Low Immediate Uptake of Pre-Exposure Prophylaxis among Men Who Have Sex with Men Using an Internet Social Networking Site. *PLoS One*, 7(3), e33119. <https://doi.org/10.1371/journal.pone.0033119>
- Kwakwa, H. A., Bessias, S., Sturgis, D., Mvula, N., Wahome, R., Coyle, C., & Flanigan, T. P. (2016). Attitudes Toward HIV Pre-Exposure Prophylaxis in a United States Urban Clinic Population. *AIDS and Behavior*, 20(7), 1443-1450. <https://doi.org/10.1007/s10461-016-1407-9>
- Nydegger, L. A., Dickson-Gomez, J., & Ko Ko, T. (2021). A Longitudinal, Qualitative Exploration of Perceived HIV Risk, Healthcare Experiences, and Social Support as Facilitators and Barriers to PrEP Adoption Among Black Women. *AIDS and Behavior*, 25(2), 582-591. <https://doi.org/10.1007/s10461-020-03015-9>
- Nydegger, L. A., Dickson-Gomez, J., & Ko, T. K. (2020). Structural and syndemic barriers to PrEP adoption among Black women at high risk for HIV: a qualitative exploration. *Culture, Health & Sexuality*, 1-15. <https://doi.org/10.1080/13691058.2020.1720297>
- QSR International Pty Ltd. (2018) NVivo (Version 12), <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>
- Smith, D. K., Toledo, L., Smith, D. J., Adams, M. A., & Rothenberg, R. (2012). Attitudes and program preferences of African-American urban young adults about pre-exposure prophylaxis (PrEP). *AIDS Education and Prevention*, 24(5), 408-421. <https://doi.org/10.1521/aep.2012.24.5.408>
- Sullivan, P. S., Mena, L., Elopore, L., & Siegler, A. J. (2019). Implementation Strategies to Increase PrEP Uptake in the South. *Current HIV/AIDS Reports*, 16(4), 259-269. <https://doi.org/10.1007/s11904-019-00447-4>

- Towe, S. L., Sullivan, C. A., McKellar, M. S., & Meade, C. S. (2020). Examining the Potential of Pre-exposure Prophylaxis (PrEP) for HIV Prevention in a Community Sample of Persons Who Use Stimulants Living in the Southern United States. *AIDS and Behavior*. <https://doi.org/10.1007/s10461-020-02987-y>
- Walters, S. M., Kral, A. H., Simpson, K. A., Wenger, L., & Bluthenthal, R. N. (2020). HIV Pre-Exposure Prophylaxis Prevention Awareness, Willingness, and Perceived Barriers among People Who Inject Drugs in Los Angeles and San Francisco, CA, 2016-2018. *Subst Use Misuse*, 55(14), 2409-2419. <https://doi.org/10.1080/10826084.2020.1823419>
- Whiteside, Y. O., Harris, T., Scanlon, C., Clarkson, S., & Duffus, W. (2011). Self-perceived risk of HIV infection and attitudes about preexposure prophylaxis among sexually transmitted disease clinic attendees in South Carolina. *AIDS Patient Care and STDs*, 25(6), 365-370. <https://doi.org/10.1089/apc.2010.0224>
- Wingood, G. M., Dunkle, K., Camp, C., Patel, S., Painter, J. E., Rubtsova, A., & DiClemente, R. J. (2013). Racial differences and correlates of potential adoption of preexposure prophylaxis: results of a national survey. *Journal of Acquired Immune Deficiency Syndromes*, 63 Suppl 1, S95-101. <https://doi.org/10.1097/QAI.0b013e3182920126>

## **Conspiracy Beliefs about HIV/AIDS among HIV-Positive African American Men and Women in Alabama's Black Belt: A Mixed-Method Analysis**

**Andrew A. Zekeri, B.Sc, M.Sc., Ph.D.**

Professor of Sociology

Department of Psychology and Sociology

Adjunct Professor of Sociology

National Center for Bioethics in Research and Health Care

Tuskegee University

Phone: 334) 727-8086

Email: [azekeri@tuskegee.edu](mailto:azekeri@tuskegee.edu)

### **Authors' Note**

Part of this research was funded by a grant from the U.S. Department of Agriculture, Economic Research Service through Southern Rural Development Center, Mississippi State University. The opinions and conclusions expressed herein are solely those of the author. I want to express my deep and sincere gratitude to the HIV-Positive patients that participated in the study. Study procedures were reviewed and approved by the Tuskegee University Office of Research Compliance. My heartfelt thanks must go to two anonymous reviewers of the journal for their review and suggestions and support of the manuscript.

### **Abstract**

Despite prior studies showing that a significant proportion of the general African-American population hold conspiracy beliefs about HIV/AIDS, limited research has investigated conspiracy beliefs among African Americans that are HIV-positive and the subgroups most likely to endorse such beliefs. I examined endorsement of HIV/AIDS conspiracy beliefs and their relationship to sociodemographic variables among 256 African Americans with HIV infection. Quantitative and qualitative methods were used in the study at an AIDS Outreach Organization clinic in Alabama that provides medical and social support services to HIV-positive persons. Patients reported agreement with statements capturing beliefs in HIV/AIDS conspiracies. Results indicated that about one-third subscribed to the notion that "AIDS is a form of genocide against Blacks" (29.7%) and some 27.7% of the respondents said that "AIDS was created by the government to control the black population." Regarding treatment-related conspiracy beliefs, over one-third (35.6%) somewhat or strongly agreed that "people who take the new medicines for HIV/AIDS are human guinea pigs for the government," while 29.9% somewhat or strongly endorsed the statement that "the medicine that doctors prescribe to treat HIV is poison."

Results of multivariate analyses indicated that stronger HIV/AIDS conspiracy beliefs were significantly associated with educational attainment and age. A set of sociodemographic

variables explained a small amount of the variance in conspiracy beliefs about HIV/AIDS ( $R^2$  range=0.13-0.14). Qualitative results indicated that conspiracy beliefs are barrier to medication adherence among these patients living with HIV/AIDS. Focus group discussions suggested that conspiracy beliefs can be important barriers to quality of life and infection control among HIV-positive individuals. These findings suggested that addressing conspiracy beliefs should be a significant issue in HIV/AIDS treatment and prevention programs in the 21st Century.

*Keywords:* Conspiracy Beliefs, HIV/AIDS, African Americans, Alabama Black Belt

### Introduction

The human immunodeficiency virus (HIV), which causes acquired immunodeficiency syndrome (AIDS) has been plaguing black communities across the United States. African Americans are infected at a disproportionately higher rate than other ethnic groups. Although they are about 13% of the population, African Americans made up 51% of HIV/AIDS cases reported in 2020 by the 33 states using confidential, name-based reporting (Parson 2021).

Clearly, there is a need for a rigorous prevention and treatment efforts as well as programs in African American communities to prevent and stop the spread of HIV/AIDS. Some studies over the past three decades revealed that many African Americans endorsed conspiracy beliefs about HIV/AIDS (Parsons 2021; Zekeri 2009; 2018; 2019) and emphasized the need to take into account these beliefs when discussing HIV/AIDS prevention strategies among African Americans.

Although these studies have documented the prevalence of HIV/AIDS conspiracy beliefs in the general African-American population and the implications of the beliefs for preventing HIV, I found limited study that examined conspiracy beliefs among African Americans with HIV infection in the rural south. Only one study examined conspiracy belief concerning the creation of AIDS by the government and information being withheld about the disease in a sample of 611 HIV-Positive individuals (Whetten et al., 2006). The reason for this dearth of information may be due to the difficulty in getting those infected with HIV/AIDS to participate in exploratory studies. If efforts to prevent and also stop the spread of HIV/AIDS in black communities are to be beneficial, we should take into consideration the beliefs of African Americans with HIV infection about the origins of the disease. Patient factors such as myth about HIV and distrust of the medical system may influence effective treatment of African American patients.

As an extension of my previous research (Zekeri 2009; 2016; 2018; 2019) and that of other researchers (Bogart and Bird 2005; Bird and Bogart 2005; Herek 1994; Klonoff and Landrine 1999; Parson et. al., 1999; Parsons 2021), the current study examined the extent to which African Americans with HIV infection living in Alabama's Black Belt, the home of the Tuskegee Syphilis study, endorse a range of conspiracy beliefs about HIV/AIDS and the relationship of their sociodemographic characteristics (gender, educational attainment,

and age) to their beliefs. It is important to document whether African Americans with HIV infection endorse a wide range of HIV/AIDS conspiracies because such beliefs can lead African Americans to be distrustful of HIV/AIDS related information and intervention efforts. Further, knowing the subgroup of the HIV-positive individuals most likely to endorse the beliefs in conspiracies about HIV/AIDS will help social workers, public health workers, health researchers, and practitioners develop efficient intervention programs for ethnic groups. Information on sociodemographic variables will be useful in HIV/AIDS prevention interventions that are culturally relevant. This is because lumping individuals of different identities and experiences into the same social category because they share a common route of infection and targeting uniform prevention programs to these social groupings will not be effective in stopping the spread of HIV/AIDS in communities of color.

As indicated above, several studies have noted that a significant percentage of African Americans hold conspiracy beliefs regarding HIV/AIDS (Bogart 2005; ) For example, Herek and Capitano (1994) found that 20% of African Americans agreed with the statement, “The government is using AIDS as a way of killing off minority groups” compared to 4% of whites. Lower levels of education and income were associated with the belief that the government is using AIDS as a way of killing off the minority groups.

Klonoff and Landrine (1999) surveyed Black adults in San Bernardino County, California and found that 14% of their respondents agreed, and 12% somewhat agreed, with the statement “HIV/AIDS is a man-made virus that the federal government made to kill and wipe out Black people.” Respondents who had higher levels of education (i.e., college versus high school graduates) were most likely to agree with this statement. This contradicts Herek and Capitano’s findings. Parsons, Simmons, Shinhoster, and Kilburn (1999) found that almost 70% of their respondents did not believe that the government is telling the truth about AIDS, and more than 25% agreed that AIDS was “intended to wipe Blacks off the face of the earth.”

Whetten et al. (2006) and her associates interviewed a sample of 611 HIV-positive individuals in 5 states of the deep south (North Carolina, South Carolina, Georgia, Alabama, and Louisiana). More than 25% of the respondents believed that the government created AIDS to kill minorities, and more than 50% believed that a significant amount of information about AIDS is withheld from the public. Though this study is useful in pinpointing the influence of conspiracy beliefs on health service use, the researchers did not examine a full range of conspiracy beliefs among African Americans with HIV infection.

Overall, prior research findings have shown the prevalence of conspiracy beliefs among African Americans in general (Parsons, Simmons, Shinhoster, and Kilburn (1999). However, the degree to which such beliefs are common among HIV-positive African Americans has not received much empirical attention. Research assessing the relationship of conspiracy beliefs to sociodemographic variables among HIV-positive African Americans is very important for understanding how such beliefs may be barriers to HIV/AIDS prevention and treatment efforts within the black communities. In the present study, I extend the horizons of previous studies

by examining the relationship between sociodemographic variables and endorsement of HIV/AIDS conspiracy beliefs among a sample of African Americans that are HIV-positive living in Black Belt Counties of Alabama one of the nation's poorest regions.

## METHODS

### *The Study Site*

The study area, Alabama's Black Belt, is a region where most of the African American Alabamians live. While there is a distribution of African Americans across Alabama, many continue to be concentrated in the southern portion of the state called the Black Belt. Black Belt as used in this work designates the counties where African Americans outnumber the whites, that is the density of black people. The region is one of the poorest in the nation and the majority of the residents are welfare dependent. The Black Belt with its higher than average percentage of African Americans (about 80%) is home to persistent poverty, poor employment, unemployment, limited education, poor health, Temporary Assistance for Needy Families (TANF) recipients, single parenthood and heavy dependence on public assistance programs (Zekeri 2020). The Black Belt is, indeed, a unique, disadvantaged region in the south.

### *Sample and Data Collection*

The present qualitative and quantitative studies were part of a larger longitudinal project that is examining HIV/AIDS, Food Insecurity and poverty in Alabama's Black Belt Counties. The study started in summer 2005 at an AIDS Outreach Organization in Alabama that provides medical and social support services to HIV-positive persons in Southeast Alabama.

For confidentiality purposes, only the staff of the AIDS Outreach informed the patients of the opportunity to participate in the study. The Adherence Nurse gave the questionnaire to patients and they completed the survey on a voluntary basis in a private room within the clinic. I obtained verbal informed consent prior to participants filling out the survey. Each patient was given a \$15 Wal-Mart gift card after completing the questionnaire. The study protocol was approved by the human subjects review board of Tuskegee University. This sub-analysis focused the 256 (114 females and 142 males) African Americans who completed the questionnaire.

### *Measures*

**HIV/AIDS Conspiracy Beliefs.** I adapted the conspiracy beliefs in Table 1 from previous studies (Zekeri 2009; 2018; 2019). Respondents were instructed to record their agreement with 10 statements capturing HIV/AIDS conspiracy theories (for example, "A lot of information about AIDS is being held back from the public," "HIV is a manmade virus," "AIDS is a real public health threat," "There is a cure for AIDS, but it is being withheld from the poor," "AIDS is a form of genocide against blacks," "The government is not telling the truth about



AIDS,” and “AIDS was created by the government to control the black population.”) The scale was from 1 (disagree strongly) to 5 (agree strongly). The items were averaged and combined into one overall scale with higher scores indicating greater endorsement of HIV/AIDS conspiracies (Cronbach’s alpha = 0.89). We reverse-scored “The government is not telling the truth about AIDS” before including it in the scale.

### *Sociodemographic Variables.*

Patients were asked questions to assess their gender, educational attainment, marital status, and age. Gender is sex of the respondent (1 = male and 2 = female). Educational attainment was measured by four categories: (1) did not graduate from high school; (2) completed high school; (3) some college or vocational school; (4) completed college. Education was dichotomized into “no high school” versus “high school and college graduates.” Age is age of the respondent in years. Age was dummy coded as young (18-34) and old (35-63) for the analysis.

### *Statistical Analyses*

Analyses to determine whether endorsement of conspiracy beliefs varied by sociodemographic variables were performed using the SPSS software version 14 (SPSS Inc, Chicago, Illinois) for Windows (Microsoft Corp, Redmond, Washington). Multiple linear regression analyses assessing the relationship between each of the sociodemographic variables to conspiracy beliefs scale were performed for the overall sample and by gender. The estimation of the probability that an association is not due to chance was based on chi-square statistics. A significance level of 0.05 was used for all analyses.

## **RESULTS**

### *Sample Characteristics*

The sample is heterogeneous in terms of socio-demographic characteristics (Table 1). Of the 256 respondents, 55.5% were men. Over half were not married, and only 18.4% were married at the time of the study. A substantial proportion were 35 years or older. Almost a third had some college or vocational education, and 29.7 had a high school diploma.

### *Conspiracy Beliefs*

Results in Table 2 indicate that many patients endorsed conspiracy beliefs about HIV/AIDS. For example, more than half (68.4%) somewhat or strongly believed that, “A lot of information about AIDS is being held back from the public,” and 51.2% somewhat or strongly endorsed the statement that “HIV is a manmade virus,” while 55.1% agreed that “there is a cure for AIDS, but it being withheld from the poor.” Moreover, almost 88% somewhat or strongly agreed that, “AIDS is a real public health threat,” and 40.2% believed that “AIDS was produced in a government laboratory.” About one-third subscribed to the notion that “AIDS is

Table 1. Characteristics of Patients (N = 256)

	n	Percent
<b>Gender</b>		
Male	142	55.5
Female	114	44.5
<b>Marital Status</b>		
Single	150	58.6
Married	47	18.4
Living with a partner	21	8.2
Separated	13	5.1
Divorced	25	9.8
<b>Educational Attainment</b>		
Did not graduate from High School	63	24.6
Completed High school	76	29.7
Some College or Vocational school	81	31.6
Completed a College Degree	35	13.7
<b>Age</b>		
0-21	51	19.9
22-34	91	35.5
35-63	114	44.5

a form of genocide against Blacks” (29.7%) and some 27.7% of the respondents said that “AIDS was created by the government to control the black population.” Regarding treatment-related conspiracy beliefs, over one-third (35.6%) somewhat or strongly agreed that “people who take the new medicines for HIV/AIDS are human guinea pigs for the government,” while 29.9% somewhat or strongly endorsed the statement that “the medicine that doctors prescribe to treat HIV is poison.” In the bivariate analysis, gender was not significantly related to conspiracy beliefs about HIV/AIDS.

*Relationships of Sociodemographic variables to HIV/AIDS Conspiracy Beliefs*

In the overall sample and among men, endorsement of HIV/AIDS conspiracy beliefs was related to education and age (Table 3). In contrast, only education was a significant predictor of endorsing HIV/AIDS conspiracy among women. This set of sociodemographic variables explained 13% of the variation in HIV/AIDS conspiracy beliefs in the total sample, 14% among men and 13% among women.

Table 2. HIV/AIDS Conspiracy Beliefs Endorsed by Patients Overall and by Gender (N= 256)

	% Agreeing Somewhat or Strongly			X <sup>2</sup>
	Overall (n=256)	Men (n=142)	Women (n=114)	
<b><i>HIV/AIDS Conspiracy Beliefs</i></b>				
A lot of information about AIDS is being held back from the public	68.4	70.3	69.0	8.10
HIV is a manmade virus.	51.2	54.2	50.6	1.98
AIDS is a real public health threat	87.9	89.8	87.4	2.14
AIDS is a form of genocide against blacks.	29.7	27.2	35.6	3.24
The government is not telling the truth about AIDS	47.3	44.9	48.2	7.25
AIDS was created by the government to control the black population.	27.7	28.9	29.9	3.77
There is a cure for AIDS, but it is being withheld from the poor	55.1	50.1	64.3	6.15
The medicine that doctors prescribe to treat HIV is poison	26.9	28.1	29.8	.54
People who take the new medicine for HIV are human guinea pigs for the government	35.6	38.1	34.5	.67
AIDS was produced in a government laboratory	40.2	46.6	37.9	5.54

Significant values are based on X<sup>2</sup> tests between women's and men's frequency distributions of the 5 category responses to each item (disagree strongly, disagree somewhat, no opinion, agree somewhat, agree strongly), df = 4.

### ***Qualitative Findings***

Focus group discussions suggested that conspiracy beliefs can be important barriers to quality of life and infection control among HIV-positive individuals. Conspiracy beliefs can reduce medication adherence. Some patients miss their medications because they think it is poisonous. This can affect the viral suppression that underpins optimal health for HIV-positive individuals. Therefore, conspiracy belief as a correlate of antiretroviral success must be addressed by HIV clinicians.

### ***Adherence to treatment***

During the interviews, I found that the consequences of conspiracy beliefs can affect adherence to treatment. Some patients indicated that disbelief in medical white people was an overarching barrier to adherence to treatment. Some said that because some of their HIV

Table 3. Multivariate sociodemographic predictors of beliefs in HIV/AIDS conspiracies

Sociodemographic Variables	Ovarall (N=205) Beta	Men (N=118) Beta	Women (N=87) Beta
Male Gender	.043	-----	-----
High School/College	-.321**	-.311**	-.332*
Married/Living with a partner	-0.50	.027	-.096
Age (ref. group >34Years)	.203**	.215**	.170
Model R <sup>2</sup>	.13	.14	.13

\* p < 0.05  
\*\* p < 0.001

medicines require taking them with food, they skip taking them when they don't have food. "Susan, a 40 year old woman frankly told of various time she skipped her medication because she has no belief in them. "I usually don't take my many medicines because I do not trust them. The medicines will make you sick in the stomach and they can kill you. Therefore, I do not take my medicines regularly as prescribed."

DISCUSSION

The objectives of the present study were to measure the extent to which conspiracy beliefs about HIV/AIDS were endorsed among African-American patients with HIV infection and to examine whether conspiracy beliefs are more concentrated among some subgroups of patients with HIV infection than others. Consistent with previous research (Hutchinson et al 2007; Parsons 2021), many of the patients endorsed HIV/AIDS conspiracy beliefs. More extreme beliefs related to genocidal and medication related conspiracies were endorsed at sizeable rates. In this rural sample, 30.7% somewhat or strongly believed that "AIDS is a form of genocide against blacks," and 36.6% somewhat or strongly agreed that "People who take the new medicine for HIV are human guinea pigs for the government." These results resemble those of previous studies in the African American population. For example, Klonoff and Landrine (1999) in their survey of blacks in California found that 12% of their respondents somewhat agreed that "HIV/AIDS is a manmade virus that the federal government made to kill and wipeout black people." Herek and Capitanio found that 20% of the African American in their studies endorsed the belief that "The government is using AIDS as a way of killing off minority groups." In a similar vein, Bogart and Thornbun found that 43.6% of African Americans aged 15 to 44 years somewhat or strongly believed that "people who take the new medicines for

HIV/AIDS are human guinea pigs for the government.” Our results support the findings of previous studies, that among HIV/AIDS positive African Americans, HIV/AIDS conspiracies may be a barrier to HIV/AIDS prevention and treatment efforts.

The sociodemographic variables as a set had a very small effect on African Americans with HIV infection endorsement of HIV/AIDS conspiracy beliefs. Education is significantly related to beliefs in conspiracies in all analyses (dealing with males and females separately). These findings

are similar to the research by Bogart and Thorburn but contrary to Parsons (2021) findings that “Educational level of the HIV+ African American participants in 2000/2001 was not related to either belief in the malicious intent of HIV/AIDS as genocide.” Taken in the context of previous studies which have documented the impact of education on attitudes, the findings of differences between low level and higher levels of education is noteworthy and suggest that the liberalizing effect of education on individual attitudes should be acknowledged in HIV/AIDS prevention and treatment messages in African American communities. Although no previous research found a statistically significant relationship (Parsons 2021), age was statistically associated with stronger endorsement of HIV/AIDS conspiracy beliefs in the analyses of the whole sample and that of men as a subgroup. This is contrary to Parsons (2021) finding that “bivariate analyses indicated that the age of the respondents (year of birth, from earliest to most recent) was not related to either of the HIV rumors.”

### *Implications for HIV/AIDS Prevention and Treatment*

Overall, these findings suggest that HIV/AIDS conspiracy beliefs among African Americans must be acknowledged and addressed in a culturally tailored HIV/AIDS prevention and education programs. This is because these conspiracy beliefs may be a barrier to HIV prevention and treatment efforts to halt the epidemic in African American communities where it is taking a terrible toll. This is particularly the case for less educated African Americans who are more likely

to endorse conspiracy beliefs. This subgroup may be suspicious of HIV prevention and treatment information distributed by the US government and the public health system. For example, HIV-positive African Americans who endorsed treatment-related conspiracy beliefs (e.g., “people who take the new medicine for HIV/AIDS are human guinea pigs for the government”) may be less likely to adhere to antiretroviral therapies and prevention messages. It is unlikely that the less educated HIV-positive African Americans who believe the government created HIV will listen to the government’s warnings and take recommended treatments or come for testing. Public health officials working against the spread of HIV/AIDS must acknowledge and address the conspiracy beliefs common in African American communities.

To be useful, HIV/AIDS prevention messages addressing conspiracy beliefs may need to be delivered by trusted members of African American communities. Whenever possible, African American professionals from local health departments and community-based organizations are to be used to present HIV/AIDS education because it may foster the trust

of African Americans. Such community-based and peer-delivered intervention messages may reduce risky sexual behaviors. Furthermore, health educators or public health officials working against the spread of HIV/AIDS must demonstrate both openness and sensitivity to questions about conspiracy beliefs and mistrust prevalent in the African American communities. This will help in understanding the historical roots and social context from which such questions arise. Conspiracy beliefs are not unique to HIV/AIDS alone but related to broader beliefs about conspiracies with the United States society as a whole such as family planning and drugs. As Bogart and Thorburn put it “to obtain the trust of black communities, government and public health entities need to acknowledge the origin of conspiracy beliefs openly in the context of historical discrimination”<sup>2</sup> 213-218.

### *Limitations of the study*

The study has some limitations. The sample size is small. Additional research on these issues with a larger sample is needed to understand the breadth and complexity of beliefs in conspiracies about HIV/AIDS and relationships to sociodemographic variables. Place of residence was not considered in this study. Future research is needed to examine the contribution of this important variable to conspiracy beliefs. We want to know if there are differences among African American in rural and urban areas with regard to HIV/AIDS conspiracy beliefs.

In sum, it is recommended that all those involved in the battle against HIV/AIDS in African American communities (individuals, community organizations, and government agencies) must give special consideration to prevention and treatment efforts that will significantly reduce the incidence and prevalence of HIV/AIDS among African Americans in the Deep South. So, they should aggressively seek and identify subgroups (e.g., less educated, young African Americans) and to target social factors that enhance HIV/AIDS in these sub-groupings.

The present analysis supports the validity of continuing to explore the link between sociodemographic variables and HIV/AIDS conspiracy beliefs. In this sample, there was evidence of significant relationships between education, age and HIV/AIDS conspiracy beliefs. Many questions, however, remain unanswered. Do the relationships found for this sample of HIV-positive African Americans, who live in Alabama, hold for other groups in the population? Do the association between education and HIV/AIDS conspiracy beliefs differ by religion, geographical region, or rural-urban residence? Additional research, focusing on other ethnic groupings and other geographic areas is needed to address these questions.

## References

- Bird, ST and Bogart LM. (2005) “Conspiracy beliefs about HIV/AIDS and birth control among African Americans: Implications for the prevention of HIV, other STIs’ and unintended pregnancy.” *J Soc Issues*. 2005;61:109-126.
- Bogart LM, Thorburn ST (2005) “Are HIV/AIDS conspiracy beliefs a barrier to HIV prevention among African Americans?” *J Acquir Immune Defic Syndr*. 2005;38:213-218.
- Herek GM, Capitanio JP (1994) “Conspiracies, contagion, and compassion: trust and public reactions to AIDS.” *AIDS Educ Prev*. 1994;6:365-375.
- Hutchinson AB, Begley EB, Sullivan P, (2007). “Conspiracy beliefs and trust in information about HIV/AIDS among minority men who have sex with men.” *J Acquir Immune Defic Syndr*. 2007;45:603-605.
- Klonoff EA, Landrine H. (1999) “Do Blacks believe that HIV/AIDS is a government conspiracy against them?” *Prev Med*. 1999;28:451-457.
- Parsons S, Simmons W, Shinhoster, F. (1999). “A test of the grapevine: An empirical examination of conspiracy theories among African Americans.” *Sociological Spectrum*. 1999;19: 201-222.
- Parsons S. (2021) “HIV Beliefs Among African Americans with HIV/AIDS in the Deep South Can Time Heal Old Wounds?” *J Health Care and Research*. May 11;2(2):70-84.
- Whetten K, Leserman J, Whetten (2006). “Exploring lack of trust in care providers and the government as a barrier to health service use.” *Am J Public Health*. 2006;96:716-721.
- Zekeri, Andrew A (2019) “Food Insecurity and Maternal Mental Health among African American Single Mothers Living with HIV/AIDS in the Alabama Black Belt.” *Journal of Health Care for the Poor and Underserved*, Volume 30, Number 4, Supplement, pp. 151-159 (Article).
- Zekeri Andrew A. (2018) “Racial-ethnic disparities in HIV/AIDS and health care in the United States: evidence from a sociological field research in Alabama’s Black Belt.” *Journal of Healthcare, Science and the Humanities*. 2018 Fall;8(2):31–44.
- Zekeri AA (2016) “Food insecurity and coping strategies among African American women living with HIV/AIDS on antiretroviral therapy in rural Alabama.” *Journal of AIDS Clinical Research* 7: 1-4.
- Zekeri AA, Habtemariam T, Berhanu T (2009) Conspiracy beliefs about HIV/AIDS among HIV-positive African-American patients in rural Alabama. *Psychological Rept*. 388-394.

# Utilizing Policy and Electronic Health Record (EHR) System Modifications to Implement and Sustain Routine Opt-Out HIV Screening and Linkage to Care During the COVID-19 Pandemic

**Alexis K. Fields, MPH**

Program Manager  
STAR Health Center - Brookdale  
The Brookdale Hospital Medical Center  
One Brookdale Plaza, Brooklyn, NY, 11212  
Tel: (718) 240-6390  
Fax: (718) 240-6510  
Email: Afields@bhmcny.org

**Pamela Kirlew**

Care Manager / Lead Patient Navigator  
STAR Health Center - Brookdale  
The Brookdale Hospital Medical Center  
One Brookdale Plaza, Brooklyn, NY, 11212  
Tel: (718) 240-6202  
Fax: (718) 240-6510  
Email: Pkirlew@bhmcny.org

**Haroon Zafar, MS**

Data Manager  
STAR Health Center - Brookdale  
The Brookdale Hospital Medical Center  
One Brookdale Plaza, Brooklyn, NY, 11212  
Tel: (718) 240-8114  
Fax: (718) 240-6510  
Email: Hzafar@bhmcny.org

**Zoraima Douglas**

Patient Navigator  
STAR Health Center - Brookdale  
The Brookdale Hospital Medical Center  
One Brookdale Plaza, Brooklyn, NY, 11212  
(718) 240-5046  
Fax: (718) 240-6510  
Email: Zdouglas@bhmcny.org



**Tenisha Gillett-Smith, MHS**

Patient Navigator  
STAR Health Center - Brookdale  
The Brookdale Hospital Medical Center  
One Brookdale Plaza, Brooklyn, NY, 11212  
Tel: (718) 240-5085  
Fax: (718) 240-6510  
Email: Tgillett@bhmcny.org

**Jessica E. Yager, MD, MPH**

Medical Director, STAR Program  
Clinical Associate Professor of Medicine  
Division of Infectious Diseases  
STAR Program - The Brookdale Hospital Medical Center/ SUNY Downstate  
450 Clarkson Avenue, Box 1240, Brooklyn, NY 11203  
Tel: (718) 270-4180  
Fax: (718) 270-4244  
Email: Jessica.Yager@downstate.edu

**Authors' Note**

The authors do not have any conflicts of interest. This project was supported by funding from Gilead Sciences, Inc. Frontlines of Communities in the United States (FOCUS) Program. FOCUS funding supports HIV and HCV screening and linkage to a first medical appointment. FOCUS partners do not use FOCUS awards for activities beyond linkage to a first medical appointment. Gilead Sciences, Inc., was not responsible for or involved in the data analysis, data interpretation, preparation, or content of the publication. The Institutional Review Board (IRB) reviewed the project and approved an exemption on May 24, 2021, in accordance with federal regulations set forth in 45 CFR 46.

**Abstract**

The burden of HIV infection disproportionately impacts Black people across the United States. New York City (NYC) has taken substantial steps to End the HIV Epidemic, boasting reductions in new HIV infections by 40% since 2015; however, racial inequities persist. In 2019, Black people living in NYC accounted for 24% of the population, yet represented 46.1% of new HIV diagnoses and 48.7% of HIV deaths. To address the high incidence of HIV in a predominately Black community in Central Brooklyn, Brookdale Hospital Medical Center (BHMC) developed a multi-faceted approach to increase routine opt-out HIV screening and linkage. In order to integrate HIV testing into routine clinical care, BHMC leadership updated screening policies; developed an Electronic Health Record (EHR) algorithm to trigger HIV screening in five BHMC ambulatory clinics; and modified the EHR to transmit positive HIV screening results to patient navigators dedicated to linking patients to HIV care. During the height of the COVID-19 pandemic, between March and April 2020, HIV screening across

all five ambulatory sites decreased by 87.3%. After activation of the EHR algorithm in three ambulatory sites in June 2020, HIV screening increased 216.3% from the prior month. By the time the final EHR algorithm launched in August 2020, HIV testing had fully rebounded to pre-pandemic levels. Policies supporting routine opt-out HIV screening coupled with EHR-prompted screening can improve and sustain HIV testing in a Black community with a high incidence and prevalence of HIV.

*Keywords:* HIV, Black Community, Policy Recommendations, EHR Modification, HIV Screening, Routine Screening, Opt-out Consent, Patient Navigator, Linkage to Care, COVID-19

### Introduction

Of the 1.2 million individuals living with HIV in the United States in 2018, an estimated 161,800 individuals are unaware of their diagnosis (Centers for Disease Control and Prevention [CDC], 2020). Expanding HIV testing to reduce this number is key both to improving the health of these individuals and to reducing forward transmission of the virus. Though persons with undiagnosed infections account for less than 15% of all those living with HIV, research shows they lead to up to 40% of subsequent new HIV infections (Li, Purcell, Sansom, Hayes, & Hall, 2019). Therefore, identifying and linking individuals with undiagnosed HIV infection to care is vital to achieving national and statewide goals to end the HIV epidemic.

Routine HIV screening is an essential tool for identifying undiagnosed HIV infections: it can capture individuals who may have lower perceived risk—by themselves or their care providers—and can reduce the stigma associated with targeted screening (Branson et al., 2006). In response to persistent barriers to HIV testing, the CDC updated HIV testing recommendations in 2006 to include routine opt-out HIV screening for all individuals between the ages of 13 and 64 years. Additionally, the CDC recommended abolishing written consent and pre-test counseling mandates in health care settings.

Beyond providing an opportunity to improve individual and community HIV outcomes through early diagnosis and treatment and reduced forward transmission, routine opt-out screening has the potential to reduce critical and persistent health disparities. While New York City (NYC) has taken substantial steps to End the HIV Epidemic, boasting reductions in new HIV infections by 40% since 2015, pronounced racial inequities persist (Morne et al., 2020; HIV Epidemiology Program, 2020). In 2019, Black people in NYC comprised 24.3% of the city's population, yet accounted for 46.1% of new HIV infections and 48.7% of HIV deaths (HIV Epidemiology Program, 2020; U.S. Census Bureau, 2019a). Evidence indicates that individual behavior does not account for racial disparities in incidence rates: even when Black individuals engaged in risk behaviors similar to their white counterparts, Black individuals were still at greater risk of acquiring HIV (Hallfors, Iritani, Miller, & Bauer, 2007). These disparities in incidence rates result from complex social and economic systems and

structures, including structural racism, which perpetuate inequitable access to quality resources and opportunities for Black individuals and communities (Aral, 2008; Lavizzo-Mourey, 2021; Link, 1995; Millett, 2020). Routine opt-out HIV testing can serve as an essential tool in addressing these disparities in access. Following routine testing, patient navigators can play a pivotal role in improving linkage to HIV care, retention, and viral suppression for people with HIV (Mizuno et al., 2018).

The literature indicates additional factors contribute to gaps in HIV testing. Some individuals are unaware of where to go or may not live in close proximity to a testing site. Others may decline HIV testing for various reasons. For many Black individuals, concerns around confidentiality and compounded stigmas related to HIV, racism, and/or homophobia remain major barriers to testing (Arnold, 2014; Gousse, 2021; Jones, 2019). Additional barriers to testing among Black individuals living in low resource areas include fear of social isolation and rejection by family, friends, or potential partners, discrimination when seeking healthcare or employment, and/or victimization (Cheong, 2019; Gwadz, 2018). Research has also revealed that individuals may forgo HIV testing to avoid fear and anxiety while waiting for their results (Matthews et al., 2020). Others preferred not knowing their HIV status because of the effect it would have on their lives: they considered a positive result a “death sentence” (Matthews et al., 2020). Perceived risk for HIV has also been a barrier to routine testing (Bond, 2015; Cheong, 2019). Moreover, foreign-born Black individuals face additional barriers to testing, including lower HIV knowledge, reduced access to testing and healthcare, and both anti-immigrant and anti-Black racism and discrimination (Gousse, 2021; Ojikutu, 2013; Taylor, 2019). Routinized HIV testing and patient education can normalize testing, thereby ensuring that more people in Black communities are aware of their HIV status.

Early in 2020, the global COVID-19 pandemic significantly disrupted service delivery for routine HIV testing in NYC. Now, over a year into the ongoing pandemic, COVID-19 remains a barrier for state and local organizations to conduct HIV and other STI surveillance and testing. Furthermore, robust data have emerged illustrating the myriad ways in which COVID-19 has exacerbated existing health disparities. In 2020, Black individuals were 2.8 times more likely to be hospitalized and almost twice as likely to die from COVID-19 compared to white counterparts (CDC, 2021). In NYC, individuals with HIV were more likely to be hospitalized or die from COVID-19 (Tesoriero et al., 2021) than those without HIV. Relatedly, among people living with HIV in NYC, increased rates of COVID-19 were identified among Black individuals and people living in high poverty neighborhoods (Braunstein, Lazar, Wahnich, Daskalakis, & Blackstock, 2020). The current pandemic has worsened access to HIV prevention and treatment services due to staffing reductions or re-deployments, required social distancing, and clients’ perceived COVID-19 risk in medical settings. In so doing, COVID-19 has synergistically impacted the same individuals and communities disproportionately impacted by the ongoing HIV epidemic.

Strong policies and practices facilitating routine opt-out HIV screening and linkage can meet testing demands and address critical public health needs despite persistent COVID-19

barriers. This paper will explore how one hospital utilized key policy and electronic health record system modifications, along with dedicated patient navigators, to implement and sustain routine HIV screening and linkage during the COVID-19 pandemic.

### Methods

Brookdale Hospital Medical Center (BHMC) is a large nonprofit, voluntary teaching hospital with 530-acute care beds, onsite specialty clinics, and six satellite ambulatory Brookdale Family Care Clinics (BFCCs). The hospital is located in Brooklyn, New York in an area that has historically been under-resourced and medically underserved. BHMC's catchment area is comprised of 76% Black residents and 20% Latinx residents, with 30% of the population born outside of the United States. In 2019, the population was 56% female and 44% male (U.S. Census Bureau, 2019b). One in four residents lived below the federal poverty level. In 2016, this area had the second-highest incidence of HIV in all of New York City (67.4 cases per 100,000); moreover, HIV was the third leading cause of premature death in the community after cancer and heart disease (Hinterland et al., 2018).

To address the high incidence of HIV in a predominately Black community in Central Brooklyn, Brookdale Hospital Medical Center (BHMC) implemented routine opt-out HIV screening in all ambulatory Brookdale family care clinics (BFCCs). The routine screening team prioritized 1) integrating HIV testing and linkage into normal clinic flow; 2) systemic policy change; 3) electronic health record (EHR) system modifications; and 4) training, feedback, and quality improvement (Sanchez, 2014). From January 2020 to December 2020, we collected and analyzed the number of HIV screening tests performed on patients aged 13 years and older by hospital setting. Data from one BFCC was excluded since the site closed prior to screening implementation. HIV transmission risk and characteristics of patients with new HIV infections were manually tracked and extracted from BHMC's electronic health record system (EHR), Epic version May 2020.

#### *Integrating HIV testing and linkage into routine clinic flow*

Before implementing this routine screening initiative, BHMC relied on an HIV testing and counseling program to conduct rapid HIV tests and link clients to care within the hospital and in most of the outlying BFCCs. Testing occurred on an opt-in basis and was limited by the number of staff conducting the test, often one staff member for a given site. To broaden testing reach and to meet CDC guidelines, our team obtained external funding in early 2019 to expand and enhance HIV testing and linkage at BHMC. The funding covered four staffing positions and the additional resources needed to update systemic policies and EHR modifications. We began the process of policy and system modifications in 2019 before the COVID-19 pandemic and continued its implementation throughout the pandemic.

By June 2019, the routine screening team became fully staffed. Staff who previously conducted rapid HIV testing and counseling received training to become patient navigators.

Patient navigators were responsible for linking all patients with a positive HIV screening test result to HIV care. Patient navigators provided HIV education and counseling, assessed for barriers to care, scheduled an appointment for the patient to see an infectious disease provider, and confirmed successful attendance at this initial visit. Lost to follow-up patients and those who refused linkage were referred to the NYC Department of Health and Mental Hygiene (NYC DOHMH) Assess Connect and Engage (ACE) team for further outreach.

To embed this screening initiative and engender buy-in for broad system change, we established a routine screening task force comprised of key hospital leadership. The taskforce decided to initiate routine screening in the BFCCs before attempting implementation in the busy Emergency Department. The implementation team met with the chair and assistant directors of the ambulatory clinics to identify optimal screening workflows for primary care providers. BHMC leaders reviewed all aspects of practice transformation and helped to address implementation barriers.

### *Systemic policy change*

The existing BHMC HIV testing policy was updated to establish routine HIV screening with opt-out consent as the standard of care. The new policy, adopted in May 2020, built on and expanded CDC HIV testing recommendations. BHMC policy now supports annual HIV screening with opt-out consent for individuals 13 years of age and older, with no upper age limits, while allowing for provider autonomy to test more regularly for individuals at high risk for infection. Furthermore, the policy expands hospital testing capacity by allowing registered nurses to order HIV screening tests as part of a standing order, rendered feasible by NYS Education Law governing medical professionals (New York State Senate, 2010) and reinforces that patient navigators from STAR Health Center will follow-up with all patients with a positive screening result.

### *Electronic Health Record (EHR) Modification*

The team developed an EHR algorithm with prompts to trigger opt-out HIV screening in all ambulatory clinics. The algorithm included patients aged 13 and older who did not have an HIV screening test within the last 12 months and excluded patients who had a known HIV or AIDS diagnosis. After finalizing the testing algorithm, the routine screening implementation team met with leadership and Epic developers to create a best practice alert (BPA) that would prompt providers to order an HIV test during a patient visit. The BPA fired during both in-person and telemedicine visits. To ensure physicians completed the BPA, it was programmed as a “hard stop”: the physician had to acknowledge the BPA prior to completing their patient encounter. Moreover, instead of prompting affirmative consent (e.g., “Would you like an HIV test today?”), the BPA included text to reinforce opt-out consent (e.g., “It is our policy to complete routine testing, including an HIV test unless you decline.”). The EHR was further modified to generate a report of HIV screening results that was made accessible to patient navigators who provided linkage services.

Training, feedback, and quality improvement

Key staff from the routine screening implementation team met regularly with ambulatory care leadership and providers to refine the BPA, improve testing workflow, and better coordinate patient care. The BPA was first piloted in one clinic to identify workflow challenges and solicit provider feedback. Findings were used to refine the BPA and inform training. Providers received training related to the HIV laboratory testing algorithm, delivering positive HIV test results to clients, and support services available to both providers and clients.

Results

BPAs were implemented in five BFCCs: one site was activated at the end of September 2019 (pilot), three sites in June 2020, and one site at the end of August 2020.

HIV Screening

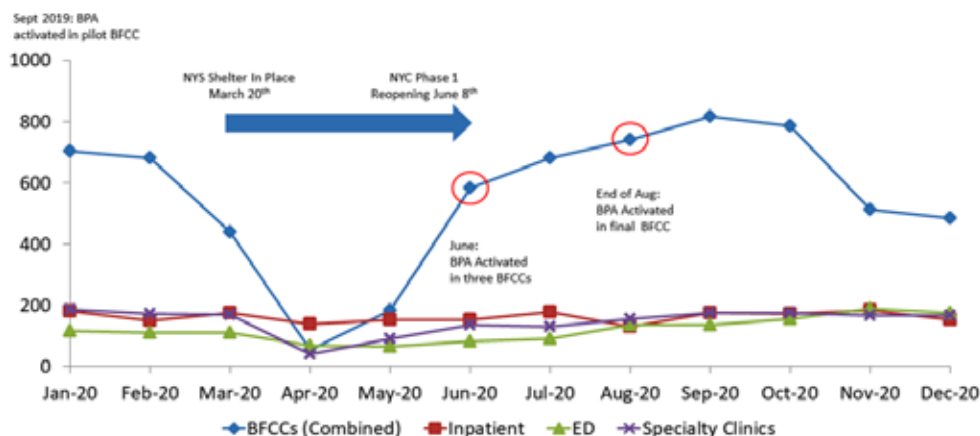
During the height of the COVID-19 pandemic and statewide shelter in place orders, HIV screening across the five ambulatory BFCCs decreased 87.3% from March to April 2020, from 441 tests to 56 tests. After activation of the EHR algorithm in three ambulatory sites in June 2020, HIV screening increased 216.3% from the prior month, from 184 tests to 582 tests. By the time the final EHR algorithm launched in August 2020, HIV testing had fully rebounded to pre-pandemic levels. HIV testing continued to increase, reaching a peak in September with 818 tests conducted before declining in December 2020 with 486 tests conducted (Table 1).

Table 1. Number of HIV tests performed on persons aged 13 and older by month and test setting, Jan 2020 to Dec 2020

Month	Setting			
	BFCCs (combined)	Inpatient	ED	Specialty Clinics
Jan	704	181	116	188
Feb	681	150	111	174
Mar	441	177	110	169
Apr	56	140	69	41
May	184	153	66	91
Jun	582	152	82	137
Jul	683	179	90	130
Aug	742	130	136	155
Sep	818	175	135	176
Oct	786	173	157	176
Nov	512	184	190	168
Dec	486	152	176	167

Overall, after BPA activation, all ambulatory testing rebounded to pre-pandemic levels in August 2020 and then exceeded pre-pandemic testing levels in the subsequent months (Figure 1).

Figure 1. Brookdale Hospital HIV Screening during COVID-19, 2020



## New HIV Diagnoses

From January 2020 to December 2020, 29 individuals tested newly positive for HIV. The vast majority of patients identified as Black or African American (93%). Seventy-six percent of patients reported their sex at birth as male. The average patient age was 38.7 years. HIV transmission risk factors included heterosexual contact (48%), unknown (28%), MSM only (14%), and MSM plus bisexual (10%). Over half (55%) of patients newly diagnosed with HIV were identified in the Emergency Department. Patients were also diagnosed in inpatient settings (17%), hospital outpatient specialty clinics (17%), and the BFCCs (10%) (Table 2).

Between January to March 2020, four patients, on average, were newly diagnosed with HIV each month. From April to June 2020, the average decreased to one new HIV diagnosis each month. July to September 2020 saw the average increase to nearly two new HIV diagnoses per month. By the last quarter of the year, from October to December 2020, new HIV diagnoses reached an average of three patients per month.

## Linkage to HIV Care

In 2020, patient navigators linked 24 of 29 (83%) patients newly diagnosed with HIV to medical care. Of the five patients who were not linked, three were lost to follow-up, and two died prior to linkage. From January 2020 to March 2020, before severe COVID-19 impacts, patient navigators linked 11 of 12 (92%) individuals newly diagnosed with HIV; one individual was lost to follow-up. From April to May 2020, they linked two of three (67%) individuals; one

individual died prior to linkage. From June to December, 11 of 14 (79%) individuals were linked, with two patients lost to follow-up and one patient deceased prior to linkage.

*Barriers and Facilitators to Routine HIV Screening*

Since initiating routine HIV screening at BHMC, the team encountered multiple barriers. Many of these related to provider responses to the initiative. Providers were wary of a BPA and excessive EHR alerts. Additionally, they reported discomfort discussing HIV screening with older adults and patients younger than 15 years old. Providers communicated uneasiness with providing HIV test results to patients, feeling ill-prepared to answer a patient’s subsequent questions. Finally, providers expressed consistent concern that individuals with new positive HIV screening tests would be lost to care.

To address these challenges and barriers, the screening team met regularly with providers for bidirectional training and feedback. We conducted role-play during training so providers could practice their skills at delivering HIV diagnoses. We have incorporated provider feedback about the BPA to ensure that it is minimally invasive to a provider’s workflow. Creating institutional policies and routinizing workflows has ultimately helped facilitate screening by creating top-down support for the endeavor and streamlining the screening process. Finally, having a dedicated team of patient navigators has been a critical facilitator of routine testing. Providers have been far more willing to proceed with routine testing when they are confident that a positive screening result will trigger outreach, linkage, and follow-up.

*Table 2. Number and percentage of persons newly diagnosed with HIV, by selected characteristics – Brooklyn, NY, Jan 2020 to Dec 2020*

Characteristics	N=29	
	n	(%)
<b>Sex at birth</b>		
Male	22	75.9
Female	7	24.1
<b>Age group (years)</b>		
20-29	9	31.0
30-39	9	31.0
40-49	2	6.9
50-59	7	24.1
60-69	1	3.4
70-79	1	3.4
<b>Race</b>		
Black	27	93.1
Unknown	2	6.9
<b>Risk Factor</b>		
Heterosexual	14	48.3
MSM	4	13.8
MSM + Bisexual Male	3	10.3
Unknown	8	27.6
<b>Identifying Department</b>		
Emergency Department	16	55.2
Specialty Clinics	5	17.2
Inpatient	5	17.2
BFCCs	3	10.3



## *Barriers and Facilitators to HIV Linkage to Care*

The patient navigation team encountered individual and institutional barriers to successful linkage to HIV care. First, individuals were often challenging to link if they were not ready to accept their diagnosis. Second, outdated or incorrect contact information in patient charts led to difficulties with linkage. Third, patients with undocumented immigration status were often challenging to reach or declined linkage out of fear of deportation. Fourth, individuals with untreated or uncontrolled mental illnesses or substance use occasionally did not acknowledge their need for medical care, withdrew consent for outreach or care, or became unreachable. Fifth, patients could resist or decline linkage based on ongoing internal or external stigma around HIV status. Furthermore, we occasionally encountered laboratory challenges that required repeat venipuncture and delayed HIV confirmatory testing. This need for repeat phlebotomy undermined patients' confidence in the testing process and delayed ongoing care.

Based on the above challenges encountered, the patient navigation team identified five primary facilitators that improved linkage to care. First, an initial face-to-face meeting between the patient and the patient navigator, either on the inpatient ward or during a provider visit, allowed the navigator to connect with the patient. This connection proved crucial in many successful linkages by providing opportunities to verify contact information, assist providers with delivering HIV results, and form bonds. Second, provider input and support for the linkage process substantially improved patient buy-in since many patients knew and trusted their provider. Third, coordination with external partners frequently enhanced linkage. For example, we work closely with the New York City Department of Health and Mental Hygiene (NYC DOHMH), which provides additional contact information, care/linkage status, and, pre-COVID, home visits. Home attendants, nursing home staff, or case managers can also help facilitate appointments or patient contact when involved in a patient's care. Fourth, reducing patient's logistical barriers facilitated linkage. Our team worked with patients to evaluate obstacles to care; resulting actions included assistance with health insurance enrollment and transportation. Finally, our skilled and experienced patient navigators engaged distraught patients, provided education, gauged readiness, and overcame additional patient barriers. We have repeatedly found that the ability to give results and share information in a caring and compassionate manner is invaluable to helping a newly diagnosed patient process their diagnosis.

## **Discussion**

After modifying our EHR to activate BPAs in ambulatory clinics, we observed HIV testing numbers drastically increase and exceed prepandemic screening levels. While decreases were noted in November and December, the numbers appear robust within the context of the second COVID-19 wave as well as the holiday season. Overall, this project solidified the importance of having hospital-wide policies and procedures to effectively implement system changes. Clear and consistent hospital-wide messaging for both patients and providers was key to supporting quality care, reinforcing the importance of routine HIV testing, and swiftly linking patients to care. Implementing this project has also highlighted the importance

of interdisciplinary communication in linking clients to care. It has been critical to have a champion in each department and to involve hospital and departmental leadership, supervisors, and line staff. Moreover, while national guidelines are important tools for local programs, it is crucial for organizations to evaluate their local needs and trends in order to better serve their patient populations. Our data indicated incident HIV infection occurs among older adults, including those over 64 years of age, which highlighted the need for routine HIV screening for this population in Central Brooklyn.

The start of the COVID-19 pandemic greatly impacted routine HIV testing and resulting linkage to care. Suddenly, health care facilities in New York City found themselves impacted by stay-at-home orders, limited personal protective equipment, and an inundation of COVID-19 patients requiring hospitalization. It was difficult for patients to access HIV testing across the city. In Brooklyn, city-sponsored HIV and STI testing sites closed or operated at reduced capacity, thereby impacting screening availability. Many individuals delayed routine healthcare visits to their primary care provider because of fear of contracting COVID-19, and telemedicine became a more prominent method to deliver care. During a time when HIV testing was not always a priority for providers and patients, the BPA consistently reinforced HIV testing and even prompted providers to place HIV orders during telehealth visits. The BPA demonstrated high utility and was an essential tool to increase and sustain testing during the pandemic.

Like many health facilities, our hospital saw an influx of patients hospitalized with COVID-19. The gravity of this illness redirected laboratory, information technology teams, and provider resources to support COVID-19 treatment and prevention efforts. One BFCC closed before BPA implementation after the hospital reallocated resources due to COVID-19 impacts. In addition, our department was displaced for months while we waited to move to a new outpatient site in order to make room for inpatient beds within the hospital. Our transition to a new clinic space that was not yet fully operational made linkage to care more complex. Space for providers to have in-person patient visits was inconsistent and varied each day.

In addition, linkage was impacted by service disruptions and patient fears caused by COVID-19. Linkage of hard-to-reach patients became more difficult because partner agencies that typically assisted with linkage were closed or suffered service interruptions. For example, the NYC DOHMH suspended their home visit outreach program and could not provide their usual assistance in tracking patients who could not be reached by phone. The workflow for our linkage team was also affected. Prior to COVID-19, patient navigators could easily meet with patients face-to-face; however, these visits were interrupted by new city and hospital restrictions. Patient navigation transitioned to remote services, and navigators facilitated linkage solely by phone. Despite these challenges, this project has shown that HIV linkage to care can be successfully facilitated by patient navigators who solely worked remotely.

To maintain and expand linkage in the face of an ongoing pandemic, the patient navigation team developed a high level of coordination and communication within our

organization and with external care teams and patients. Patient navigators often worked with a patient's medical provider to determine the best strategy for linking a patient to HIV care. Because the barriers faced by each patient were individual, the team worked to implement an individualized action plan for each person. In our setting, the patient navigators were key in creating these action plans. Additionally, navigators formed a bond with patients and proved critical in addressing stigma, substance use, and mental health challenges. This key navigation role has been supported in the literature (Freeman & Rodriguez, 2011).

In spite of the COVID-19 pandemic, the systems we enacted at an institutional level can greatly enhance the success of routine HIV testing and linkage to care. To increase and sustain HIV screening and linkage, we recommend organizations:

- I. Adopt a routine HIV screening policy with opt-out consent.  
Healthcare organizations should adopt an organizational policy that reinforces the importance of routine HIV screening with opt-out consent. This process helps normalize and destigmatize HIV testing and capture individuals who may perceive themselves at low risk.
- II. Modify the EHR to facilitate routine HIV screening and populate orders.  
EHR alerts can prompt providers to order HIV screening for eligible patients. The prompt can automatically populate an HIV order, which streamlines the process and can sustain testing amid other competing priorities.
- III. Ensure HIV screening policies are inclusive of older adults.  
Local HIV testing policies should be inclusive of individuals 65 years old and older. Since individuals over the age of 65 years engage in behaviors that can expose them to HIV, older adults must be included in the testing population. As the national and international population continues to age, preventative efforts must acknowledge the importance of ongoing prevention throughout an individual's lifespan.
- IV. Obtain updated contact information.  
Organizations must develop processes to obtain accurate contact information for patients. Contact information can change frequently, and inaccurate or outdated contact information was a common reason clients were deemed "lost to follow-up."
- V. Enhance support for intensive linkage efforts.  
Our project implementation and success required staff dedicated to all phases of implementation and evaluation. Increased support mechanisms must be established to allow healthcare organizations to hire patient navigators and support the practice transformations needed to provide quality HIV prevention and care services. Moreover, funding is necessary to ensure that all patients have access to critical wrap-around services, such as transportation and communication services, which are essential components of successful linkage to care.

Given the disparities in HIV incidence faced by individuals living in our catchment area, as well as our experience with patients who are uninsured or underinsured and therefore have limited access to HIV testing, we highlight opportunities backed by the literature to address widely recognized barriers to HIV testing:

- I. Increase testing access and reduce barriers to the cost of STI and HIV testing.  
Providing equitable access to testing ensures that individuals at the greatest risk for infection have nearby testing locations with free testing, especially in communities with the highest burden of infection. Such access will enable individuals without insurance or who are financially insecure to obtain testing.
- II. Explore linking COVID-19 and HIV testing (Zang et al., 2020).  
National and local resources have been funneled into communities to provide free COVID-19 testing. Coupling COVID-19 testing with HIV testing would capitalize on the existing COVID-19 testing infrastructure and further increase access to free HIV testing.

There were several limitations to this project. While HIV testing increased following the launch of the BPAs, we were not able to determine the specific extent to which COVID-19, hospital utilization, or the reopening of NYC following stay at home orders contributed to increases in testing. Moreover, this study did not assess barriers and challenges for each individual tested. As a next step, we aim to analyze the proportion of eligible patients tested for HIV to more accurately gauge the impact of the BPA. We also plan to implement routine screening in the Emergency Department, a setting that diagnosed the highest proportion of new HIV infections across our hospital system.

In the face of an ongoing COVID-19 pandemic, institutions may need to bolster their HIV screening and linkage practices to sustain efforts to end the HIV epidemic. This goal can be accomplished by ensuring HIV screening and linkage are embedded into clinical procedures. Policies supporting routine opt-out HIV screening, EHR-prompted testing, and dedicated patient navigators can improve and sustain HIV testing and rapid linkage in a Black community with high incidence and high prevalence of HIV even during the ongoing COVID-19 pandemic. Implementing these fundamental changes can improve care outcomes and move us closer to ending the HIV epidemic.

## References

- Aral, S. O., Adimora, A. A., & Fenton, K. A. (2008). Understanding and responding to disparities in HIV and other sexually transmitted infections in African Americans. *Lancet* (London, England), 372(9635), 337–340. [https://doi.org/10.1016/S0140-6736\(08\)61118-6](https://doi.org/10.1016/S0140-6736(08)61118-6)
- Arnold, E. A., Rebchook, G. M., & Kegeles, S. M. (2014). ‘Triply cursed’: racism, homophobia and HIV-related stigma are barriers to regular HIV testing, treatment adherence and disclosure among young Black gay men. *Culture, Health & Sexuality*, 16(6), 710–722. <https://doi.org/10.1080/13691058.2014.905706>
- Bond, K. T., Frye, V., Taylor, R., Williams, K., Bonner, S., Lucy, D., Cupid, M., Weiss, L., Koblin, B. A., & Straight Talk Study Team (2015). Knowing is not enough: a qualitative report on HIV testing among heterosexual African-American men. *AIDS Care*, 27(2), 182–188. <https://doi.org/10.1080/09540121.2014.963009>
- Branson, B. M., Handsfield, H. H., Lampe, M. A., Janssen, R. S., Taylor, A. W., Lyss, S. B., Clark, J. E., & Centers for Disease Control and Prevention (CDC) (2006). Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings. *Morbidity and Mortality Weekly Report*. Recommendations and reports, 55(RR-14), 1–CE4.
- Braunstein, S. L., Lazar, R., Wahnich, A., Daskalakis, D. C., & Blackstock, O. J. (2020). COVID-19 infection among people with HIV in New York City: A population-level analysis of linked surveillance data. *Clinical infectious diseases: an official publication of the Infectious Diseases Society of America*, ciaa1793. Advance online publication. <https://doi.org/10.1093/cid/ciaa1793>.
- Centers for Disease Control and Prevention. Estimated HIV incidence and prevalence in the United States, 2014–2018. HIV Surveillance Supplemental Report 2020;25(No. 1).
- Centers for Disease Control and Prevention. Risk for Covid-19 infection, hospitalization, and death by race/ethnicity. (2021, April). Retrieved May 04, 2021, from <https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html#footnote02>
- Cheong, J., Tucker, J. A., & Chandler, S. D. (2019). Reasons for Accepting and Declining Free HIV Testing and Counseling Among Young African American Women Living in Disadvantaged Southern Urban Communities. *AIDS Patient Care and STDs*, 33(1), 25–31. <https://doi.org/10.1089/apc.2018.0090>

- Cooke, I. J., Jeremiah, R. D., Moore, N. J., Watson, K., Dixon, M. A., Jordan, G. L., Murray, M., Keeter, M. K., Hollowell, C. M., & Murphy, A. B. (2017). Barriers and Facilitators toward HIV Testing and Health Perceptions among African-American Men Who Have Sex with Women at a South Side Chicago Community Health Center: A Pilot Study. *Frontiers in Public Health*, 4, 286. <https://doi.org/10.3389/fpubh.2016.00286>
- Freeman, H. P., & Rodriguez, R. L. (2011). History and principles of patient navigation. *Cancer*, 117(15 Suppl), 3539–3542. <https://doi.org/10.1002/cncr.26262>
- Gousse, Y., Wilson, T. E., McFarlane, D., Browne, R. C., Fraser, M., Yusim, D., Stewart, M., Salifu, M. O., & Joseph, M. A. (2021). HIV Testing Correlates: U.S. and Foreign Born High-Risk Black Heterosexual Men. *Journal of Immigrant and Minority Health*, 10.1007/s10903-021-01140-8. Advance online publication. <https://doi.org/10.1007/s10903-021-01140-8>
- Gwadz, M., Leonard, N. R., Honig, S., Freeman, R., Kutnick, A., & Ritchie, A. S. (2018). Doing battle with “the monster:” how high-risk heterosexuals experience and successfully manage HIV stigma as a barrier to HIV testing. *International Journal for Equity in Health*, 17(1), 46. <https://doi.org/10.1186/s12939-018-0761-9>
- Hallfors, D. D., Iritani, B. J., Miller, W. C., & Bauer, D. J. (2007). Sexual and drug behavior patterns and HIV and STD racial disparities: the need for new directions. *American Journal of Public Health*, 97(1), 125–132. <https://doi.org/10.2105/AJPH.2005.075747>
- Hinterland K, Naidoo M, King L, Lewin V, Myerson G, Noubissi B, Woodward M, Gould LH, Gwynn RC, Barbot O, Bassett MT. (2018) Community Health Profiles 2018, Brooklyn Community District 16: Brownsville; 2018; 40(59):1-20.
- HIV Epidemiology Program. HIV Surveillance Annual Report, 2019. (2020). New York: New York City Department of Health and Mental Hygiene.
- Jones, J., Carter, B., Wilkerson, R., & Kramer, C. (2019). Attitudes toward HIV testing, awareness of HIV campaigns, and using social networking sites to deliver HIV testing messages in the age of social media: a qualitative study of young black men. *Health Education Research*, 34(1), 15–26. <https://doi.org/10.1093/her/cyy044>
- Lavizzo-Mourey, R. J., Besser, R. E., & Williams, D. R. (2021). Understanding and Mitigating Health Inequities - Past, Current, and Future Directions. *The New England Journal of Medicine*, 384(18), 1681–1684. <https://doi.org/10.1056/NEJMp2008628>

- Li, Z., Purcell, D. W., Sansom, S. L., Hayes, D., & Hall, H. I. (2019). Vital Signs: HIV Transmission Along the Continuum of Care - United States, 2016. *MMWR. Morbidity and Mortality Weekly Report*, 68(11), 267–272. <https://doi.org/10.15585/mmwr.mm6811e1>
- Link, B. G., & Phelan, J. (1995). Social conditions as fundamental causes of disease. *Journal of health and social behavior*, Spec No, 80–94.
- Mathews, A., Farley, S., Conserve, D. F., Knight, K., Le'Marus, A., Blumberg, M., Rennie, S., & Tucker, J. (2020). “Meet people where they are”: a qualitative study of community barriers and facilitators to HIV testing and HIV self-testing among African Americans in urban and rural areas in North Carolina. *BMC Public Health*, 20(1), 494. <https://doi.org/10.1186/s12889-020-08582-z>
- Millett, G. A., Honermann, B., Jones, A., Lankiewicz, E., Sherwood, J., Blumenthal, S., & Sayas, A. (2020). White Counties Stand Apart: The Primacy of Residential Segregation in COVID-19 and HIV Diagnoses. *AIDS Patient Care and STDs*, 34(10), 417–424. <https://doi.org/10.1089/apc.2020.0155>
- Mizuno, Y., Higa, D. H., Leighton, C. A., Roland, K. B., Deluca, J. B., & Koenig, L. J. (2018). Is HIV patient navigation associated with HIV care continuum outcomes?. *AIDS* (London, England), 32(17), 2557–2571. <https://doi.org/10.1097/QAD.0000000000001987>
- Morne, J. E., Tesoriero, J. M., Martin, E. G., Birkhead, G. S., Holtgrave, D. R., Hagos, K., & Zucker, H. (2020). Ending the HIV Epidemic: New York’s Quest to Become the First State to Reduce HIV Prevalence. *Public Health Reports* (Washington, D.C. : 1974), 135(1\_suppl), 65S–74S. <https://doi.org/10.1177/0033354920917403>
- New York State Senate. (2010) The Laws of New York, Consolidated Laws, Education, Title 8: The Professions, Article 131: Medicine, Section 6526, Special Previsions related to non-patient specific standing orders. Retrieved April 28, 2021, from <https://www.nysenate.gov/legislation/laws/EDN/6527>.
- Ojikutu, B., Nnaji, C., Sithole, J., Schneider, K. L., Higgins-Biddle, M., Cranston, K., & Earls, F. (2013). All black people are not alike: differences in HIV testing patterns, knowledge, and experience of stigma between U.S.-born and non-U.S.-born blacks in Massachusetts. *AIDS Patient Care and STDs*, 27(1), 45–54. <https://doi.org/10.1089/apc.2012.0312>

- Sanchez, T. H., Sullivan, P. S., Rothman, R. E., Brown, E. H., Fitzpatrick, L. K., Wood, A. F., Hernandez, P. I., Nunn, A. S., Serota, M. L., & Moreno-Walton, L. (2014). A Novel Approach to Realizing Routine HIV Screening and Enhancing Linkage to Care in the United States: Protocol of the FOCUS Program and Early Results. *JMIR Research Protocols*, 3(3), e39. <https://doi.org/10.2196/resprot.3378>
- Taylor, T. N., DeHovitz, J., & Hirshfield, S. (2020). Intersectional Stigma and Multi-Level Barriers to HIV Testing Among Foreign-Born Black Men From the Caribbean. *Frontiers in Public Health*, 7, 373. <https://doi.org/10.3389/fpubh.2019.00373>
- Tesoriero, J. M., Swain, C. E., Pierce, J. L., Zamboni, L., Wu, M., Holtgrave, D. R., Gonzalez, C. J., Udo, T., Morne, J. E., Hart-Malloy, R., Rajulu, D. T., Leung, S. J., & Rosenberg, E. S. (2021). COVID-19 Outcomes Among Persons Living With or Without Diagnosed HIV Infection in New York State. *JAMA Open Network*, 4(2), e2037069. <https://doi.org/10.1001/jamanetworkopen.2020.37069>
- U.S. Census Bureau. (2019a) New York City, New York. (2019, July 1). Retrieved April 28, 2021, from <https://www.census.gov/quickfacts/newyorkcitynewyork>
- U.S. Census Bureau. (2019b). American Community Survey 1-year estimates. Profile page for NYC-Brooklyn Community District 16--Brownsville & Ocean Hill PUMA, NY. Retrieved May 5, 2021, from <http://censusreporter.org/profiles/79500US3604007-nyc-brooklyn-community-district-16-brownsville-ocean-hill-puma-ny/>
- Zang, X., Krebs, E., Chen, S., Piske, M., Armstrong, W. S., Behrends, C. N., Del Rio, C., Feaster, D. J., Marshall, B., Mehta, S. H., Mermin, J., Metsch, L. R., Schackman, B. R., Strathdee, S. A., & Nosyk, B. (2020). The potential epidemiological impact of COVID-19 on the HIV/AIDS epidemic and the cost-effectiveness of linked, opt-out HIV testing: A modeling study in six US cities. *Clinical infectious diseases: an official publication of the Infectious Diseases Society of America*, ciaa1547. Advance online publication. <https://doi.org/10.1093/cid/ciaa1547>



## Routine Opt-Out Screening is Key to Understanding and Identifying HIV/HCV Incidence

**Cordella Lyon, RN, BS**

Program Coordinator (Opt-Out HIV Screening)

Baptist Hospitals of Southeast Texas

810 Hospital Drive

Suite 170

Beaumont, Texas 77701

409-212-7525 (Office)

409-212-7527 (Fax)

409-679-0017 (Cell)

cordella.lyon@bhset.net

### Abstract

In 2006, the Centers for Disease Control (CDC) recommended routine HIV screening for all patients aged 13- 64 years old who access healthcare for services. To date, 40% of people in the United States have never had an HIV test, and less than 30 % of people in the United States most at risk for acquiring HIV were tested in the past year.

Description of Services: Baptist Hospital of Southeast Texas (BHSET) through support from Texas Department of State Health Services (TXDSHS) implemented Routine HIV screening in their ED in October 2011, and with additional support from Gilead Sciences, Inc. FOCUS program in 2016. Patients 18 and older, are tested for HIV/HCV and linked to medical care within BHSET, and external community partners.

Opt-out routine screening tests those who may not perceive themselves to be at risk and identifies those previously diagnosed for re-engagement in care. CDC reported 15% of those who do not know their status account for 38% of new transmissions, and 23% of those who knew their status, but were not engaged in care accounted for 43% of new transmissions.

Results: BHSET performed 160,000 tests, identified (0.3 % seropositivity) (0.1%) of new diagnosis (.05%) of acute cases, and (95%) linked to care. October 2016 HCV testing has performed 52% testing on patients outside the birth cohort, with a positivity rate of tested 43%.

During COVID-19, HIV tests numbered 11,960 (0.1% seropositivity) with (.02%) new diagnosis, (98%) linked to care. HCV tests 9, 487, identified (6% HCV Ab seropositivity), (38% RNA positivity) linked (40%) to care.

Conclusion: BHSET has utilized its policy-driven opt-out HIV routine screening practices, protocols, and processes to improve Jefferson County's HIV prevalence from being ranked 4th in the state with cases of people who are living in 2010 to 14th in 2018.

### Introduction

The administrative team at Baptist Hospitals of Southeast Texas (BHSET) implemented a policy-driven opt-out routine HIV screening program in its emergency department with the support of the Texas Department of State Health Services in 2011, and with additional support from Gilead Sciences, Inc. FOCUS program in 2016.

BHSET's HIV screening program offers routine opt-out screening to patients who are 18 and older, getting labs drawn, not screened the past three months, and can opt-out of screening. The program is built on the 2006 CDC recommendations for healthcare providers to offer routine HIV screening to patients who are 13-65 years old in all healthcare settings. A separate consent is not required for HIV testing, general consent for medical care is sufficient to encompass consent for HIV testing, and prevention counseling is not required for HIV diagnostic testing or as part of HIV screening programs in healthcare settings.

Opt-out routine HIV screening destigmatizes HIV, and offers the test to all patients regardless of their real or perceived risk of living with HIV. It also removes the implicit bias of healthcare providers in determining which patients are screened, and normalizes HIV screening as a routine aspect of comprehensive healthcare. Emergency Departments are ideal facilitators of routine screening because they provide medical care to all people regardless of age, race, gender, sexual identity, or ability to pay. Additionally, they provide services to those who may not access care until it is critical.

Opt-out routine HIV screening is an integral tool for early HIV detection and linkage to care. There are approximately 40,000 new HIV infections each year. One in seven people in the United States are unaware of their diagnosis, and seven out of ten people who access health care are not screened for HIV during their healthcare visit. In the US, many people live with HIV for years before they receive a diagnosis. Overall, fewer than 40% of people in the United States have ever had an HIV test. Nationally, less than 30% of people in the United States most at risk of acquiring HIV were tested in the past year. In the 50 local jurisdictions where more than half of HIV diagnoses occur, less than 35% of people recommended for annual HIV testing were tested in the past year; and in states with rural areas that are particularly affected by HIV, just 26% of people recommended for annual HIV testing were tested in the past year.

In 2019, CDC reported HIV screening and early diagnosis are critical to improved health outcomes for people with undiagnosed HIV, and screening reduces the number of new community infections. However, many people are not screened when they access services for medical care. CDC data reports more than 75% of patients at high risk for HIV who saw a primary care provider in the last year were not offered an HIV test during their visit; and 80% of new infections are caused by 20% of those who do not know their status or are out of care.

In June 2019, the United States Preventative Services Task Force (USPSTF) offered two Grade A recommendations for HIV screening: One for all pregnant women, including those who present in labor, or at delivery with HIV status unknown, and the other for HIV

screening in adolescents and adults aged 15 to 65 years old. Younger adolescents and older adults who are at increased risk of infection should also be screened.

In 2012 CDC and USPSTF formally recommended routine Hepatitis C screening (HCV) of all Baby Boomers (those born between 1945 and 1965). Baby Boomers are at high risk for living with HCV with estimates that more than three out of every 100 individuals are infected due to the unsafe blood supply prior to 1992, when blood donations began to be screened for HCV. In 2020, USPSTF updated its guidelines and called for universal screening of patients 18 and above.

## Method

BHSET overlaid its routine HCV screening onto the already existing opt-out routine HIV screening effort with the assistance of the Gilead Sciences FOCUS program in 2016. BHSET's HCV screening program offers routine opt-out screening to patients who are 18 and older, getting labs drawn, and can opt-out of screening. This hospital policy is in keeping with the 2020 CDC recommendation guidelines to offer routine HCV screening to individuals who are 18 and older.

At BHSET, HIV and HCV screens are referenced in the patients' general consent, and incorporated into the normal clinical flow of the emergency department. Additionally, signs are posted throughout the ED that informs patients about the hospital's routine screening policy per CDC recommendations, and patients are verbally informed that HIV/HCV screens are included in their lab work. All patients have a right to opt-out of screening as they would any other medical care. Screening guidelines are included in our EMR, and HIV/HCV screens are included in our diagnostic protocols. The EMR also allows for a smart screening algorithm that helps BHSET identify those who meet the screening criteria.

The routine screening policy implemented at BHSET is a nurse driven program. If patients opt-out of screening, the HIV/HCV order is canceled, and patient care continues uninterrupted. Reactive screens are automatically reflexed for confirmation from the original sample. Patients receive face-to-face notification, and linkage to care from the Patient Navigator under Texas Health and Safety Code Chapter 81.109. Non-reactive screens are considered "no news is good news," and are reported in the patients' medical record. All patients have an opportunity to receive education and risk reduction intervention from the routine screening team. Interventions include education, and effective condom use, access to clean syringes, and linkage to care for Pre-Exposure Prophylaxis (PrEP).

At the implementation of the HIV and HCV opt-out routine screening program, BHSET included many internal stakeholders to address systemic changes needed to develop a sustainable program. External stakeholders were engaged to help build community awareness, and develop additional linkage to care options to address patient care preference, patient advocacy, access to social services, and patient empowerment. They included state and local

health department leadership, Disease Intervention Specialists, pharmacist, mental health and substance use specialists, and other social service providers.

Internal stakeholders included BHSET's Chief Nursing Officer, Chief Financial Officer, and Department Directors from Information Technology, Emergency Department and Nursing, Accounting, BHSET Hospital Foundation, Admissions, and Billing and Coding.

The policy-driven approach to routine HIV/HCV screening by BHSET builds consistency and sustainability for HIV/HCV detection and linkage to care in the emergency department. The EMR facilitates smart screening algorithms, decreases under and over screening and eliminates provider bias for screening per CDC and USPTSF guidelines. Diagnosed patients are linked to care with adequate public health follow-up to enhance patient health outcomes, decrease unknowing transmission, and the opportunity to eliminate the HIV and HCV epidemics.

### Results

Baptist Hospitals of Southeast Texas achieved the following results from its Routine Opt-Out HIV/HCV Screening program. HIV implemented in 2011, and HCV overlaid in 2016.

HIV Screens (since 2011): 160,000

HIV # of Diagnosis / Seropositivity: 553 (3%)

HIV # of Newly Diagnosed/ Seropositivity: 53 (0.1%)

HIV # Linked to Care (first medical appointment) / Percentage: 523 (98%)

HCV Ab Screens (since 2016): 49,699

HCV Ab # of Diagnosis / Seropositivity: 2801 (6%)

HCV RNA # of Tests Completed / 2704

HCV RNA # of Diagnosis / Positivity: 1095 (40%)

HCV RNA Positives attended first appointment: 533 (49%)

HCV # Tested outside the Birth Cohort: 52% of testing was conducted on patients who were born outside the birth cohort, with a positivity rate of 43%.

During the peak of the COVID, 19 pandemic, April to December 2020, HIV Screens numbered 11,960 with a 0.1% seropositivity rate (0.2%) new diagnosis and 98% linkage to care. HCV screens numbered 9,487 identified 6% Ab + seropositivity, 38% RNA seropositivity and linked 40% to care.

## Conclusion

Individuals do not present to emergency departments for HIV or HCV screening because they perceive themselves to be living with either or both of those diagnoses. They present for medical care relating to the symptoms that they are experiencing at that time. Those symptoms are not always indicative of viral illness, but the inclusion of HIV and HCV screening in their lab work provides comprehensive healthcare at the time of their visit. The screening and linkage to care program provides seamless notification and navigation to care through the policy-driven practices, processes, and protocols implemented by Baptist Hospitals of Southeast Texas in 2011.

Routine Screening allows for stigma-free screening of individuals in healthcare settings and normalizes HIV and HCV testing as comprehensive aspects of healthcare for all patients. An administration-supported approach to routine screening withstands pandemics and other disasters, and decreases missed opportunities to identify HIV and HCV during medical visits. Opt-out routine screening at Baptist Hospitals of Southeast Texas has improved Jefferson County's prevalence rank of fourth in the state with people who are living with HIV and unaware of their diagnosis in 2010 to 14th in 2018.

## References

- Centers for Disease Control and Prevention. Estimated HIV incidence and prevalence in the United States, 2010–2016. *HIV Surveillance Supplemental Report 2019*; 24. (2019).
- Diagnoses of HIV Infection in the United States and Dependent Areas, 2017*. (2018). <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2017-vol-29.pdf>
- Dailey, A. F., Hoots, B. E., Hall, H. I., Song, R., Hayes, D., Fulton, P., Prejean, J., Hernandez, A. L., Koenig, L. J., & Valleroy, L. A. (2017). Vital Signs: Human Immunodeficiency Virus Testing and Diagnosis Delays — United States. *MMWR. Morbidity and Mortality Weekly Report*, 66(47), 1300–1306. <https://doi.org/10.15585/mmwr.mm6647e1>
- Ending the HIV Epidemic: A Plan for America*. (2019, February 5). HHS.gov. <https://www.hhs.gov/blog/2019/02/05/ending-the-hiv-epidemic-a-plan-for-america.html>
- Havens, P. L., & Anderson, J. R. (2020). Updated CDC Recommendations for Universal Hepatitis C Virus Screening Among Adults and Pregnant Women. *JAMA*, 323(22), 2258. <https://doi.org/10.1001/jama.2020.3693>
- HHS Blog Posts*. (2019, February). HHS.gov. <https://www.hhs.gov/blog/2019/02/05/ending-the-hiv-epidemic-a-plan-for-america.html>. <https://www.cdc.gov/mmwr/preview/mmwrhtml/00043883.htm>

## Articles

---

<https://www.dshs.texas.gov/hivstd/pops/chap16.shtm?terms=provider%20hiv%20notification%20to%20patient>

*JAMA US Preventive Screening Task Force: Recommendation.* (2017). <https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/human-immunodeficiency-virus-hiv-infection-screening>

Raymond Chung MD posted May 1, 2019-Baby Boomers and Hepatitis C: What's the connection? <https://www.health.harvard.edu/blog/baby-boomers-and-hepatitis-c-whats-the-connection-2019050116532>

*Recommendation | United States Preventive Services Taskforce.* (2019, June 11). [www.uspreventiveservicestaskforce.org. https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/human-immunodeficiency-virus-hiv-infection-screening](https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/human-immunodeficiency-virus-hiv-infection-screening)

Salvant Valentine, S., Caldwell, J., & Tailor, A. (2020). Effect of CDC 2006 Revised HIV Testing Recommendations for Adults, Adolescents, Pregnant Women, and Newborns on State Laws, 2018. *Public Health Reports, 135*(1\_suppl), 189S196S. <https://doi.org/10.1177/0033354920930146>

## References

Access to Health Services | Healthy People 2020. (n.d.). Retrieved November 15, 2021, from <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/access-to-health>.

American Psychological Association. (n.d.). *HIV/AIDS and socioeconomic status*. American Psychological Association. Retrieved November 15, 2021, from <https://www.apa.org/pi/ses/resources/publications/hiv-aids>.

Ayele, T. A., Worku, A., Kebede, Y., Zuma, K., Kasim, A., & Shkedy, Z. (n.d.). *Model-based prediction of CD4 cells counts in HIV-infected adults on antiretroviral therapy in northwest Ethiopia: A flexible mixed effects approach*. PLOS ONE. Retrieved November 15, 2021, from <https://doi.org/10.1371/journal.pone.0218514>.

## The (Contrasted) Ethics of Covid-19 and HIV: Will the Favor be Returned?

**Hope E. Campbell, PharmD, BCPS**

Associate Professor, Department of Pharmacy Practice  
Belmont University College of Pharmacy  
1900 Belmont Blvd, MCWH #330  
Nashville, TN 37212  
Office: (615)-460-6530  
Email: hope.campbell@belmont.edu

**Jacinda C. Abdul-Mutakabbir, PharmD, MPH, AAHIVP**

Assistant Professor of Pharmacy Practice | Critical Care- Infectious Diseases Pharmacist  
Loma Linda University | School of Pharmacy  
Loma Linda University Medical Center | East Campus  
24745 Stewart Street, Shryock Hall Room 212  
Loma Linda, California 92350  
Office Phone Number: (909)-651-9221  
Email: jabdulmutakabbir@llu.edu

**David Augustin Hodge, Sr., Ph.D., D.Min., M.T.S., M.Ed.**

Associate Director of Education,  
Associate Professor at National Center of Bioethics in Research and Health Care  
Director of the Bioethics Honors Program  
Associate Senior Editor of the Journal of Healthcare, Science, and Humanities  
Tuskegee University  
1200 W. Montgomery Rd.  
Tuskegee, Alabama 36088  
Phone: 334-727-4654  
Email: dhodge@tuskegee.edu

### Abstract

With 118,000 cases in 114 countries and 4291 global mortalities, the World Health Organization (WHO) declared COVID-19 a pandemic on March 11, 2020. The origins were believed to be from Wuhan, China, and SARS CoV-2, a coronavirus, was quickly identified as the causative organism. Researchers at the National Institute of Health Vaccine Research Center identified the spike protein as the critical portion of the virus that allows for attachment to human cells. In just 66 days after identifying the genetic sequence, the first COVID-19 vaccine candidate began the enrollment of human subjects into a Phase I clinical trial. This accelerated effort was due to a collective and collaborative global response. Currently, one COVID-19 vaccine has been approved and two others have received an emergency use authorization (EUA) from the United States Food and Drug Administration (FDA). Thus, there has been a clear comparison of the COVID-19 response efforts and that which

was utilized in addressing the human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) epidemic. For over four decades, the HIV/AIDS epidemic has been historically defined by a disproportionate number of infections and related mortalities amongst racially and ethnically minoritized individuals, including those that identify as homosexual. While novel drug therapies have been developed for the treatment of HIV/AIDS; there have been key components employed amid the global health response to COVID-19, that have been absent from the management of the HIV/AIDS epidemic. Majorly, the development and availability of vaccine against HIV/AIDS. Many of the ideas and initiatives that have resulted in a positive COVID-19 response and the eventual successful vaccination development; have been those learned from the trial and error of mitigating increasing global rates of HIV/AIDS infections. Hence, the question remains as to whether the lessons and approaches learned during the COVID-19 pandemic, namely vaccination development, will be applied to managing the HIV/AIDS epidemic. Herein, we aim to compare the HIV/AIDS epidemic and COVID-19 pandemic, by describing how the fight against HIV/AIDs equipped global scientific leaders with effective strategies to overcome future public health crises (COVID-19), discuss the ethical considerations associated with the differences in the global health responses to the HIV/AIDS epidemic versus the COVID-19 pandemic, and finally, identify lessons learned from the COVID-19 pandemic that can be applied to the quest for an HIV/AIDS vaccine..

*Keywords:* HIV, AIDS, COVID-19, ethics, bioethics, public health ethics, epidemic, pandemic

### Introduction

The year 2020 was dominated by the effects of the coronavirus pandemic that caused widespread deaths and hospitalizations<sup>1</sup>. Lockdowns, travel restrictions, business closures, vacated places of worship and play, social distancing and mask wearing became common place. Its origin was traced to December 2019 in Wuhan, China. With 118,000 cases in 114 countries and 4291 persons already dead, the World Health Organization (WHO) declared COVID-19 a pandemic on March 11, 2020<sup>2</sup>. To aid in the detection, prevention and treatment of SARS-CoV-2 infection, the government of the United States created a taskforce called Operation Warp Speed<sup>3</sup>. This was a partnership between components of the Department of Health and Human Services (DHHS) and the Department of Defense (DoD). Its goals were to (1) develop highly sensitive and specific tests for detection of the virus; (2) to develop an effective vaccine to prevent infection from this virus; and (3) to identify or create effective therapeutic options/strategies to manage patients infected with the disease<sup>4</sup>. All three were important but provision of a vaccine by the end of the year was most critical. The healthcare system and economy were severely strained as the number of hospitalizations and death mounted, and restrictive public health measures were implemented.

Researchers at the National Institute of Health Vaccine Research Center identified the spike protein as the critical portion of the virus that allows for attachment to human cells. In just 66 days after the genetic sequence of the virus was identified, the first COVID-19 vaccine candidate was being injected into humans in Phase I clinical trials<sup>5</sup>. By the end of the year, fear



had turned to hope as two vaccine candidates were granted emergency use authorization by the US Food and Drug Administration (FDA) after showing efficacy rates greater than 90%; vaccination of the nation could now begin<sup>6,7</sup>.

Four decades earlier a similar epidemic emerged. A mysterious disease later known as acquired immunodeficiency syndrome (AIDS) was identified in five gay men who presented with pneumocystis carinii pneumonia in Los Angeles. Additional cases popped up in New York City and San Francisco, as did a rare cancer, Kaposi sarcoma<sup>8</sup>. By the end of 1981, 120 gay men had died but it was not until 1984 that the causative pathogen was identified as the human immunodeficiency virus (HIV)<sup>9</sup>. Much like it was at the start of the COVID-19 pandemic, there was widespread misinformation, missteps, blame and sheer panic. Some saw HIV/AIDS as a “gay man’s” disease and a consequence of sexual perversion. Today, with a global death toll from AIDS related diseases of 32.7 million people since the start of the pandemic (UNAIDS) and 38 million people living with the disease, a vaccine remains as elusive as the Scarlet Pimpernel<sup>10</sup>. In the U.S., male to male sexual contact and Black persons (male and female) account for most of the new cases. Both COVID-19 and HIV/AIDS had a multi-modal approach to stem the spread of the virus, and they also had a similar consequence between the impacts of these two devastating social determinants of health.

The government, through a network of agencies, sought to tackle the HIV/AIDS crisis within its borders. Widespread education measures were implemented, and safe sex practices were promoted by public health officials in conjunction with community partners. Scientists developed and refined HIV/AIDS tests, antiretroviral therapies and therapeutic approaches and worked towards a safe and effective vaccine. At the forefront of the quest for a vaccine, is a governmental network called the HIV/AIDS Vaccine Trials Network (HVTN). Unfortunately, after more than 30 years, few vaccine candidates have made it into efficacy trials, and none have proven to be safe and effective. By contrast, the speed with which a vaccine against SARS-CoV-2 was produced, was unprecedented. In the United States, until COVID-19, the fastest timeline was four years and this was for the mumps vaccine, developed by Merck<sup>11</sup>. The extremely short timeline was assisted by improvements in lab techniques, developed during the creation of the polio and measles vaccines. Similarly, much of the success of COVID-19 vaccines were due to prior work done in the fight against the human immunodeficiency virus (HIV/AIDS)<sup>12</sup>. Table 1 compares the key differences and similarities between these two global health threats, HIV/AIDS and COVID-19.

Despite the global threat that both these diseases cause, the governmental response to the two diseases have been vastly different and so has the outcome. We aim to describe the differences in approach and how management of the COVID-19 pandemic was aided by lessons and approaches learned and perfected to fight the HIV/AIDS epidemic. Also, we will identify the lessons learned from the COVID-19 pandemic that can be applied to the HIV/AIDS epidemic and the quest for a targeted vaccine. Nonetheless, it is essential to evaluate the ethical framework governing these two catastrophic and deadly social determinants of health.

### *The HIV/Covid-19 ethical asymmetry*

Our first critical assertion (though not the most important) is to fulminate against the naming (i.e., the categorization) of HIV/AIDS as an epidemic, when in truth HIV/AIDS is a pandemic. This asymmetrical category-naming misstep is a violation of the ethics of naming because it infringes upon the potential resources of those living with HIV/AIDS. To be sure, “An epidemic is defined as “an outbreak of disease that spreads quickly and affects many individuals at the same time<sup>13</sup>.” A pandemic is a type of epidemic (one with greater range and coverage); it is an outbreak of a disease that occurs over a wide geographic area and affects an exceptionally high proportion of the population<sup>13</sup>. While a pandemic may be characterized as a type of epidemic, you would not say that an epidemic is a type of pandemic.” Given the data and explication we’ve already accentuated throughout this paper, what would be the justification for HIV/AIDS being labeled an epidemic, thus limiting its resources and potential future resources, and COVID-19 being labeled a pandemic, thus availing it to worldwide resources? Even a cursory view of the world map would indicate the prevalence of HIV/AIDS worldwide, especially among Black people in Africa and the diaspora<sup>14</sup>. Clearly, HIV/AIDS is not just a local or regional epidemic; it’s a worldwide epidemic and it has been such for many years. Once there is concurrence about correctly naming the HIV/AIDS whirlwind as a *pandemic*, people of good will may be more discursive about the nature and ethical considerations of COVID-19 and HIV/AIDS.

Further, the present asymmetry that exists between the HIV/AIDS epidemic and the COVID-19 pandemic is an artificial one (as was just demonstrated), and the (concrete) social justice component of (abstract) justice demands equity, even in light of patience. Social justice demands impartiality, particularly with respect to human-animals and their right to personhood. If individuals who have contracted HIV/AIDS and individuals who have contracted COVID-19 are both not non-persons, then they are both persons. Therefore, there *should be* no valid ethical justification for prioritizing the treatment of one over the other.

### *Behavior as Asymmetrical Justification*

First, the ethical asymmetry between HIV/AIDS and COVID-19 should be quite obvious to any objective spectator, but often the contrast is stymied by the macro *category-naming* of the former as an epidemic and the latter as a pandemic. Although lives are lost in large numbers in both category-names, there is both a cognitive and an emotional (and psychological) perception that gives less weight—less gravitas—to the more local “epidemic” and more priority to the globalized “pandemic.” The obvious prioritization of the pandemic over the epidemic is rationally and ethically justified on a utilitarian calculus—the planet is a better (and happier) place to live without panic, trauma, and devastatingly magnanimous loss of lives—and on (what would normally be) a “cold” detached rationalistic (Kantian--*absolutist*) deontology. On a utilitarian account, the “right” action is to prioritize pandemics over epidemics. From a (Kantian) deontological point of view, the “right” action is to (roughly) “Always act so that you may also wish that the maxim of your action become a universal law.” It is rational—it is commonsense—to prioritize pandemics over epidemics. At its worse, an epidemic has the capacity to take many lives; but at its worse, a pandemic has the capacity to

terminate *all lives*. Thus, there is no valid argument, given the backdrop of the world context, where an epidemic would have more moral priority and attention than a pandemic. As a result, the naming of a public health or bioethical event as either an epidemic or a pandemic, is extremely crucial.

Scarce resources are diverted to pandemics, even if they require the (utilitarian) sacrifice of those in an (non-pandemic) epidemic—and as we have already intimated, this makes moral sense. Therefore, in this paper we are not fool-heartedly inveighing against diverting scarce resources from an epidemic to a pandemic. On the contrary, we recognize that there is an ethical asymmetry between HIV/AIDS and COVID-19, mostly because of how each is perceived. COVID-19 is perceived as a kind of involuntary disease that is not easily mitigated by personal behavior. HIV/AIDS, contrarily, was initially understood and previewed as, first, a disease contracted through some level of immorality and behavior, namely, homosexuality or intravenous drug users. Heteronormative bias (often correlated with religious dissociation because of the “sin of homosexuality”) has created and maintained a culture that associated morality with medicine and healthcare. One this view, “reckless behavior”—irresponsibility—is what caused HIV/AIDS to flourish; HIV/AIDS contracted through behavior is voluntary. This way of thinking is quite mistaken, but even if it was correct, attempting to justify the priority of one illness over another seems to forget the notion and value of *personhood*—i.e., what it means to be a person and what it means to have human rights. The presence of HIV/AIDS and much of what we’ve learned about epidemics have been a methodological blessing in the fight against the novel coronavirus. As such, the world has paid attention to COVID-19; and (perhaps because of the perceived differences between the two) the world has paid less attention to HIV/AIDS. Consequently, we concur with the utilitarian bias of prioritizing the COVID-19 pandemic over the HIV/AIDS epidemic, *but* we foresee a (Kantian/deontological) ethical violation *if the favor is not returned*. Kant categorically states, “So act in such a way that you treat humanity, in your own person as well as in the person of any other, always at the same time as an end, never merely as a means.”<sup>15</sup> Utilizing the genius and resources gained from COVID-19 without universalizing the good to HIV/AIDS, should be regarded as both a bioethical and public health ethical violation.

Secondly, it seems clear that the semantic ambiguity between epidemic and pandemic is only partially culpable for how we are to understand the attention given to COVID-19 and the less profound attention given to HIV/AIDS over the last four decades. Prior to March 2020, any comparison between HIV/AIDS and the attention given to other pandemics were mostly anecdotal, but with the catastrophic emergence of COVID-19, public health ethicist and bioethicist now have a rubric to surveil and assess what has been done for the one and not the other. An ethical chasm is not formed post-COVID-19 unless the learned genius and resources gained in the combat of the novel coronavirus are not re-directed to the ongoing fight against HIV/AIDS. In other words, a reasonable ethical theory can (at least anecdotally) defend a rejection of the asymmetrical import of pandemic vs epidemic or COVID-19 as pandemic vs HIV/AIDS as epidemic but defending a view that prioritizes the health of one person over the health of another person is far less attractive and defensible. An asymmetrical view of

person is a necessary condition for discriminatory practices—i.e., a revulsion of equity—thus, post-COVID-19 prioritization of HIV/AIDS clinical trials, medications, and other curative initiatives should not be an unreasonable compulsion.

### *Personhood as Symmetrical Justification*

Asymmetry of a person fosters discrimination and is unethical. Asymmetry of social determinants of health, as we've addressed at this point, are only morally adverse if there is a lack of equity in treatment once all other considerations have been satisfied. For example, on a utilitarian calculus, re-directing of funds and other resources to halt the devastating coronavirus pandemic is morally sound. On the other hand, on a virtue-based, empathic care ethics consideration, failure to re-direct funds and other resources to halt the HIV/AIDS epidemic is morally unsound. Failure to demonstrate empathy and care for those living with HIV/AIDS, in ways which have occurred for those who are living through the COVID-19 pandemic, seems to reflect either an arbitrary valuation of persons or a discriminatory devaluation of persons. On the former account, valuation of persons is based upon a host of variables (e.g., the self as other, life of individuals, filial considerations); on the latter account, devaluation of persons is based upon implicit biases (e.g., race, gender, heteronormativity, essentialism, etc.). Consequently, to avoid (the appearance of) inequities in healthcare, it is imperative that all persons—COVID-19/persons and HIV/AIDS/persons, et al.—have equal access to healthcare, as much as possible. Paul Farmer states this far more succinctly and candidly, “The idea that some lives matter less is the root of all that is wrong with the world.<sup>16</sup> The same energy garnered for one should be garnered for the other. Annette Baier’s “interdependence of persons” and Martin Luther King, Jr.’s, “We are caught in an inescapable network of mutuality, tied in a single garment of destiny. Whatever affects one directly, affects all indirectly”, shapes the *communitas* of our point rather nicely<sup>17,18</sup>. Certainly, there is much philosophical discussion regarding what makes a human a person (Is an infant a person, or “My Uncle Charlie is not much of a person but he’s still my Uncle Charlie”), but this is not our focus in this paper. Our ethical concern is the maximizing of efforts to treat those infected with HIV/AIDS in a similar fashion as we are presently witnessing with COVID-19.

### *HIV/AIDS Established Protocols that Benefits COVID-19*

There has been a consistent juxtaposition of the HIV/AIDS epidemic and the COVID-19 pandemic, boiling down to the inclusion of pivotal scientists in HIV/AIDS research, (e.g., Dr. Anthony Fauci), in the national COVID-19 response<sup>19</sup>. To that, many institutions known for their HIV/AIDS research, took on the task of pioneering COVID-19 investigations, concurrently<sup>20</sup>. Thus, it would be a severe oversight to not acknowledge the ideas/ influence that navigating the HIV/AIDS epidemic has had on the COVID-19 pandemic response.

Foremost, the engagement of minority community members and racial concordance between healthcare providers and patients were shown to be a cornerstone of HIV/AIDS treatment and testing success<sup>21</sup>. As with the HIV/AIDS epidemic, false information regarding the COVID-19 virus has been issued across minoritized communities, resulting in a decline in testing and increased vaccination hesitancy amongst Black, Latino, and Native American

populations; irrespective of the disproportionate COVID-19 mortalities amongst these racial and ethnic groups<sup>22, 23</sup>. With that, the delivery of COVID-19 information has been done so by trustworthy messengers of minoritized communities<sup>24, 25</sup>. Additionally, COVID-19 testing, and vaccination efforts specifically tailored to minoritized communities have been spearheaded by culturally representative individuals belonging to these minoritized groups<sup>21</sup>. The success of these COVID-19 mitigating efforts are often attributed to the unique positioning of minoritized healthcare professionals to the racial and social determinant of health inequities that permeate through minoritized populations; thus, paralleling components of success in HIV/AIDS treatment<sup>22, 26, 27</sup>.

Further, the HIV/AIDS epidemic enforced the necessity of harm reduction rather than elimination, which has been consistent in COVID-19 messaging<sup>28, 29</sup>. As the COVID-19 virus was widely disseminated globally, scientists vehemently stated that social distancing, masking, and eventually vaccination would be essential to a reduction in COVID-19 infection<sup>3, 22, 30</sup>. Similarly, pre-exposure prophylaxis (PrEP), safe sex practices, and a cessation in illicit drug usage have been publicized to society as necessary measures to reduce the burden of HIV/AIDS<sup>29</sup>. Healthcare professionals have been realistic in affirming that while PrEP and safer sex practices will not completely eliminate HIV/AIDS, it would be sufficient in reducing the impact that HIV/AIDS has had globally, and the number of those that perish due to the virus<sup>29, 31</sup>. With this, messaging pertaining to the COVID-19 vaccinations has been explicit in stating that while the vaccines will not completely eradicate COVID-19 (with none of the viruses have 100% efficacy), they will reduce (along with other mitigation measures like masking and physical distancing) the burden of the disease and the related deaths<sup>6, 7</sup>.

Global collaborations have been pivotal in managing the HIV/AIDS epidemic, and the same can be said for COVID-19 management<sup>32, 33</sup>. Historically, knowledge in HIV/AIDS treatment, testing, and other related measures have consisted of global task forces, with positions held by various global health leaders<sup>20</sup>. These task forces have resulted in the creation of treatment algorithms, innovative approaches to HIV/AIDS drug therapy resistance testing, and the concerted communication measures to increase the identification of people living with HIV (PLWH)<sup>32, 33</sup>. The same can be said about the global response to COVID-19, if not in a more organized and intense manner. As COVID-19 swept through the continents and claimed the lives of millions, task forces were created to develop responsive immunizations, testing procedures, and antivirals targeted against SARS-COV-2. In respect to the vaccines, success of therapy was shared inter-region amongst the scientific community. Notably, drug companies such as Merck and Janssen joined forces to ensure the quick manufacturing and delivery of Janssen's, Ad26.COV2.S, vaccine; indicating that external collaboration amongst drug companies for global health's greater good, is a true possibility<sup>34</sup>.

Perhaps most importantly, the HIV/AIDS epidemic emphasized the importance of healthcare multidisciplinary collaboration in delivering optimal patient care<sup>21, 22</sup>. To this point, the American Academy of HIV/AIDS Medicine offers HIV/AIDS specialist credentialing to various disciplines including medicine, nursing, and pharmacy<sup>35</sup>. Of note, each discipline

has a very distinct role in ensuring that each HIV/AIDS positive patient is well managed<sup>36</sup>. Mirroring this model of multiple disciplines being essential to care; it has been very clear that the adequate management of each COVID-19 patient requires teamwork and collaborative relationships<sup>21,22</sup>. These relationships encompass many disciplines including, but not limited to physicians, nurses, pharmacists, and respiratory therapists. Additionally, *a trusting relationship* with each healthcare professional involved in care has been shown to be essential in overcoming the COVID-19 pandemic, paralleling the utility shown through established trusting patient-provider relationships in HIV/AIDS management<sup>24,25</sup>. The trusting relationships are imperative to addressing and overcoming the decades of medical mistreatment, which have inevitably resulted in the healthcare hesitancy observed amongst minoritized groups.

While HIV/AIDS has provided a strong infrastructure to guide COVID-19 management, it is important to acknowledge that there is a clear difference in the amplification and allocation of funding, scientific talent, engagement of specific community figures, and overall priority when comparing the two<sup>37</sup>. When considering funding, the United States has spent over 19 billion dollars towards the acquisition of COVID-19 vaccines from several pharmaceutical companies. Most notable was the collaboration of the sharing of scientific data between the pharmaceutical companies<sup>34</sup>. In HIV/AIDS, the same cannot be said. Currently, there is a lack in evidence attesting to the sharing of findings when considering the development of novel agents to aid in HIV/AIDS management (NNRTIs, fusion inhibitors). This includes even the knowledge of the pathogenesis of each virus, the genome of COVID-19 was at once shared amongst the continents, but this was not the case with HIV/AIDS<sup>38</sup>. Although it can be said that COVID-19 is widely and rapidly spread, and has quickly claimed the lives of millions globally, which in turn was the catalyst for novel and innovative approaches; it cannot be understated that HIV/AIDS, in 2020, was causative of over 500,000 global deaths, with this number rising steadily<sup>14</sup>. This begs the question of whether the populations majorly affected (Black, Latino, Native American, men who have sex with men) has contributed to the HIV/AIDS epidemic's comparable, unhurried response.

Notably, faith leaders, specifically those of minoritized groups, have been amongst the most influential in calling into action COVID-19 testing amongst these populations, and in encouraging their community members to be vaccinated against the virus<sup>21,22</sup>. The faith leaders have been intentional in creating and promoting collaborative relationships with scientists and healthcare professionals, to increase their community's access to evidence-based information regarding the vaccine and the virus. This is of high importance, as religion is heavily engrained in the foundation of the US. Nevertheless, HIV/AIDS has been described as a disease with major prominence in the homosexual community, thus, not given major emphasis in the religious setting. Considering the impact that faith leaders have in minoritized communities, translating their methods for combatting COVID-19, to overcoming HIV/AIDS would be significant.



## The Road Ahead

The following recommendations are born out of the lessons learned from COVID that can be applied to the AIDS epidemic:

1. *Invest in pandemic preparedness:*

The lack of investment in pandemic preparedness was evident in the government's response to the challenges posed by the COVID-19 pandemic. Stockpiles were not maintained, and preparedness taskforce and experts were disbanded. State officials competed with and against each other for scarce resources from personnel to personal protective equipment and medical supplies. Science and scientists were marginalized, and the country's health was being wagered against its economy. Listening to the experience of infectious disease experts, researchers working in HIV/AIDS and public health officials, however, were invaluable.

2. *Increase Funding and Expand Funding Sources:*

Continued financial investment in HIV/AIDS research and HIV/AIDS vaccine more specifically must be prioritized. Funding sources for HIV/AIDS research needs to be expanded to include more public-private partnerships. Funding from philanthropists such as Bill and Melinda Gates have been pivotal in expanding care to areas of the world most affected by the AIDS epidemic, but more support is needed.

3. *Collaboration/Partnerships:*

Few pharmaceutical companies are actively involved in the quest for a vaccine against HIV/AIDS. The government invested financially in the quest for a COVID vaccine by providing funds for research and development and pre-purchased said products. In that environment there were many manufacturers who joined the vaccine marketplace as barriers to development were removed. Sharing of scientific information and collaboration between vaccine manufacturers occurred at levels previously not seen. Information about the spike protein was shared among manufacturers and the collective and collaborative effort was unprecedented leading to two vaccines being available to the public in less than one year. A global research agenda where researchers strategically work together as a team sharing information to develop a specific vaccine before moving on to another would help in making more vaccines being available. During the pandemic there were at least 70 vaccine candidates being studied across the globe<sup>39</sup>. With that level of focus, significant progress was made but it came at a cost. Work on diseases such as HIV/AIDS were put on hold or their momentum slowed<sup>40</sup>. Some patients living with HIV (PLWH) had their care interrupted as supply chains were impacted by COVID. In-person visits were often limited and some patients afraid of exposure to the SARS CoV-2 virus declined to access care in health facilities. Vaccines are not a business priority of most drug manufacturers, in part due to the litigious US environment and vaccine hesitancy among the public. The World Health Organization (WHO) identified vaccine hesitancy as a global health threat prior to the SARS CoV-2 pandemic<sup>41</sup>. The government must continue to explore ways to incentivize the research and development needed while employing best practices to address vaccine hesitancy.

4. *Invest in Innovation:*

Understandably, the failure to develop a HIV vaccine after more than 30 years may be a deterrent for young scientists, but to some it may simply be a challenge to conquer. Funding drove innovation for the COVID vaccines and if expanded to HIV could also drive innovation in the quest for a vaccine against HIV. Such work requires advanced technologies, improved understanding of the science about the virus and its actions and brilliant minds. Given the slow progress made towards creating a HIV vaccine, new scientists will need to be incentivized to join or to remain in the fight.

5. *Globalization vs Nationalism:*

Recognizing the inter-connectedness of our world through travel, public health officials and governments must seek to support the “least of these” because we are only as strong as the country with the weakest health infrastructure. If the health of any country is threatened, we all are threatened with disease and death. sub-Saharan Africa bears the highest burden of disease and without global assistance and an integrated approach, combating the spread of HIV/AIDS is likely to fail<sup>42</sup>. The Global Fund is a partnership that seeks to end AIDS, tuberculosis (TB) and malaria epidemics<sup>43</sup>. This fund project that due to the impact of COVID-19 on vulnerable countries and communities, progress made in AIDS, TB and malaria are being rolled-back. They estimate that in sub-Saharan Africa there will be an increase in AIDS related deaths to levels seen back in 2008. The wiping out of 10 years of progress is due to the treatment interruption for as much as six months during the COVID-19 pandemic<sup>44</sup>.

6. *Embrace diversity:*

A diverse workforce and research team will drive innovation and expand the scope of the research. Members of minoritized communities will bring a perspective and a focus to areas of research that is not likely to be seen by others. The notion that Black persons are vaccine hesitant due to historic research atrocities such as the infamous Tuskegee Syphilis Trial is not a free pass to avoid recruitment of Black individuals to clinical trials. The atrocities were real and there is hesitancy but as Moderna® showed in their trial; Black people will enroll; but it requires more effort on the part of the researchers and recruiters to make it a priority.

7. *Policy Equity:*

The policies that regulate the pharmaceutical industry and the availability of novel agents will need to be formulated with the consideration of socioeconomic factors and contributors. With the consideration that minoritized individuals are more likely to have less access to innovative drug therapies due to systemic racism, policies, and monetary resources; pharmaceutical companies will need to reevaluate their pricing mechanisms. Additionally, federal, state, and local drug administration authorities must mandate that there is affordability of and accessibility to the medications by the public. The distribution of free COVID-19 vaccines serves as a template.



## Conclusion

It is imperative that the lessons, knowledge, and tools gained from navigating the COVID-19 pandemic be applied to combating the HIV/AIDS epidemic. Furthermore, we must align our ethical behaviors and morals to adequately define and address the HIV/AIDS crisis as the pandemic that it is. This begins with the global dedication of more novel therapies, including a suitable vaccine, to combat the virus. To this, Moderna® has taken a lead role in HIV vaccine rollout, with their pilot mRNA vaccine human trial<sup>45</sup>. Nevertheless, this lone study should not be a stopping point for investigation. With that, there must be a diverse, inclusive, and equitable approach in terms of the study investigators and participants enrolled. Additionally, the study protocols and results should be transparent and evaluated by a diverse panel of informed science and medical professionals. Also, should the vaccine prove to be effective, the equitable availability and affordability of the vaccine to those individuals that are heavily represented amongst those infected, is of extreme importance. It is essential, irrespective of impact designation (epidemic vs pandemic), that combating the HIV/AIDS epidemic be met with the same fervor and innovation as the COVID-19 pandemic.

Table 1.

CHARACTERISTIC	AIDS	COVID-19
Classification	Epidemic	Pandemic
Cause	Virus	Virus
Pathogen	Human Immunodeficiency Virus (HIV/AIDS)	Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2)
Vaccine availability	No	Yes
Discovery (1st cases)	1981	2019
Effective treatments	Yes	Limited
Prevention	Condoms, PrEP	Social distancing, mask-wearing, hand hygiene, vaccines
Primary Transmission	Blood and Body Fluid, IVDU	Respiratory
Susceptible persons	MSM, multiple sex partners, IVDU, Maternal fetal transmission, heterosexual contact	Everyone
Highest disease burden	Black, Hispanic, MSM,	Black, Hispanic, Older persons, Immunocompromised
Country/region with most cases	Sub-Sahara Africa	United States of America
Funding	Government and Bill & Melinda Gates Foundation	Government, Bill & Melinda Gates Foundation Private Enterprise
Statistics	75.5 M infected 32.7 M dead [38 years]	124 M cases 2.7M deaths [15 months]
Cure	No (chronic infection) Virus integrates into host DNA	Yes (acute +/- chronic state)

Included in Table 1 is a comparison of the HIV/AIDS epidemic and the COVID-19 pandemic

\*IVDU= Intravenous drug use HIV/AIDS= Human Immunodeficiency virus COVID-19 = Coronavirus disease

PrEP= Pre-exposure, MSM= Men who have sex with men\*

### References

1. COVID Data Tracker Centers for Disease Control. Accessed August 21, 2021. [https://covid.cdc.gov/covid-data-tracker/#cases\\_casesper100klast7days](https://covid.cdc.gov/covid-data-tracker/#cases_casesper100klast7days)
2. World Health Organization . WHO Director-General's opening remarks at the media briefing on COVID-19 - 11 March 2020. Accessed August 21, 2020. <https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020>
3. Woolf SH, Chapman DA, Lee JH. COVID-19 as the Leading Cause of Death in the United States. *JAMA*. Jan 12 2021;325(2):123-124. doi:10.1001/jama.2020.24865
4. Department of Human Health Services . Explaining Operation Warp Speed. Accessed August 21, 2021. <https://www.nihb.org/covid-19/wp-content/uploads/2020/08/Fact-sheet-operation-warp-speed.pdf>
5. Corbett KS, Edwards DK, Leist SR, et al. SARS-CoV-2 mRNA vaccine design enabled by prototype pathogen preparedness. *Nature*. 2020/10/01 2020;586(7830):567-571. doi:10.1038/s41586-020-2622-0
6. Polack FP, Thomas SJ, Kitchin N, et al. Safety and Efficacy of the BNT162b2 mRNA Covid-19 Vaccine. *N Engl J Med*. Dec 31 2020;383(27):2603-2615. doi:10.1056/NEJMoa2034577
7. Baden LR, El Sahly HM, Essink B, et al. Efficacy and Safety of the mRNA-1273 SARS-CoV-2 Vaccine. *N Engl J Med*. Feb 4 2021;384(5):403-416. doi:10.1056/NEJMoa2035389
8. HIV.gov. A Timeline of HIV and AIDS. Accessed August 21, 2021. <https://www.hiv.gov/hiv-basics/overview/history/hiv-and-aids-timeline>
9. Kaiser Family Foundation . The HIV/AIDS Epidemic in the United States: The Basics. Accessed August 21, 2021. <https://www.kff.org/hiv/aids/fact-sheet/the-hiv-aids-epidemic-in-the-united-states-the-basics/>
10. UNAIDS. Global HIV & AIDS statistics — Fact sheet. Accessed August 21, 2021. <https://www.unaids.org/en/resources/fact-sheet>
11. History. How a New Vaccine Was Developed in Record Time in the 1960s. Accessed August 21, 2021. <https://www.history.com/news/mumps-vaccine-world-war-ii>
12. Celum C, Barnabas R, Cohen MS, et al. Covid-19, Ebola, and HIV - Leveraging Lessons to Maximize Impact. *N Engl J Med*. Nov 5 2020;383(19):e106. doi:10.1056/NEJMp2022269

13. Columbia University School of Public Health Health. Epidemic, Endemic, Pandemic: What are the Differences? Accessed August 21, 2021. <https://www.publichealth.columbia.edu/public-health-now/news/epidemic-endemic-pandemic-what-are-differences>
14. HIV.gov. The Global HIV/AIDS Epidemic. Accessed August 21, 2021. <https://www.hiv.gov/hiv-basics/overview/data-and-trends/global-statistics>
15. Kant I. Kant: *The metaphysics of morals*. Cambridge University Press; 2017.
16. Partners in Health. Accessed August 21, 2021. <https://www.pih.org/>
17. Baier A. *Moral prejudices: Essays on ethics*. Harvard University Press; 1995.
18. King Jr ML. Letter from Birmingham jail. *UC Davis L Rev*. 1992;26:835.
19. Eisinger RW, Lerner AM, Fauci AS. Human Immunodeficiency Virus/AIDS in the Era of Coronavirus Disease 2019: A Juxtaposition of 2 Pandemics. *The Journal of Infectious Diseases*. 2021;
20. HIV.gov NIH-Funded AIDS Clinical Trials Group Conducts COVID-19 Treatment Study. Accessed August 21, 2021. <https://www.hiv.gov/blog/nih-funded-aids-clinical-trials-group-conducts-covid-19-treatment-study>
21. Abdul-Mutakabbir JC, Casey S, Jews V, et al. A three-tiered approach to address barriers to COVID-19 vaccine delivery in the Black community. *Lancet Glob Health*. Mar 10 2021;doi:10.1016/S2214-109X(21)00099-1
22. Marcelin JR, Swartz TH, Bernice F, et al. Addressing and Inspiring Vaccine Confidence in Black, Indigenous, and People of Color (BIPOC) during the COVID-19 Pandemic. 2021:
23. Macias Gil R, Marcelin JR, Zuniga-Blanco B, Marquez C, Mathew T, Piggott DA. COVID-19 pandemic: disparate health impact on the Hispanic/Latinx population in the United States. *The Journal of infectious diseases*. 2020;222(10):1592-1595.
24. Jacobson RM, St Sauver JL, Finney Rutten LJ. Vaccine Hesitancy. *Mayo Clin Proc*. Nov 2015;90(11):1562-8. doi:10.1016/j.mayocp.2015.09.006
25. Warren RC, Forrow L, Hodge DA, Sr., Truog RD. Trustworthiness before Trust - Covid-19 Vaccine Trials and the Black Community. *N Engl J Med*. Nov 26 2020;383(22):e121. doi:10.1056/NEJMp2030033
26. Pottinger AM, Passard N, Gordon Stair A. Using faith-based organisations to promote mental health education to underserved populations in Jamaica. *Health Education Journal*. 2021/06/01 2021;80(4):461-471. doi:10.1177/0017896920988036

27. Kaiser Family Foundaiton . Pulling It Together: Changing the HIV Testing Message. Accessed August 21, 2021.<https://www.kff.org/health-reform/perspective/pulling-it-together-changing-the-hiv-testing/>
28. Wodak A, McLeod L. The role of harm reduction in controlling HIV among injecting drug users. *AIDS*. 2008;22 Suppl 2(Suppl 2):S81-S92. doi:10.1097/01.aids.0000327439.20914.33
29. International HR. HARM REDUCTION FOR HIV PREVENTION. 2010;
30. Louis-Jean J, Aime,M. . On the novel coronavirus (COVID-19): A global pandemic. *Jurnal Teknologi Laboratorium*. 2020;doi:10.29238/teknolabjournal.v9i1.230
31. Chou R, Evans C, Hoverman A, et al. Preexposure Prophylaxis for the Prevention of HIV Infection: Evidence Report and Systematic Review for the US Preventive Services Task Force. *JAMA*. Jun 11 2019;321(22):2214-2230. doi:10.1001/jama.2019.2591
32. Fonseca BdPFe, Albuquerque PC, Noyons E, Zicker F. South-south collaboration on HIV/ AIDS prevention and treatment research: when birds of a feather rarely flock together. *Globalization and Health*. 2018/03/01 2018;14(1):25. doi:10.1186/s12992-018-0341-1
33. Balachova TN, Batluk JV, Bryant KJ, Shaboltas AV. International collaboration in HIV prevention research: evidence from a research seminar in Russia. *AIDS Res Hum Retroviruses*. 2015;31(2):163-172. doi:10.1089/AID.2014.0078
34. Merck. Merck to Help Produce Johnson & Johnson's COVID-19 Vaccine; BARDA to Provide Merck With Funding to Expand Merck's Manufacturing Capacity for COVID-19 Vaccines and Medicines. Accessed August 21, 2021.<https://www.merck.com/news/merck-to-help-produce-johnson-barda-to-provide-merck-with-funding-to-expand-mercks-manufacturing-capacity-for-covid-19-vaccines-and-medicines/>
35. American Academy of HIV Medicine . Accessed August 21, 2021. <https://aahivm.org/credentialing/>
36. Horberg MA, Hurley LB, Towner WJ, et al. Determination of optimized multidisciplinary care team for maximal antiretroviral therapy adherence. *J Acquir Immune Defic Syndr*. 2012;60(2):183-190. doi:10.1097/QAI.0b013e31824bd605
37. JSI. Sharing Lessons Between Epidemics: What can we learn from the responses to HIV and COVID-19? 2021. Accessed August 21, 2021. <https://www.jsi.com/sharing-lessons-between-epidemics-what-can-we-learn-from-the-responses-to-hiv-and-covid-19/>

38. Horizon Magazine . Covid-19: How unprecedented data sharing has led to faster-than-ever outbreak research. Accessed August 21, 2021. <https://ec.europa.eu/research-and-innovation/en/horizon-magazine/covid-19-how-unprecedented-data-sharing-has-led-faster-ever-outbreak-research>
39. New York Times . Coronavirus Vaccine Tracker. Accessed August 21, 2021. <https://www.nytimes.com/interactive/2020/science/coronavirus-vaccine-tracker.html>
40. Friends of the Global Fight. How COVID-19 is Affecting the Global Response to AIDS, Tuberculosis and Malaria. Accessed August 21, 2021. <https://www.theglobalfight.org/covid-aids-tb-malaria/>
41. World Health Organization. Ten threats to global health in 2019. Accessed August 21, 2021. <https://www.who.int/news-room/spotlight/ten-threats-to-global-health-in-2019>
42. Kharsany AB, Karim QA. HIV Infection and AIDS in Sub-Saharan Africa: Current Status, Challenges and Opportunities. *Open AIDS J.* 2016;10:34-48. doi:10.2174/1874613601610010034
43. The Global Fund. Global Fund Overview. Accessed August 21, 2021. <https://www.theglobalfund.org/en/overview/>
44. The Global Health Fund. The Global Health Fund COVID-19 Response. Accessed August 21, 2021. <https://www.theglobalfund.org/en/covid-19-plan/>
45. Clinicaltrial.gov. A Phase 1 Study to Evaluate the Safety and Immunogenicity of eOD-GT8 60mer mRNA Vaccine (mRNA-1644) and Core-g28v2 60mer mRNA Vaccine (mRNA-1644v2-Core). Accessed August 21, 2021. <https://clinicaltrials.gov/ct2/show/NCT05001373>

# From Policy to Funding: A Case Study of Inequitable Funding Allotments Towards Chicago Illinois' Black-Led HIV/AIDS Service Providers

**Sista Yaa Simpson, MPH**

Community Epidemiologist

TACTS (The Association of Clinical Trial Services)

10 W. 35th, OFC 9, Chicago, IL 60616-3717

312-961-6189

Tacts4us@gmail.com

www.Tacts4us.org

## Author Notes

Source: preliminary discussions/presentations

Supported by Black Leadership Advocacy Coalition for Health Equity (BLACHE)

Disclaimer: As a member of BLACHE, TACTS has no financial conflicts.

No IRB submission required, no human subjects were studied, or clinical trials ensued.

Acknowledgements: All members of BLACHE-more specifically convener of the coalition and Reviewer Creola A. Kizart-Hampton, President/Founder, GREATERWORKS! INC and Reviewer/Editor Ajua Pryor, MBA, TACTS Board Member

## Abstract

According to census and surveillance reports (2018), Black people in Illinois make up 15% of the state population (12,587,530) but comprise more than 46% of people living with HIV infections (35,841) and 51% of people newly diagnosed infections (1,361). Comparably, Blacks in Chicago make up 30% of the population (2,693,976) but comprise more than 51% of people living with HIV infection (18,719), as well as 54% newly diagnosed infections (724). (Dawson, Kates, 2021) (AIDSVU, 2020) This trend has been consistent for the past 15 years, whereas Blacks accounted for the highest proportion of people living with and newly diagnosed HIV infections. However, HIV funding to Black-Led HIV/AIDS Service Providers was not equitably distributed as compared to White-Led Service Providers. As there was no justification or accountability for these grossly inequitable funding allotments, Black-Led HIV/AIDS Service Providers unified to form the BLACK LEADERSHIP ADVOCACY COALITION FOR HEALTH EQUITY (BLACHE). This case study will relay how BLACHE brought awareness to the public, legislators, and others. Moreover, how this organization moved the needle for funding by increasing the allotment from zero dollars (\$0) in 2019 to \$15M in the 2021 Illinois State budget through the African American HIV/AIDS Response Act (AAHARA).

*Keywords:* Black-Led Service Providers, Blacks, Funding Inequities, Health Equity, HIV

## Introduction

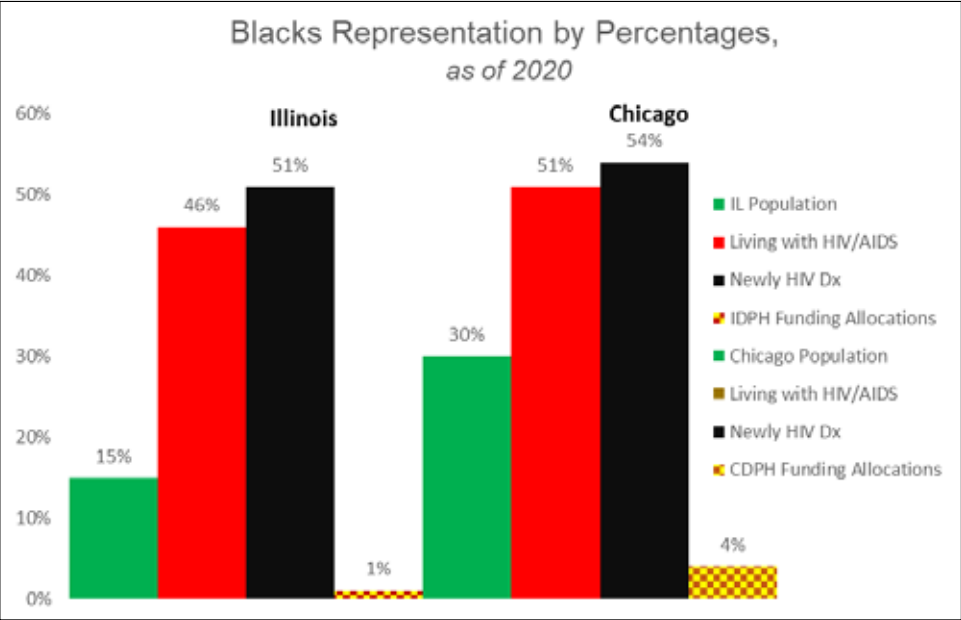
Since the beginning of the Human Immunodeficient Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) pandemic community involvement has become more pronounced in addressing this health ailment. Community activist and advocates brought increased awareness and education to mainstream public about the devastating impact HIV/AIDS was having on various sectors of the population. Community members also challenged government institutions to initiate plans and provide funding for these newly formed Community Based Organizations (CBO) who would carry out the work of public health programs. With the advent of new technological testing apparatus, and the development of behavioral interventions it became easier for people to access health services more directly within their own communities.

In the United States (US) organizations like the National Association of People with AIDS (NAPWA) was formed to get involve in all aspects of decision-making surrounding AIDS policies and funding strategies. As the epidemic persisted more people living with HIV/AIDS, at risk for or affected by the virus was included in governmental prevention and treatment efforts to “ensure buy in support”. (Valdiserri & Holtgrave, 2019) By 1994 the federal government unveiled a new process whereas state and local health departments would receive federal funding to prevent the disproportionate spread of HIV infections among marginalized communities. Presently from 2017-2021 federal, state, and local governments have launched another new initiative to end HIV infections within the US. These ‘Ending HIV Epidemic Plans’ were accompanied by additional funding. Each plan uses a targeted-population strategy to reduce the number of new HIV cases within their geographical areas. (HRSA, 2021) More specially, the Illinois and Chicago plans have included language about Health Equity as a category marker to provide resources in projects that address root causes of health disparities including systematic racism. However, when the lens of Equity is applied to federal, state, and local government agencies funding allocations, \*Black-Led HIV/AIDS Service Providers are not receiving equitable funding as compared to their White-Led HIV/AIDS Service Providers. The burgeoning challenge for ending the HIV epidemic also includes equitable funding for HIV/AIDS Service Providers. The question is should White-Led HIV/AIDS Service Providers continue to receive greater proportions of federally funded allocations to provide services to majority Black communities as compared to Black-Led HIV/AIDS Service Providers who are also capable of providing the same services? Theoretically, any HIV/AIDS Service Providers ought to be able to service all people, regardless of race/ethnicity. But are these funding allocations in-line with the ‘Ending HIV Epidemic Plans’ or contradictory in addressing root causes of health disparities including systematic racism? As seen through the experiences of Black-Led HIV/AIDS Service Providers, this case study aims to relay how they challenged the status quo by calling for a legislative cease and desist order in racial inequity funding tactics towards Black-Led HIV/AIDS Service Providers. And like their NAPWA predecessors, the efforts they took to bring awareness to the public, legislators, and other agencies pertaining to this issue. Additionally, what they did to move the needle for more equitable funding through the African American HIV/AIDS Response Act (AAHARA), with an allotment of zero dollars (\$0) in 2019 to \$15M in the 2021 Illinois State budget. (*\*Blacks also refers to African Americans, African-Descendants residing in the US*)

Epidemiological Overview

According to most current census (2020) and surveillance reports (2018), Blacks in Illinois make up 15% of the state population (12,587,530) but comprise more than 46% of people living with HIV infections (35,841) and 51% of people newly diagnosed infections (1,361). Comparably Blacks in Chicago make up 30% of the population (2,693,976) but comprise more than 51% of people living with HIV infection (18,719), as well as 54% newly diagnosed infections (724). (CDPH HIV/STI Bureau,2019 & AIDSVU,2020) This trend has been consistent for the past 15 years, whereas Blacks accounted for the highest proportion of people living with and newly diagnosed HIV infections. However, HIV funding from both the Illinois and Chicago Departments of Public Health has decreased, more specifically the allocations to Black-Led HIV/AIDS Service Providers were not equitably distributed in accordance with the disproportionate impact of HIV/AIDS on Blacks.

Chart 1. Black Representation



Funding Sources

By 1990 the Comprehensive AIDS Resources Emergency Act (currently known as Health Resources and Services Administration (HRSA) Ryan White HIV/AIDS Program (RWHAP)) was passed by congress. The Act named after a young boy diagnosed with AIDS, was a culmination of legislation which provided funding for people living with HIV infection. The HRSA RWHAP funding was placed in letter categories/parts (A-D &F), whereas part A funding is given to metropolitan areas with high incidence of HIV and part B, provides



grants to states and territories. According to HRSA Fiscal Year (2021) funding announcements recipients should work with their community and public health partners to improve outcomes across the HIV care continuum. The HIV care continuum has five main stages that include: HIV diagnosis, linkage to care, retention in care, antiretroviral use, and viral suppression. The HIV care continuum allows recipients and planning groups to measure progress and to direct HIV resources most effectively. RWHAP recipients are encouraged to assess the outcomes of their programs along this continuum of care. In other words, it encourages “a participatory planning process in which consumers (community voices) have a voice in establishing priorities for the allocation funds”. (Valdiserri, & Holtgrave, 2019)

Section 2602(b)(4)(C) of the PHS Act **requires** Planning Councils/Planning Bodies (PCs/PBs) to determine the priority for RWHAP allowable services and service allocations of RWHAP Part A funds every year. The RWHAP Part A PCs/PBs are also responsible for evaluating the efficiency of the recipient in distributing funds to service providers. (HRSA, 2021)

The U.S. Department of Health and Human Services (HHS) launched Ending the HIV Epidemic (EHE) initiative in 2019. The initiative aims to reduce new HIV infections in the U.S. by 90% by 2030. The commitment to “ending the HIV epidemic” has been accompanied by additional federal funding, including reprogrammed FY 2019 funding and new Congressional appropriations in FY 2020 and FY 2021.

The HHS Office of the Assistant Secretary for Health coordinates this cross-agency initiative. Collaborating agencies include the Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), Indian Health Service (IHS), National Institutes of Health (NIH), Office of the HHS Assistant Secretary for Health, and Substance Abuse and Mental Health Services Administration (SAMHSA).

Funds Allotment for FY 2020 Phase 1 Chicago Eligible Metropolitan Area (EMA Ryan White) Program EHE Award- \$1,818,306, EHE Primary Care HIV Prevention Awards (to Health Centers) \$2,393,970 and EHE CDC Integrated HIV Programs for Health Depts. Component A- \$2,683,773 Total Cook County \$5,077,743 Ending HIV Epidemic Plan, federal, Getting to Zero State Plan and the newly developed Ending the HIV Epidemic Plan for Cook County 2021-2025.

Both state and city health departments have not adhered to requirements for consulting with PCs/PBs. Illinois Department of Public Health (IDPH) and Chicago Area HIV Integrated Services Council (CAHISC) planning bodies are currently inept or totally disbanded (CDPH since Jan. 2019). So, if this is a federal requirement why are they not being held accountable for their actions, and continually receiving increased federal funding?

### *IDPH and CDPH Funding Portfolios*

Based on a Funding Portfolio prepared by the IDPH HIV Section Chief, the Excel Spread Sheets accounts HIV/AIDS funding allocations for February 2020. It lists

the name of the project, funding source either federal or state, descriptions, award period, total award amount, uses, distribution by Priority Population percentages, and notes with more descriptions. Of the \$107,542,107 (107.5M) 60% of the budget is funded by federal sources [Integrated HIV Surveillance and Prevention Programs, Morbidity & Risk Behavior Surveillance (MMP), Ryan White Part B Care, Ryan White Part B Care, Ryan White Part B ADAP Supplemental, RW 3rd Party Reimb (REBATE), Housing Opportunities for Persons w/ AIDS (HOPWA)]. The remaining budget is funded by the State of Illinois [General Revenue Fund, Quality of Life (QOL), African American AIDS Response Act (AAARA)]. In reference to the AAARA the only fund that was created to be 100% dedicated to Blacks was earmark for barely 1% (\$1,218,000) of the entire 2020 budget. However, there are no listings of which Service Providers received what funding.

In contrast, the report issued by the Deputy Commissioner for CDPH STI/HIV Bureau 2019 HIV Services Portfolio RFP Outcomes lists the allocations awarded to Service Providers but not all the federal sources. The document provides the 13 funding categories, the amount for Total category allocations, the number of awards, the total number of Black-Led Provider awards and the total allocations to Black-Led Providers. The aggregate amount awarded was \$40,420,285 (40.4M), with a total of 56 awards of which 7 were awarded to Black-Led Providers for a total of \$1,488,680 (1.4M) which comprised less than 4% (3.6%) allocated funding to Black-Led Providers.

Table 1. CDPH HIV/STI Bureau 2019 HIV Service Portfolio Outcomes

Categories	Total Award Allocation	Total Number Awards	Number Awards Black Providers	Total Award Allocation for Blacks Providers
Community Development	\$1,150,000	4	2	\$575,000
Services for Persons Who Use Drugs	\$1,275,000	3	0	
Housing People Living with AIDS	\$8,600,693	19	4	\$553,608
Housing People Vulnerable to HIV	\$750,000	1	0	
Essential Supportive Services	\$1,350,002	4	1	\$360,072
HIV Screening	\$1,500,000	1	0	
HIV Resource Coordination HUB	\$1,800,000	1	0	
HIV Primary Care	\$633,386	3	0	
Population Centered Health Homes	\$16,153,304	12	0	
Financial Assistance	\$850,000	1	0	
Foodbank & Home Delivered Meals	\$950,000	3	0	
Medical Care Management	\$4,557,900	1	0	
Other Professional Services	\$850,000	3	0	
<b>Total</b>	<b>\$40,420,285</b>	<b>56</b>	<b>7</b>	<b>\$1,488,680</b>
				less than 4% to Black Providers

## Discussion

### BLACHE ACTIVITES

In reaction to these grossly inequitable government funding allotments, Black-Led HIV/AIDS Service Providers across Chicago, Illinois unified to form the BLACK LEADERSHIP ADVOCACY COALITION FOR HEALTH EQUITY (BLACHE). By January 2019 there was a shift in policies funding requirements and funding from state and local governments for HIV/AIDS Service Providers. In the previous year there was a full body CAHISC vote to maintain the funding model that had been in place for years, however the CDPH administration was not in support of the vote, thusly canceling all further meetings and disbanding CAHISC without any prior notice or explanations. Additionally, in February of 2019, state legislators had announced their intent to change the language of the AAHARA, 410 ILCS 303 funding solely to Black-Led Providers, defined as 51% board and an Executive Director/CEO was also Black. The proposed language was to allow for 'Black serving' provider agencies, not just Black-Led Providers to become eligible to apply for funding from this source. What made this proposal so egregious is that one of the White-Led Service Provider had already received \$12M from IDPH to build their capacity and headquarter in a majority White section of Chicago. Similarly, for the CDPH Housing People Living with AIDS category, total award amount was \$8,600,693, there were 20 applications, 19 were awarded, including 4 Black-Led Providers, but a very prominent, White-Led Service Provider was awarded 3.6M, more than double any Black-Led Service Provider combined (1.4M) and was also awarded 1.8M for another category. Thusly they received more than 13% (5.4M) of the total CDPH HIV Service Provider budget. Furthermore, for the HIV Screening category, total award amount was \$1,500,00, there were 3 applications, only one was awarded, no Black-Led Providers awarded. And this same provider was also awarded \$5M from the National Institute of Health's (NIH) Rapid Acceleration of Diagnostics (RADx) Underserved Populations program, receiving 6.5M in federal funding.

In response to this unprecedented actions Creola A. Kizart-Hampton, President/ Founder, GREATERWORKS! INC started a petition to keep the fidelity and initial legacy intent of the AAHARA. Approximately 7 Black-Led Service Providers and 4 Black State Legislators signed/supported the petition.

After the petition was signed and sent to the Mayor's and Governor's Offices, the group held various press releases with speakers from both Black-Led Service Providers and Black State Representatives.

From their perspective changing the language and receiving less funding was not fair or equitable treatment towards them. Overall, their sentiments were:

*"We are burdened by a multitude of disease comorbidity. We tackle Donald Trump, HIV, Cancer, Diabetes, Hypertension, Asthma, Civil unrest, Black male violence, Intimate partner violence, Mass incarceration and Sexual abuse and now COVID-19; and these were still, just a few of our burdens. We can only win as a team not divided. Only, we know best how to reach our community and arm our people, with lifesaving health literacy."*

The original funding (pre-COVID-19) for the AAHARA fund through a reimbursement process was set to fund up-to 52 Black-Led Providers for a maximum of \$50 K and addition funding of \$750k for a Black Oversight and Training Group what have yield approximately \$2.8 M (\$2,779,000) for the fiscal year 2020. However, by May 2020, no (\$0) state dollars had been allocated for the AAHARA fund. This had never happened before to any HIV/AIDS providers in the State of Illinois. Moreover, it was not expected since in 2019 Illinois Infrastructure Bill provided a \$15 million appropriation for White-Led HIV/AIDS Service Provider to build a new healthcare and social services facility on the Southside of Chicago. The future development will include healthcare and other essential services affirming the lives of LGBTQ+ people and allies. Through publicly promoted virtual Zoom sessions, press-releases, and other community engaging activities during World AIDS Day, Black HIV Awareness Day, HIV Vaccine Awareness Day, and National HIV Testing Day, the Black-Led HIV/AIDS Service Providers through BLACAAFI will continue to speak truth to power as one unified voice. Another BLACHE member stated, *“Addressing issues like CDPH funding inequity, R3, AAHARA, IDPH inequity could be more effectively addressed if there was truly a Black-Led CBO Collaborative. That way the Collective/Collaborative would be included in ‘inequity discussions’ as opposed to the city and others, cherry picking what agencies they include. If we don’t do it a White-Led organization will form one and engage legislators in policy, apply for funding and determine/define ‘equity’ on their terms, not ours!”*

### **Responses from Both Heath Departments (IDPH and CDPH)**

Currently, House Bill 3653 is still in committee and awaiting the Governor’s signature during the Spring 2021 session. This legislation is intended to increase the AAHARA funding allocation from 1% (\$1,2M) to 14% (15M) of the 2021 budget and all Federal and State funding categories have been earmarked for majority Black populations. Nevertheless, as of May 2021 no funding will be reimbursed to the Black-Led Service providers for their 2020 fiscal year work activities. This is supposedly due to an internal investigation of the IDPH funding mechanism that has been violating state regulations by not stipulating correct target populations for the past 14 years. Although it was an inexcusable mistake on behalf of the IDPH, to date there has been no accountability, repercussion or consequence for this debacle. And once again it is the Black-Led HIV/AIDS Service providers who will suffer.

Comparably, CDPH stated 77% of funding is also earmarked for Blacks more than any other group. On the contrary, Black-Led Service Providers are not receiving even a third of the total budgets, due to the stance of health department leadership, specifically CDPH Deputy Commissioner. During a call with a national HIV/AIDS advocacy group\*\* the Deputy Commissioner touted that “70% of Chicago residents receive HIV Services”, thusly not in agreement that Black-Led Service Providers (CBOs) should be allocated more funding because of racial inequity of incidence of HIV, or the funding should be based upon ethnicity of HIV. And that “as long as Black people receive services; it should not matter what agencies are awarded funding”. Refence from the “Blacker the Plan” meeting call March 2021.

Furthermore, the Deputy Commissioner went on to admit they had not maintained the Chicago Area HIV Integrated Service Council (CAHISC) to provide guidance on the allocation of funding providers to deliver HIV prevention, care and housing services for the Chicago Eligible Metropolitan Area (EMA). He went on to say “We will be convening CAHISC soon to review feedback on HIV planning efforts. Feedback was collected through a variety of forums, including focus groups of CAHISC members and community partners”. To date no members of the disband CAHISC board has been included and selected ‘cherry-picked’ community members for the focus groups were from Black-Led Service Providers who had never received funding from CDPH, thusly not having any background knowledge of how the process should work when in compliance and for parity. *\*\*Due to ongoing negotiations with specific Provider Agencies, will not be identified or named.*

## Summary

This case study reveals how power and historical privilege benefits White-Led Service Providers through inequitable funding allocations. Sentiments touted by the CDPH Deputy Commissioner echo past exclusionary measures and historical practices under the guises of institutional racism. Nevertheless, one must address a fundamental question of why are these Black-Led Service Providers more suited to provide quality service as compared to some of the White-Led Service Providers? Bailey and others state “Structural racism refers to the totality of ways in which societies foster racial discrimination through mutually reinforcing systems of housing, education, employment, earnings, benefits, credit, media, health care, and criminal justice”. (Bailey, 2017) Although structural racism and unequal treatment remain as contributing factors to higher rates of disease and death among Blacks; they argue that by focusing on the impact of structural racism, it can be used as an approach for advancing health equity and improving population health. (Bailey, 2017; Huerto, 2020) Collectively Black physicians and researchers are providing evidence that if Black patients are seen by Black doctors had more improved health outcomes. Specifically, in a randomize study conducted at Stanford University paired Black men in Oakland with Black or non-Black doctors. They found that Black patients seen by Black doctors agreed to more, and more invasive, preventive services than those seen by non-Black doctors. (Torres, 2018) And this effect seemed to be driven by better communication and more trust. The researchers point to evidence suggesting that better trust and communication between Black doctors and Black patients was what made the difference. (Torres, 2018) Similarly, the quality of care by Black doctors or Black-Led Service Providers was not questionable or noted as substandard. However, Black doctors only account for 5% of the physician work force, like Black-Led HIV Service Provider only account for less than 4% of total HIV funding in Illinois. More importantly as previously stated Blacks in Illinois for the past 15 years continue to be disproportionately infected with HIV as White-Led Providers have received more funding for their treatment during the same time. Thusly structural racism and unequal treatment persist.

### Recommendations

The following are possible recommendations that may provide more clarity and possible strategies for resolving these unfair practices.

An additional in-dept analysis of racism is through the utilization of The Critical Race Theory (CRT). CRT represents a broad social scientific approach on how to study race, racism, and society. In the 1980s, Kimberlé Crenshaw and Derrick Bell promoted the CRT as a notion within the subfield of critical legal studies. They referred to the fact that despite the civil rights legislation in the US, the social and economic conditions of Blacks (African Americans) had not improved. “Through the concept of ‘interest convergence’, Bell even claimed that the reason why civil rights legislation passed in the first place was largely because it served the interests of America’s White elite.” (Bonilla-Silva, 2015). Another example of CRT was illustrated in the education field, whereas Jones presents evidence in his dissertation on how similar to pre-segregation era, in the post-segregation era White teachers are still able to teach both Black and White students at Black or White schools but, Black teachers were only able to teach at predominated Black schools, thusly exemplifying economic disadvantages for Black teachers and cultural disadvantages for White students. (Jones, 2016).

In Bonilla-Silva review of CRT, she offers an insight of invaluable set of literature for scholars of race and society to engage with. As a social scientific approach, she encourages us to appreciate how races are constructed into hierarchies, with societal resources distributed unequally across this hierarchy. She goes on to state “in a time often declared as ‘post-racial’, critical race theory helps remind us that race is omnirelevant – it may not always be the single determining factor of a given inequality, nor even the most important one, but ‘race’ is fundamental to understanding current regimes of inequality, and that analyses of inequality and its inverse (privilege and domination), are incomplete without a systematic discussion of race”. (Bonilla-Silva, 2015)

Although Bonilla-Silva builds on the work of Crenshaw and Bell she has recently redeveloped the tenets of CRT to the following:

Racism is ‘embedded in the structure of society’.

Racism has a ‘material foundation’.

Racism changes and develops over different times.

Racism is often ascribed a degree of rationality.

Racism has a contemporary basis.

The author recommends Cultural Humility sessions for the leadership at IDPH and CDPH. The responses from the leadership of the health departments demonstrates a culture of bias, barriers, and stigma. McGee-Avila writes about Cultural Humility for health providers and what it means to have an in-depth understanding of structural inequities and how they manifest in the patient/provider relationships. It also compels one to step outside of own identity and be open to other’s identities by acknowledging they have the authority over their

owned lived experiences. Although in this instance what connects providers are the services surrounding HIV infected and affected people, but disease identity is not at the forefront when one is experiencing racism, poverty, lack of housing, food insecurities, or stigma. It is more about understanding their complexities daily. Without being stereotypical, Black Providers bring a unique perspective to those they serve and may have the platform to give voice to those who are on mute. “Cultural Humility isn’t about studying someone to better figure them out. It’s about acknowledging power imbalances, developing partnerships, and practicing self-reflection. When we integrate these concepts in the delivery of care, we lift-up the voices of our patients, says McGee-Avila. (2018)

To advance health equity in the long term, leaders need to address these community-level factors that impact historically marginalized groups at disproportionate rates. To start, leaders need to understand structural inequities and why provider organizations have a role to play. “Health disparities typically result from two factors: inequitable care delivery and the impact of unmet social needs. Maintaining a diverse workforce and an inclusive culture is a key first step to improving equitable care delivery”. (Simmons, & Sullivan, 2021).

One of the BLACHE members questioned how can ‘we’ strengthen the community when leadership doesn’t provide the resource to those who come from those communities? For example, what if people living with HIV left their prevention, interventions, treatments, and research up to others non-infected people, would the progress that has been made come to fruition. The formation of National Minority AIDS Council (NMAC) was due to a denial by one of the leading public health associations to not have any people of color on their first ever panel on AIDS. During that meeting in 1986 Craig Harris, an African American gay man living with AIDS, announced the formation of NMAC during that panel discussion after he rushed the stage, shouting «I WILL BE HEARD» and took the microphone away from Dr. Mery Silverman, then the San Francisco Health Commissioner. (NMAC History, 2018)

The Building Leaders of Color (BLOC) program works to increase the number of Persons of Color Living with HIV who are prepared to engage in leadership roles and activities related to HIV service delivery. In 2019, the increased visibility of the program led to a larger number of applicants for programming. Additional community trainings were requested and provided. This is relevant because Harris, Kawata and others started NMAC out of the need to have White leadership, specifically a health commissioner acknowledge the unfair treatment and exclusion of people of color. Thirty-four years later, BLACHE must do the same, and reclaim their right to receive equitable funding, especially from health departments using federal funding sources. How can Health Equity be a goal when unfair and unequal funding for Service Providers persist? An additional recommendation is for all governmental agencies (more specifically IDPH and CDPH) to post on their websites the names of all registered HIV Service Providers, race/ethnicity of the agency (denoted by board CEO/ED or other leadership criteria), funding source and amount received by year. This type of documentation will provide more transparency to a process that is presently difficult to access. In other words, this information should be readily available to the public without any special requests. Moving forward both BLACHE members and state and local governments should seek out guidance



from federal regulators like Department of Labor, HRSA and CDC. Women's Bureau Director Wendy Chun-Hoon. "Engaging stakeholders as we seek to make sure our actions and policies support workers across many identities and experiences, including gender, race, sexuality, ability, religion, geography and wealth, is a core priority that ensures better employment outcomes for all." "The Office of Federal Contract Compliance Programs plays a vital role in rooting out entrenched employment inequities and ensures that federal contractors – which employ about 25 percent of the U.S. workforce – fulfill their contractual promise and deliver equal opportunity and affirmative action in their workplaces," said Office of Federal Contract Compliance Programs Director Jenny R. Yang. (Department of Labor, 2021)

The author offers a four-prong approach for guidance as to not only hold people accountable, but also determine what are the liabilities, repercussions, and right perspectives of the situations. This case study provided an exploration of the core moral issues attributed to racism and to brought forth a voice that may benefit other Black-Led Service Providers and Black health professionals experiencing inequities as it relates to the allocations of governmental funding. Whether it is 'Ending the HIV Epidemic', 'Getting to Zero' or restructuring the US failed healthcare system, Black people must continue to move the needle by advocating for what is needed, Economic Parity, Health Equity and a Better Quality of Life.

## References

- AIDSVU (2020) Retrieved from <https://aidsvu.org/local-data/united-tates/midwest/illinois/chicago/>
- Bailey, Z. D., Krieger, N., Agénor, M., Graves, J., Linos, N., & Bassett, M. T. (2017). Structural racism and health inequities in the USA: evidence and interventions. *Lancet* (London, England), 389(10077), 1453–1463. [https://doi.org/10.1016/S0140-6736\(17\)30569-X](https://doi.org/10.1016/S0140-6736(17)30569-X)
- Bonilla-Silva, E. (2015). More than Prejudice: Restatement, Reflections, and New Directions in Critical Race Theory, *Sociology of Race and Ethnicity*, 1(1), pp. 73–87
- CDPH HIV/STI Bureau. (2019). Getting to Zero Chicago: 2019 Chicago, Department of Public Health HIV Services, Portfolio Funding Summary 2020, Census Retrieved from <https://2020census.gov/en.html>
- Dawson, L., & Kates, J. (2021). KFF Tracker Retrieved from <https://www.kff.org/hiv/aids/issue-brief/ending-the-hiv-epidemic-che-funding-tracker>
- Department of Labor (2021). Retrieved from <http://www.dol.gov>



HRSA FY 2021 Funding Announcement Retrieved from <https://hab.hrsa.gov/about-ryan-white-hiv-aids-program/about-ryan-white-hiv-aids-program>

Huerto R., Lindo, E. (2020) Minority patients benefit from having minority doctors, but that's a hard match to make. *The Conversation*. <https://theconversation.com/minority-patients-benefit-from-having-minority-doctors-but-thats-a-hard-match-to-make-130504>

Jones, S., Jr. (2016). *Untold Narratives: The Experiences of Black Teachers in Predominantly White Schools*, Dissertation

McGee-Avila, J. (2018). Practicing Cultural Humility to Transform Health Care. Retrieved from <https://www.rwjf.org/en/blog/2018/06/practicing-cultural-humility-to-transform-healthcare.html>

NMAC History PDF (2018). Retrieved from <http://www.nmac.org>

Simmons, M., & Sullivan, M. (2021). Strategic Planning and Growth, Advancing Equity. Retrieved from <https://www.advisory.com/Topics/Strategy-Planning-and-Growth/2020/08/Advancing-equity-resources>

Torres, N. (2018) Research: Having a Black Doctor Led Black Men to Receive More-Effective Care. *Harvard Business Review*. <https://hbr.org/2018/08/research-having-a-black-doctor-led-black-men-to-receive-more-effective-care>

Valdiserri, R., Holtgrave, D. R. (2019). Ending HIV in America: Not Without the Power of Community. *AIDS and Behavior* (2019) 23:2899–2903. Retrieved from <https://doi.org/10.1007/s10461-019-02496-7>

### **The Evolution of Dignity: An Intervention Model to Engage and Retain HIV-Positive Black Women in Care**

**Ivy Turnbull, MA, EDM, DLP**

Deputy Executive Director,  
AIDS Alliance for Children Youth & Families  
1627 Eye St. NW, Suite 835  
Washington, DC 20006  
Chair, National Black Women's HIV/AIDS Network, Inc  
1813 Laurel Street  
Columbia, SC 29201-2626  
Tel: 202-754-1858  
Email: bpanivy1@aol.com

**Deane Taylor**

Member, Advisory Board  
AIDS Alliance for Women, Infants, Children, Youth & Families  
1627 Eye St. NW, Suite 835  
Washington, DC 20006  
Tel: 312-498-8629  
Email: taylorcdc47@aol.com

**Alicia Beatty**

Member, Advisory Board  
AIDS Alliance for Women, Infants, Children, Youth & Families  
1627 Eye St. NW, Suite 835  
Washington, DC 20006  
Tel: 215-704-7380  
Email: aliciabeatty1@gmail.com

**June Trimble**

1525 Kentucky Avenue  
Lancaster, TX 75134  
Tel: 469-664-2117  
Email: june\_trimble@yahoo.com

**Elizabeth Cabrera, MED, EDD**

Member, Advisory Board  
AIDS Alliance for Women, Infants, Children, Youth & Families  
1627 Eye St. NW, Suite 835  
Washington, DC 20006  
Tel: 469-569-0160  
Email: cabrerab43@gmail.com

### Authors' Note

We have no conflict of interest to disclose. Correspondence concerning this paper should be addressed to Ivy Turnbull at bpanivy1@aolcom.

### Abstract

The Black community is currently battling two pandemics, one is HIV, and the other is COVID-19. Similarly, as with HIV, COVID-19 has shone a spotlight on our healthcare system's structural failings and revealed the disproportionate impact on the Black community, particularly Black women. Black women accounted for the largest proportion of new HIV diagnoses (58 %) among all women in 2018 and represented about one-quarter of new HIV diagnoses among all Black Americans. Additionally, Black women's exposure to an abundance of misinformation about the COVID-19 infection resulted in an increased risk of complications and death from the COVID-19 virus compared to other racial and ethnic groups.

Factors that increase HIV transmission risks for Black women include living in poverty, intimate partner violence, and stigma associated with HIV. Moreover, environmental, physical, cultural, financial, social, and psychological barriers are identified as unique challenges for this population's cohort. After being diagnosed with HIV, Black often were unable to access quality HIV care. Access and retention in care are tantamount to the overall well-being of women who are HIV positive.

Frequently healthcare providers may attempt to engage and retain patients using only clinical measures. Our non-clinical intervention, The Evolution of Dignity, supports medical outcomes by creating a process that empowers women to motivate themselves toward improved health outcomes while ensuring their engagement and retention in care. Thus, by implementing our comprehensive intervention, all of the necessary elements contributing and promoting improved service utilization and medical adherence are integrated.

*Keywords:* HIV, Black women living with HIV, COVID-19, Healthcare, Intervention

### Introduction

Like HIV the COVID-19 pandemic has shone a spotlight on our healthcare system's structural failings and revealed the disproportionate impact on the Black community, particularly Black women. Black women who are HIV positive are often challenged by circumstances that result in an inability to access care which is tantamount to their overall well-being.

According to the Centers for Disease Control and Prevention (CDC), (2020), more than 7,000 women received an HIV diagnosis in the United States. Black women accounted for the largest proportion of new HIV diagnoses (58%) among all women in 2018 (CDC, 2020). The rate of new diagnoses among Black women is 14 times the rate among white women. Black women also represented about one quarter (26%) of new HIV diagnoses among all Blacks in

2018 (CDC, 2020). Notably, the rate of new infections among Black women has decreased over time, the decline has plateaued in recent years (Ojikutu & Mayer 2021).

Recent epidemiological data show that Black communities are being disproportionately impacted by COVID-19, resulting in higher morbidity and mortality rates compared to other racial and ethnic groups. For Black women in particular, a long-standing history of systemic racism and marginalization has resulted in increased vulnerability and susceptibility to certain adverse health outcomes. (Chandler, 2021).

As with HIV, the advent of COVID-19 underscores the enduring connection between systemic racism and health. Initially information circulated that people with HIV who were on effective treatment were not at greater risk of contracting COVID-19 (Cole, 2020). Nevertheless, Black women were more likely to suffer from pre-existing health conditions that exacerbates their vulnerability to COVID-19. These pre-existing conditions, coupled with a myriad of health disparities and inequities experienced by Black women living with HIV, profoundly impacted their ability to maintain positive health outcomes.

### Background

The unprecedented COVID-19 pandemic has exacerbated the marginalization, stigma, health disparities, and structural racism that was already crippling Black communities (Nydegger & Hill, 2020). Black Americans experience worse health outcomes, decreased access to healthcare, and lower quality healthcare across various diseases and conditions than other races (Ford, 2017). Clear overlaps exist between the COVID-19 pandemic and the HIV epidemic. Across the United States, the number of COVID-19 cases, hospitalizations, and deaths among Black people are considerably overrepresented compared to population density (Artiga et al., 2020; Garg et al., 2020). Similarly, as HIV rates decline overall nationally, rates in the South remain alarming because vulnerable communities, particularly those of color, endure a disproportionate burden of HIV (Centers for Disease Control and Prevention, 2005; Fleming et al., 2006; Hill et al., 2020).

Disparities in health in America have been documented since the early 20th century. W.E.B. Dubois first observed racial and ethnic inequalities in health in 1906 (Dubois, 2003). Despite decades of awareness, most of the gaps in life expectancy and disease incidence between racial and ethnic groups have remained the same, while in some they have even widened. It is estimated that 83,000 deaths occur each year as a result of racial and ethnic health disparities (Satcher, et al., 2005).

Smedley, et al. (2003) in the Institute of Medicine's report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, discussed tracing the dimensions of racial health disparities in the United States. In addition to having higher rates of morbidity and mortality diabetes, cardiovascular disease and HIV/AIDS, health care received by Black Americans was of lower quality and more difficult to access than that received by Whites

(Smedley, et al., 2003). Black women are much more likely to have higher rates of diseases and disabilities and have shorter life spans. It is essential that HIV/AIDS must not be relegated to the litany of other health disparities that continues to jeopardize the health and longevity of Black women living with and vulnerable to HIV.

### *Problem/Challenge*

According to Randolph, et al., (2020) mistrust in the U.S. health care system, grounded in perceived structural racism, is a key factor preventing Black women from seeking out HIV prevention and treatment services. For many Black women, their own health is not a priority when choosing between taking care of themselves and their families. Black women living with HIV often times sacrifice their own health and well-being by ignoring their unmet healthcare needs.

For the Black woman living with HIV there is an overwhelming sense of being seen as invisible to their care providers, and the disregard of their lived circumstances is often overlooked or not considered outside of their viral load. Given the challenges that HIV introduces to the newly diagnosed woman at access points to care, creates a significant opportunity for the HIV service-provider to consider interpersonal concerns faced by these individuals regarding HIV care and treatment.

### *Black Woman Living with HIV and the Provider*

To serve Black women who historically have been disproportionately impacted by HIV/AIDS and now COVID 19, it is critical to start with providers working to build trust and nurture dignity through each encounter to offer the services. Thus, Jacobson (2009, p.1) argued that “actions taken to respect, protect, and fulfill human rights promote dignity, while those that violate human rights also violate dignity.” To establish a mutual bond between the Black woman living with HIV and her provider, requires time to build trust and understanding. In such, a mutual relationship is not limited to discussions of adherence to medication.

Every encounter between the provider and the patient should lead towards building of a respectful relationship that nurtures the Black woman living with HIV dignity and dissolves the traditional one-sided hierarchical walls often found in healthcare systems. Additionally, the inclusion of non-clinical protocols are essential to the goal of better healthcare outcomes for Black women living with HIV. In order for these women to fully engage in their care it is critical that they believe their providers understand and respect their values and culture. Thus, the provider begins to foster the human-rights and dignity of the Black women living with HIV.

Access to care for Black women living with HIV was as unpredictable as a “roll” of the dice. The women often admitted their lives were chaotic and managing multiple medical care appointments were difficult. These women often felt invisible and found it difficult to engage in care because of logistical and structural barriers and service delivery models that are often highly centralized. Evidence suggests that larger investments in decentralized HIV services may hold significant benefits to both the cost and better health outcomes (Rochat, et al. , 2011).

The healthcare system's failure prompted us to create a comprehensive, culturally competent, coordinated system of care to address the service fragmentation. The goal was to expand access points to reduce barriers to care and further increase the engagement and retention of Black women living with HIV. Thus, we introduced a family-centered care approach.

### *Family Centered Care Approach*

Central to any definition of family-centered care is the concept of partnerships between consumers and providers of health care. Family-centered care is described as *"an approach to health care that offers a new way of thinking about the relationships between families and health care providers."* Specifically, family-centered care is an approach to the planning, delivery, and evaluation of care that is governed by mutually beneficial partnerships between the providers and consumers of health care (Johnson, et al., 2008).

The role of service providers is not to "fix" the family. Rather, the service providers' responsibility is to address the whole family system and assist members in developing the communication, power, boundaries, roles, flexibility, and cohesion they need to create a healthy family ecosystem (Werner, et al., 2007). Thus, the key to developing rapport is flexibility of behavior and the desire to step into someone else's world. It's not about how many family members you can tell what to do, it's about how many *family members* you can understand empower and motivate (Comaford, 2013). By implementing a family-centered care approach and creating our non-clinical intervention Evolution of Dignity (EOD) it allowed us to decentralize our traditional HIV healthcare delivery-system which was cost-effective and beneficial to the health outcomes of the Black women living with HIV.

### *Non-clinical intervention*

The relationship between care team providers and Black women living with HIV must be nurtured. Therefore, the intent for designing an appropriate non-clinical intervention was to mitigate the systems barriers which prevented these women from achieving their best healthcare outcomes. The non-clinical intervention, EOD, supports medical outcomes by creating a process that empowers women to motivate themselves toward becoming active partners in their care.

## Literature Review

### *HIV/AIDS and COVID-19*

The history of the AIDS epidemic in the U.S. is exacerbated by racism, bias, and discrimination resulting in disparities in access to care, treatment, and prevention for Black women at risk of HIV/AIDS. Structural racism, not race, is the true driver of health inequities and poor health outcomes among this cohort of the population. Reducing the racial disparity in HIV will require interventions that address structural and social factors, including lack of access to quality health care.

The initial public health response on HIV/AIDS was not focused on Black communities in most of the country, despite evidence of an emerging epidemic. Thus, leaving

a segment of the population ignorant in its understanding of the virus, its spread, and its potentially devastating impact on Black America.

The HIV/AIDS epidemic presents a much different challenge than the one faced at its initial appearance 40 years ago. According to the CDC, forty-eight women died from AIDS from 1980-1981. Based on the epidemiological data since then, it can be concluded that these women were, most likely women of color, specifically Black women between the ages of 15 and 44 years (Zierler & Kreiger, 1997). By 2004, HIV became the leading cause of death for Black women between the ages of 25-44 (Kaiser Foundation, 2007). In 2005, the rate of AIDS diagnoses for Black women became 20 times that of the rate for White women (Gavett, 2012). In 2018 the highest rates of diagnoses of HIV infection among Black women were in the South (CDC, 2020).

According to the CDC, the rate of new infections among Black women has decreased over time, however this decline has plateaued in recent years. As we enter the 4th decade of the epidemic, Black women continue to be disproportionately affected by HIV. The majority of new HIV infections, showing the greatest prevalence, and the highest rates of HIV-related deaths were among Black women living with HIV in the U.S., despite making up less than 15% of the female population (CDC, 2020).

Harvard University researchers, Rushovich's et al., (2021) study shows that Black women are dying from COVID-19 at significantly higher rates than white men. Key findings of the study include Black women have COVID-19 mortality rates that are almost 4 times higher than that of white men and three times higher than that of Asian men, as well as higher than white and Asian women. The disparity in mortality rates between Black women and white women is over three times the disparity between white men and white women.

The study is the first to quantify the inequities in COVID-19 mortality looking at both race and sex group. It is well understood that racism and social inequities, not genetics, are responsible for racial disparities in COVID-19 mortality. The Harvard researchers' findings challenge the focus of biology as an explanation for sex differences in COVID-19 mortality. Thus, the researchers argue that societal factors related to gender in combination with racism and socioeconomic status are also important explanatory factors.

### *Family-Centered Care and Dignity*

Family-centered approaches represent the most appropriate and cost-effective models for responding to the challenge of HIV prevention, treatment, and care in poorly resourced settings. Leeper, et al. (2010) posit that data from family-centered care sites suggest that this model is an effective tool for recruiting Black women living with HIV, preventing mother to child transmission, supporting patient adherence and clinic attendance, and improving clinical outcomes. Family-centered care is an approach to the planning, delivery, and evaluation of care that is governed by mutually beneficial partnerships between the providers and consumers of health care (Smedley, et al., 2003). Family-centered care based on a bio-psychosocial systems

approach: the primary focus of health care is the client in the context of their family (Shelton, et al., 1987).

Family-centered care is a comprehensive strategy that addresses the biopsychosocial nature of HIV. It is a highly individualized, gender-responsive approach treatment of HIV for women. Gender-responsive treatment is predicated on the distinctive characteristics of the female physiology and women's roles, socialization, experiences, and relative status in the larger culture (Werner et al., 2007).

Gender-responsive treatment is trauma informed, strengths based, and relational (Grella, 2004). For treatment to be responsive for women also requires that the focus of treatment is organized around maintaining affiliations and creating healthy connections to others, especially other family members (Werner et al., 2007). Such treatment provides a full range of services to address the array of problems associated with HIV prevention, care, and treatment.

*See me before you attempt to treat me* is the sentiment of many Black women in healthcare settings. At the very least, healthcare professionals must extend the courtesy of listening to the patient before concluding that the answer rests solely with the provider without the patient's input. Furthermore, an individual's dignity is manifested in such things as self-respect and self-value. Clearly, dignity is fragile and can be dishonored or eroded, especially in established hierarchical settings, like healthcare facilities. Jacobson (2009) suggest that there is an established hierarchy in healthcare settings in which the provider and patient are not seen as partners in the patient's care.

Furthermore, Jawad (2020) agreed with the researchers' findings and suggested that an additional pre-existing condition rarely discussed in healthcare is racial inequality. Such an omission may reveal a lack of understanding of the contributing factors to poorer health outcomes for Black women living with HIV. Many minority groups could not follow universal policies such as social distancing during the pandemic due to living in densely populated areas (Jawad, 2020). Similar issues regarding housing and access to affordable healthcare were also problematic for Black women living with HIV. These women are often the working poor who are also underinsured and live in inadequate housing conditions.

Therefore, Jacobson (2009) contended that dignity abuses could be connected to inequalities rooted in social influences. Schmidt, Trappenburg, and Tonkens (2020) agree with Jacobson (2009), suggesting that socially marginalized groups have contributing factors such as sicknesses, drug abuse, or poverty, increasing the risk of dignity abuse. Still, dignity can evolve if nurtured. If both providers and Black women living with HIV seek to understand, empathize, and work to build trust, dignity can be built (Jacobson, 2009).

### Evolution of Dignity Intervention

The non-clinical intervention, The Evolution of Dignity, supports clinical outcomes by creating a process that empowers women to motivate themselves toward improved health



outcomes while ensuring their engagement and retention in care. Thus, by implementing our comprehensive intervention, all of the necessary elements contributing and promoting improved service utilization and medical adherence are integrated.

### *The Evolution of Dignity Change Model*

While designing the Evolution of Dignity intervention (EOD) a review of the following models were used to develop the framework for our intervention. The Cycle of Change (Prochaska, DiClemente, & Norcross, 1993); The Multicultural Organizational Development Model (Jackson & Holvino, 1988); and (Chronic Care Model (Glasgow, et al., 2001). The five phases of the EOD intervention focused on establishing and arranging clear ways to develop the relationship between the collaborative care team and the woman. The model also provided a process to making the system changes necessary by breaking down the intervention into organized phases. The collaborative care team consisting of Black women living with HIV, and clinical and non-clinical providers were charged with spearheading the systems changes.

### *Phases of the Evolution of Dignity Intervention*

**Phase 1: Integration of Service (4 months):** During the initial assessment of the healthcare system, multiple issues were identified that hindered easy access to care. The team identified strategies to integrate both the clinical and non-clinical services to create greater access points. The team balanced two tasks, one was to address system barriers and the other was to gain buy-in from the stakeholders. A project manager was assigned to ensure that team remained focused on the established targets.

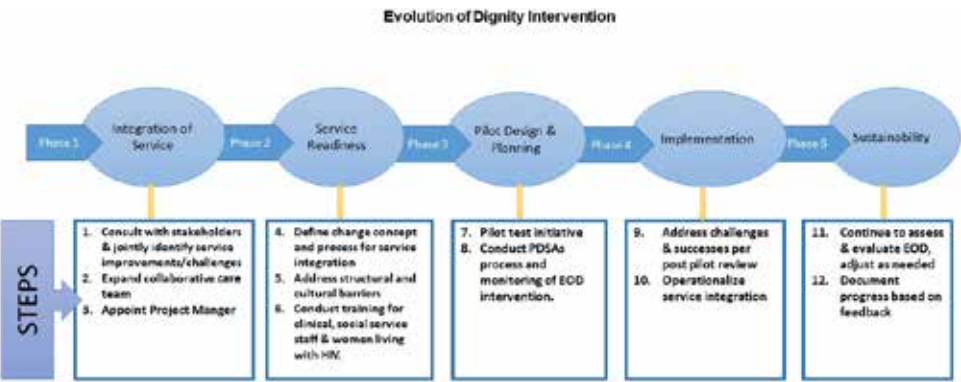
**Phase 2: Service Readiness (5 months):** A facilitated strategic process by which providers, Black women living with HIV, and other stakeholders identified an appropriate change concept. The process for service integration was streamlined, to address structural and cultural barriers that were inclusive of empowerment training for the Black women living with HIV.

**Phase 3: Pilot Design and Planning (3 months):** Planning focused on the integration of clinical and non-clinical services. A Plan Do Study Act (PDSA) process was implemented to monitor the EOD intervention. The result of this phase was the initial pilot test for a one day per week integration of clinic and non-clinical services.

**Phase 4: Implementation (3 months):** The findings from the PDSA process provided insight to the collaborative care team on what to adjust and where to monitor improvements of the EOD intervention. To operationalize the EOD intervention, team members prepared a weekly report to summarize their work.

**Phase 5: Sustainability: (On-going):** Continuous assessment and evaluation occurred throughout all phases of the EOD intervention process by using a PDSA framework. Service and sustainability decisions continued based on lessons learned from the pilot.

Figure 1.



*Findings of the Intervention*

The Evolution of Dignity (EOD) intervention contributed to the improved engagement and retention of Black women living with HIV in care. Designed as a non-clinical intervention, the EOD consisted of five phases adapted from the models listed above. The EOD intervention created a process that supported, empowered, and motivated Black women living with HIV towards improved health outcomes.

The EOD intervention featured a comprehensive, coordinated culturally competent family-centered care approached in the design that addressed the lived experience of Black women living with HIV which encouraged trusted relationships between the women and providers that nurtured dignity. Finally, the EOD endorsed the decentralization of traditional healthcare delivery systems and limited access to care barriers.

**Discussion**

Dignity matters. Black women are often subject to discrimination when accessing healthcare. Respecting the human rights of Black women seeking care is critical for better health outcomes. This is particularly true for Black women living with HIV. A growing body of literature suggests that discrimination against Black women living with HIV in health care settings may be especially harmful to their overall health and well-being (Rice, et al., 2019). The healthcare system ignores the values, culture, and the lived experiences of Black women living with HIV leading to the women often feeling diminished. Those feelings result in the women’s lack of engagement in their HIV care and treatment that is essential for sustaining their lives.

The paper’s intent is to convey that service delivery systems created without the input of Black women living with HIV/AIDS impedes efforts to reverse the course of the HIV/AIDS epidemic in this population and further exacerbates this public health crisis. It also examines how structural racism, health inequities, race, class, and gender shape how healthcare is offered and delivered in this country.

We looked beyond existing service delivery systems and proposed an intervention EOD that features a comprehensive, coordinated, culturally competent family-centered care approached in the design and takes into account the lived experience of Black women living with HIV/AIDS. The purpose of the intervention was to encourage trusted relationships between the women and providers that nurtured dignity. Another purpose of the EOD was to decentralize traditional healthcare delivery systems that limited access to care for Black women living with HIV.

The work we embarked upon in designing the EOD was part of our commitment to ensuring that Black women living with HIV had long, healthy, and productive lives. We believed that the relationship between the women and their providers was essential to their survival and wanted to create a process which provided them with an “active” voice in their health care decisions. We anticipated that creating service delivery systems that were responsive to Black women living with HIV would inform their providers on how to better treat them based on their culture and lived experience. Though our model may have limitations more research is needed in this area.

## Lessons Learned

The lessons learned have national implications, as they set forth promising strategies. By implementing the Evolution of Dignity intervention, we learned three significant lessons that will assist healthcare leaders in being more mindful of the importance of dignity for all patients accessing healthcare and specifically about Black women living with HIV. These keys steps are only a starting point in retaining Black women living with HIV in healthcare and the beginning of the evolution of dignity for this population.

1. *Seize the opportunity to listen.* When working with Black women living with HIV, it is crucial to understand that they balance a variety of family demands that often prevent them from prioritizing their care. It does not suggest that the women do not care about their health. First, Black woman living with HIV need to share their issues with a provider in the healthcare system regarding their care. Second, there must be a mechanism in place to address the women’s non-clinical needs. Finally, the women will be able to focus on adherence to her medical regimen.
2. *Build trusting relationships.* Take small steps to build trust between the Black woman living with HIV and her providers. Understand that all parties need to recognize that they are on the same team, with the same objective: the woman’s best health outcomes. Here’s the thing, when we all are more flexible, we are capable of achieving trust between all parties. Establish appropriate boundaries. Dissolve inflated impenetrable walls of hierarchies that may hinder the woman from being honest. Mutual trust beginning with good communication, must be a priority.
3. *Make the system work.* Send signals to the Black women living with HIV they are important by creating healthcare systems that work for their needs, not the other way

around. Healthcare systems serving Black women must be built to assist the women in remaining in care. So often, leaders responsible for healthcare systems overlook this critical step.

### Conclusion and Policy Implications

Many of the existing HIV/ AIDS policies and interventions fail to respond to Black women's needs and realities, and therefore fail to significantly reduce their HIV risk and vulnerabilities. Since the beginning of the epidemic in the United States 40 years ago, Black women living with and at risk for HIV/AIDS have not only confronted the disease but continue to face many related obstacles. Their race, class, gender, economic and political status in society causes them to have the least access to resources and benefits which can significantly improve their lives (Albertyn, 2000).

The available evidence on race, class, gender inequities within relationships, the workplace, the economy, and political structures confirm that Black women are more vulnerable than other groups of women to HIV/AIDS. Though the data clearly reveal that Black women are disproportionately affected by this disease, there are very few HIV/AIDS-related policies that specifically focus on the needs of Black women as a group.

Black women have been ignored in the HIV/AIDS epidemic far too long, being invited to the *political table* long after agendas have been set and policy decisions have been made. This practice perpetuates the belief that participation in the HIV/AIDS policy decision-making process is a privilege rather than a "right." The political engagement and leadership of Black women living with and vulnerable to HIV/AIDS is an essential component of an effective and comprehensive national response to the epidemic in this country. Influencing mechanisms and processes by which Black women living with and vulnerable to HIV/AIDS become integral actors in determining federal, state, and local HIV policies hold significant promise for transforming the infection rates in this population.

As with HIV, Black Americans have some of the highest COVID-19 infection rates (Godoy & Wood, 2020). For Black women living with HIV, COVID-19 is particularly life-threatening. Obinna (2021) submits that bold interventions must be taken in order to protect those most vulnerable to COVID-19. Moreover, the effects of COVID-19 have exposed harsh truths about health inequities in our healthcare systems. These truths reveal that historical practices of racial exclusion and discrimination have contributed to race-based disparities in health. Addressing the spread of COVID-19 must include a closer examination of the legacies of discrimination which have shaped Black communities in the U.S. (Obinna, 2021).

## References

- Albertyn, C. (2000). Using rights and the law to reduce women's vulnerability to HIV. *Canadian HIV/AIDS policy & law review*, 5(4), 72–79.
- Artiga, S., Garfield, R., & Orgera, K. (2020). Communities of color at higher risk for health and economic challenges due to COVID-19. San Francisco, CA.
- Centers for Disease Control and Prevention. HIV Surveillance Report, (2018) (Updated); vol. 31. <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Published May 2020. Accessed [June 15, 2021].
- Centers for Disease Control and Prevention (CDC). HIV Surveillance Report: Diagnoses of HIV Infection in the United States and Dependent Areas 2019: Special Focus Profiles, Women vol 32. (Accessed June 3, 2021). <https://www.cdc.gov/hiv/library/reports/hiv-surveillance/vol-32/content/special-focus-profiles.html#Women>.
- Centers for Disease Control and Prevention. (2005). Health disparities experienced by black or African Americans--United States. *MMWR: Morbidity and mortality weekly report*, 54(1), 1-3.
- Chandler, R., Guillaume, D., Parker, A. G., Mack, A., Hamilton, J., Dorsey, J., & Hernandez, N. D. (2021). The impact of COVID-19 among Black women: evaluating perspectives and sources of information. *Ethnicity & health*, 26(1), 80–93. <https://doi.org/10.1080/013557858.2020.1841120>
- Cole, S. (2020) We can't ignore racism when thinking about HIV and COVID-19. <https://www.aidsmap.com/news/jun-2020/we-cant-ignore-racism-when-thinking-about-hiv-and-covid-19>. Nam aidsmap news 2020
- Comaford, C. (2013). *Smart Tribes*. New York, NY: Penguin Group
- DuBois, W. B. (2003). The health and physique of the Negro American. 1906. *American journal of public health*, 93(2), 272–276. <https://doi.org/10.2105/ajph.93.2.272>
- Fleming, P. L., Lansky, A., Lee, L. M., & Nakashima, A. K. (2006). The epidemiology of HIV/AIDS in women in the southern United States. *Sexually Transmitted Diseases*, 33(7), S32-S38. [Google Scholar]
- Ford, C. L. (2017). Notions of Blackness in the Context of HIV/AIDS Disparities and Research. *The Black Scholar*, 47(4), 18-31. [Google Scholar]

- Garg, S., Kim, L., Whitaker, M., O'Halloran, A., Cummings, C., Holstein, R., ... & Fry, A. (2020). Hospitalization rates and characteristics of patients hospitalized with laboratory-confirmed coronavirus disease 2019—COVID-NET, 14 States, March 1–30, 2020. *Morbidity and mortality weekly report*, 69(15), 458. <https://www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6915e3-H.pdf> [Google Scholar]
- Gavett, G. (2012) Timeline:30 Years of AIDS in Black America. Frontline Article. <https://www.pbs.org/wgbh/frontline/article/timeline-30-years-of-aids-in-black-america/>
- Glasgow, R. E., Tracy Orleans, C., Wagner, E. H., Curry, S. J., & Solberg, L. I. (2001). Does the chronic care model serve also as a template for improving prevention? *The Milbank Quarterly*, 79(4), 579-612. [Google Scholar]
- Godoy, M., & Wood, D. (2020). What do coronavirus racial disparities look like state by state. *National Public Radio*. <https://www.npr.org/sections/health-shots/2020/05/30/865413079/what-docoronavirus-racial-disparities-look-like-state-by-state>.
- Grella, C. E. (2004). "Current Issues in Research on Substance Abuse Treatment for Women." Presented at California Department of Alcohol & Drug Programs, Women's Constituent Committee Forum, October 24, 2004 in Sacramento, CA.
- Hill, M. J., Cardenas Turanzas, M., Prater, S., Campbell, J. W., & McNeese, M. (2020). Racial and sex disparities in HIV screening outcomes within emergency departments of Harris County, Texas. *Journal of the American College of Emergency Physicians Open*, 1(4), 476-483. doi: 10.1002/emp2.12046 [Google Scholar]
- Jackson, B. W., & Holvino, E. (1988). Multicultural organization development. [Google Scholar]
- Jacobson, N. (2009). A taxonomy of dignity: a grounded theory study. *BMC International Health and Human Rights*, 9(1). <https://doi.org/10.1186/1472-698x-9-3>
- Jawad, B. A. (2020). Hindsight is 2020: Lessons on Racial Health Disparity during the COVID-19 Pandemic.
- Johnson, B, Abraham M., Conway J., Simmons, L., Edgman-Levitan, S. Sodomka, P., Schlucter, J. and Ford, D (2008) Partnering with Patients and Families to Design a Patient and Family-Centered Health Care System Recommendations and Promising Practices. Institute for Patient- and Family-Centered Care Bethesda, MD 20814 [www.ipfcc.org](http://www.ipfcc.org)
- Kaiser Foundation. (2007). Black Americans and AIDS. *HIV/AIDS Policy Fact Sheet*. Retrieved from <https://www.kff.org>

- Leeper, S. C., Montague, B. T., Friedman, J. F., & Flanigan, T. P. (2010). Lessons learned from family centered models of treatment for children living with HIV: current approaches and future directions. *Journal of the international AIDS Society*, 13, S3-S3. <https://doi.org/10.1186/1758-2652-13-S2-S3>
- Nydegger, L. A., & Hill, M. J. (2020). Examining COVID-19 and HIV: The impact of intersectional stigma on short- and long-term health outcomes among African Americans. *International Social Work*, 63(5), 655-659. <https://doi.org/10.1177/0020872820940017>
- Obinna, D. N. (2021). Essential and undervalued: health disparities of African American women in the COVID-19 era. *Ethnicity & health*, 26(1), 68-79. doi: 10.1080/13557858.2020.1843604
- Ojikutu BO, Mayer K. (2021) HIV Prevention Among Black Women in the US—Time for Multimodal Integrated Strategies. *JAMA Netw Open*. 4(4):e215356. doi:10.1001/jamanetworkopen.2021.5356
- Prochaska, J. O., DiClemente, C. C., & Norcross, J. C. (1993). In search of how people change: Applications to addictive behaviors. *Addictions Nursing Network*, 5(1), 2-16.
- Randolph, S. D., Golin, C., Welgus, H., Lightfoot, A. F., Harding, C. J., & Riggins, L. F. (2020). How Perceived Structural Racism and Discrimination and Medical Mistrust in the Health System Influences Participation in HIV Health Services for Black Women Living in the United States South: A Qualitative, Descriptive Study. *The Journal of the Association of Nurses in AIDS Care : JANAC*, 31(5), 598–605. <https://doi.org/10.1097/JNC.0000000000000189>
- Rice, W. S., Turan, B., Fletcher, F. E., Nápoles, T. M., Walcott, M., Batchelder, A., ... & Turan, J. M. (2019). A mixed methods study of anticipated and experienced stigma in health care settings among women living with HIV in the United States. *AIDS patient care and STDs*, 33(4), 184-195. [Google Scholar]
- Rochat, T. J., Bland, R., Coovadia, H., Stein, A., & Newell, M. L. (2011). Towards a family-centered approach to HIV treatment and care for HIV-exposed children, their mothers and their families in poorly resourced settings. *Future virology*, 6(6), 687-696. <https://doi.org/10.2217/fvl.11.45>
- Rushovich, T., Boulicault, M., Chen, J. T., Danielsen, A. C., Tarrant, A., Richardson, S. S., & Shattuck-Heidorn, H. (2021). Sex disparities in COVID-19 mortality vary across US racial groups. *Journal of General Internal Medicine*, 36(6), 1696-1701. <https://doi.org/10.1007/s11606-021-06699-4>

- Satcher, D., Fryer, G. E., Jr., McCann, J., Troutman, A., Woolf, S. H., & Rust, G. (2005). What if we were equal? A comparison of the black-white mortality gap in 1960 and 2000. *Health affairs*, 24(2), 459-464.
- Schmidt, J., Trappenburg, M., & Tonkens, E. (2020). Social dignity for marginalized people in public healthcare: an interpretive review and building blocks for a non-ideal theory. *Medicine, Health Care and Philosophy*, 1-13.
- Shelton, T. L., Jeppson, E. S., & Johnson, B. H. (1987). *Family-centered care for children with special health care needs*. Association for the Care of Children's Health, 3615 Wisconsin Ave., NW, Washington, DC 20016. [Google Scholar]
- Smedley, B. D., Stith, A. Y., & Nelson, A. R. (Eds). (2003). *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Institute of Medicine, Washington, D.C., The National Academies Press. <https://doi.org/10.17226/12875>.
- United Nations. General Assembly. (1949). *Universal declaration of human rights* (Vol. 3381). Department of State, United States of America. Published online by Cambridge University Press: 20 April 2017
- Werner, D., Young, N. K., Dennis, K., & Amatetti, S. (2007). Family-centered treatment for women with substance use disorders: History, key elements and challenges. *Substance Abuse and Mental Health Services Administration*.
- Zierler, S., & Krieger, N. (1997). Reframing women's risk: social inequalities and HIV infection. *Annual review of public health*, 18(1), 401-436. <https://www.annualreviews.org/doi/pdf/10.1146/annurev.publhealth.18.1.401> (accessed June 4, 2021).



## HIV Testing and Associated Characteristics Among Black Cisgender and Transgender Women in the United States

Jaleah D. Rutledge, MA  
Kaston Anderson-Carpenter, PhD,  
Jae Puckett, PhD  
Department of Psychology  
Michigan State University  
East Lansing, MI  
Email: rutled72@msu.edu

### Author Note

This study received approval from the Institutional Review Board at Michigan State University (MSU STUDY ID: STUDY00003157). I would like to thank my committee members Drs. Kaston Anderson-Carpenter, William Chopik, Ignacio Acevedo Polakovich, and Jae Puckett for their support and guidance on this project. I have no conflicts of interest to declare.

### Abstract

Black women in the United States continue to be disproportionately affected by HIV. HIV testing is an important preventative step in the HIV continuum of care, however there is little known about HIV testing among these groups. Therefore, the purpose of this study is to examine the HIV testing behaviors of Black transgender women and explore differences in predictors of HIV testing among Black cisgender and transgender women. This study uses secondary data from the 2014-2017 modules of the Behavioral Risk Factor Surveillance System. Analyses included multiple hierarchical regression. There are no major differences in HIV testing between Black cisgender and transgender women. A number of sociodemographic characteristics have been shown to predict HIV testing among Black cisgender women, but only employment status and age were significant predictors of HIV testing among Black transgender women. A moderation analysis suggested that gender identity significantly moderates the association between employment status and HIV testing such that the relationship between employment status and receiving an HIV test differs by gender identity. The findings of this study highlight nuances in HIV testing among Black cisgender and transgender women that are useful for improving HIV testing as a mode of HIV prevention. Overall, the findings contribute to our understanding of HIV testing practices among Black cisgender and transgender women.

*Keywords:* HIV testing, Black women, transgender health

## Introduction

Current estimates suggest that one in seven transgender (hereafter, trans) women have HIV (Becasen et al., 2018); it is suspected that the rates are even higher among Black trans women (Bukowski et al., 2018), therefore, they are not receiving treatment and are likely to continue to engage in risky sexual behaviors that further contributes to the increased rates of HIV in the Black community. The prevalence of HIV/AIDS among Black women is particularly alarming with Black women comprising 11% of all new HIV diagnoses and 60% of HIV diagnoses among all American women (Centers for Disease Control and Prevention, 2018). In recent years, the rate of infection among Black women has declined but is still significantly higher than other ethnicities (Bradley, 2019).

Trans women, women who were assigned male at birth but currently identify as female, are considered to be high risk for HIV (Clements-Nolle et al., 2001) and are 34 times more likely to acquire HIV in the United States relative to the general population (Baral et al., 2013). Similar to trends among Black cisgender women—women who are assigned female at birth and currently identify as female (hereafter, cis), Black trans women are more susceptible to HIV infection. The literature suggests that of all racial, gender, and sexual minority groups, Black trans women are among the most susceptible to HIV infections and diagnosis (Denson et al., 2017; Herbst et al., 2008; Hwang & Nuttbrock, 2007). Research attributes the high rates of HIV among Black trans women to factors such as violence, limited access to care, stigma, high levels of engagement in sex work, riskier sexual behavior, substance abuse and intravenous drug use (De Santis, 2009; Wansom et al., n.d.).

The needs of trans communities are distinct and independent from those of other groups, and thus require a separate analysis from the typical, dichotomous understanding of gender (World Health Organization, 2014). Often times, research exploring HIV among trans women has not been distinguished from findings on HIV among men who have sex with men (MSM) (Frye et al., 2015; Golub & Gamarel, 2013; Muessig et al., 2014; Poteat et al., 2016). HIV research that presents trans women and MSM in the same analysis leaves unanswered whether trans women are at a uniquely higher risk of HIV. It is crucial to conduct HIV research that focuses explicitly on trans women, as studies have demonstrated that discrimination, stigma, and social oppression of individuals with marginalized identities may be a more significant determinant HIV testing and acquisition than the aforementioned risk behaviors (Peterson et al., 2014; Ransome et al., 2016).

HIV testing is an important step in prevention, yet there is a gap in the literature concerning HIV testing among Black trans women. In the current study, we aim to describe HIV testing behaviors among Black trans and cis women. Specifically, we examine whether rates of HIV testing vary between Black trans and cis women and whether HIV risk is a particularly strong predictor of HIV testing among these groups. The hypothesis that guides study is informed by an intersectional framework which suggests that multiple social and political identities overlap or intersect to create different forms of advantages or oppression (Crenshaw, 1990). Therefore, we hypothesize 1) Black trans women will be less likely to receive an HIV

test than Black cis women, 2) both cis and trans women who engage in high risk behaviors will be less likely to receive an HIV test, and 3) the relationship between the statistically significant sociodemographic predictors and HIV testing will vary by gender identity.

## Methods

This study used secondary data from the Behavioral Risk Factor Surveillance System (BRFSS) to examine HIV testing behaviors, the association between sociodemographic factors and HIV testing, and the association between high-risk behaviors and HIV testing among Black cis and trans women. This study received approval from the Institutional Review Board at Michigan State University (MSU STUDY ID: STUDY00003157).

## Sample

The sample for this study was constructed from participants in the CDC's 2014-2017 BRFSS modules, a national telephone survey that assesses health risk in the United States. The 2014-2017 BRFSS modules were administered to non-institutionalized adults (i.e., age  $\geq 18$ ) in the United States. Across all four years, there were 1,842,439 participants in the BRFSS modules. Participants were contacted via cell phone and landlines. Disproportionate stratified sampling was used for landline samples and simple random sampling was used for cellular samples. The median response rate for cellphones and landlines 2014-2017 was 46.13% across all states. More information about the methodology of the BRFSS can be found on the BRFSS website (CDC, n.d.). Only self-identified Black women were selected for this study ( $n = 36,056$ ). A subpopulation of trans women ( $n = 170$ ) was drawn to examine the odds of a lifetime HIV test and associated sociodemographic factors among Black trans women alone.

## Measures and Variables

The data for this study focused on sociodemographic characteristics, gender identity, HIV risk, and HIV testing behaviors. Our outcome variable, HIV testing behaviors, is defined as whether or not one has ever received an HIV test. Receiving an HIV test was assessed by one item that assesses if the participant had ever been tested for HIV (yes/no). For gender identity, we created an indicator based on one's reported sex and gender identity. Participants who identified as female and not transgender received a 0 and participants who identified as female and transgender received a 1. Sociodemographic variables included age, education, income, marital status, employment status, having a primary care provider, receiving delayed healthcare, having health insurance, and metropolitan status. Age was categorized into three groups (i.e., 18-34 years, 35-49 years, 50 years or older).

Education was collapsed into two categories (high school or less, college or more). Income level was defined categorically as less than \$20,000, \$20,000-\$49,999, \$50,000-\$74,999, and \$75,000 or more. Categories for marital status included married/partnered, not married, and widowed. Employment status was measured by four categories: employed, unemployed,

retired, and other (i.e., students and home makers). Our indicator for having a primary care provider, receiving delayed healthcare, and having health insurance were each set to 1 if the participant responded yes and 0 if the participant responded no. Metropolitan status was categorized as metropolitan, suburban, and non-metropolitan. HIV risk was assessed only in 2016 and 2017 by one item for which participants responded “yes” certain high-risk behaviors and situations applied to them.

### *Data Analysis*

We summarized participant demographics using weighted proportion descriptive statistics. Hierarchical logistic regression analyses was used to identify the association between the sociodemographic variables and HIV testing and to determine if whether or not the statistically significant associations varied by gender identity. Results from the hierarchical logistic regression models are presented as exponentiated odds ratios and 95% confidence intervals. All analyses were completed using SPSS Version 25, and statistical significance was established at  $\alpha < .05$ .

## Results

### *Sociodemographic Characteristics*

Table 1 contains sociodemographic statistics of the analytic sample ( $N = 32,226$ ). Of that number, 99.5% ( $n = 36,056$ ) were cis women and 0.5% ( $n = 170$ ) identified as trans women. The sample ranged in age from 18 to 80 years ( $M = 55.36$ ,  $SD = 17.09$ ). The majority of the sample was married or partnered (56.3%). Approximately 35.1% of trans women had completed college or more compared to 59.1% of cis women. Among trans women, 47.5% of the sample had an income of \$20,000 or less, compared to 28.4% of cis women with an income level of \$20,000 or less. Approximately 45.8% of the sample was employed, and 70.9% lived in a metropolitan area.

### *Differences in HIV Testing Behaviors among Black Trans and Cis Women*

The results indicated that 50% of trans women reported lifetime HIV testing compared to 51.2% of cis women. There was no statistically significant difference in odds of lifetime HIV testing between cis and trans women (see Table 2). Although Black trans women had relatively higher odds of being tested for HIV compared to Black cis women (AOR= 1.01, 95% CI= 0.69-1.47), this finding was not statistically significant.

*Table 1. Sociodemographic characteristics of Black women by gender identity.*

Sociodemographic characteristic	Cis women <i>n</i> (%)	Trans women <i>n</i> (%)	Total sample <i>n</i> (%)
Age			
18-34 years	6,109 (16.9)	37 (0.1)	6,146 (17.0)
35-49 years	7,517 (20.8)	24 (0.07)	7,551 (20.8)
50+ years	22,420 (61.9)	109 (0.30)	22,529 (62.2%)
Income			
less than \$20,000	10,249 (28.3)	66 (0.18)	10,315 (33.1)
\$20,000-\$49,999	11,964 (33)	50 (0.14)	12,014 (38.5)
\$50,000-\$74,999	3,732 (10.3)	9 (0.02)	3,741 (12.0)
\$75,000+	5,123 (14.1)	14 (0.04)	5,137 (16.5)
Education Level			
High School or Less	14,698 (40.6)	109 (0.30)	14,807 (40.9)
College or More	21,256 (58.7)	59 (0.16)	21,315 (58.8)
Employment Status			
Employed	16,402 (45.3)	71 (0.20)	16,473 (45.8)
Unemployed	7,304 (20.2)	49 (0.14)	7,353 (20.5)
Retired	9,431 (26.0)	38 (0.10)	9,469 (26.3)
Other	2,646 (7.3)	12 (0.03)	2,658 (7.4%)
Marital Status			
Married/Partnered	10,635 (28.6)	51 (0.14)	10,686 (29.7)
Not Married	19,320 (53.3)	93 (0.26)	19,413 (54.0)
Widowed	5,855 (16.2)	24 (0.07)	5,879 (16.3)
Metropolitan Status			
Metropolitan	15,367 (42.4)	54 (0.15)	15,691 (70.9)
Suburban	3,122(8.6)	10 (0.03)	3,132 (14.1)
Non-metropolitan	3,301 (9.1)	19 (0.05)	3,320 (15.0)

### *Factors Associated with HIV Testing among Black Trans Women vs Black Cis Women*

Table 2 shows adjusted odds ratios and 95% confidence intervals for predictors of HIV testing in the overall sample and stratified by gender identity. All variables except gender identity, income, unemployment, and health plan were statistically significant predictors of HIV testing in the overall sample. For example, among Black women, those between the ages of 35 and 49 were almost one and one quarter times more likely to receive an HIV test compared to those in the 18-34 age group (AOR: 1.24, 95% CI: 1.13, 1.35). However, Black women 50 years or older were significantly less likely to receive an HIV test (AOR: 0.30, 95% CI: 0.28, 0.33). Additionally, those who had a college education or more showed significantly differential odds of receiving an HIV test (AOR: 1.38, 95% CI: 1.30, 1.46). Black women who were retired

Table 2. Regression results for sociodemographic covariates by gender.

Predictor	Black Cisgender Women		Black Transgender Women		Total	
	AOR	95% CI	AOR	95% CI	AOR	95% CI
Gender Identity					1.01	(0.69, 1.47)
Age						
18-34 years old	--	--	--	--	--	--
35-49 years old	1.23***	(1.13, 1.35)	1.80	(0.41, 7.99)	1.24***	(1.13, 1.35)
50 years or older	0.30***	(0.28, 0.33)	0.30	(0.09, 1.05)	0.30***	(0.28, 0.33)
Income	0.98	(0.95, 1.01)	0.93	(0.56, 1.55)	0.98	(0.95, 1.01)
Education	1.38***	(1.30, 1.46)	2.44	(0.94, 6.37)	1.38***	(1.30, 1.46)
Employment Status						
Employed	--	--	--	--	--	--
Unemployed	1.06	(0.98, 1.14)	5.71**	(1.71, 19.07)	1.06	(0.99, 1.14)
Retired	0.37***	(0.35, 0.40)	1.74	(0.52, 5.87)	0.38***	(0.35, 0.40)
Other	0.65***	(0.59, 0.73)	4.50	(0.63, 32.00)	0.66***	(0.59, 0.73)
Marital Status						
Married/Partnered	--	--	--	--	--	--
Not Married	1.30***	(1.22, 1.38)	0.98	(0.34, 2.83)	1.30***	(1.22, 1.38)
Widowed	0.76***	(0.70, 0.83)	0.61	(0.15, 2.46)	0.76***	(0.70, 0.83)
Metropolitan Status						
Metropolitan	--	--	--	--	--	--
Suburban	0.89**	(0.81, 0.97)	3.54	(0.68, 18.47)	0.89*	(0.81, 0.97)
Not Metropolitan	0.61***	(0.56, 0.67)	0.91	(0.25, 3.33)	0.61***	(0.55, 0.67)
Healthcare	1.03	(0.94, 1.14)	1.55	(0.39, 6.21)	1.03	(0.94, 1.14)
Primary Care Provider	1.26***	(1.15, 1.37)	2.21	(0.61, 7.99)	1.26***	(1.16, 1.38)
Delayed Care	1.33***	(1.19, 1.48)	1.13	(0.25, 5.21)	1.33***	(1.19, 1.48)
HIV Risk	2.01***	(1.65, 2.45)	15.09*	(1.50, 151.82)	2.05***	(1.69, 2.50)

Note. \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$

(AOR: 0.38 95% CI: 0.35, 0.40), students or homemakers (AOR:0.66, 95% CI: 0.59, 0.73) reported a significantly lower odds of receiving an HIV test compared to Black women who were employed. Compared to Black women who were married or partnered, Black women who were widowed were significantly less likely to receive an HIV test (AOR: 0.76, 95 %CI: 0.70, 0.83) while those who were not married were reported significantly greater odds of receiving an HIV test (AOR: 1.30, 95% CI: 1.22, 1.38) relative to married or partnered Black women. Metropolitan status was a significant predictor in the overall sample such that those in suburban (AOR:0.89, 95% CI: 0.81, 0.97) and other types of non-metropolitan areas (AOR: 0.61, 95% CI: 0.55, 0.67) are significantly less likely to receive an HIV test compared to those in metropolitan areas. Having a primary care provider (AOR: 1.26, 95% CI: 1.16, 1.38), delaying medical care (AOR: 1.33, 95% CI: 1.19, 1.48), and engaging in HIV risk behaviors (AOR: 2.05, 95% CI: 1.69, 2.50) were all associated with having a significantly higher odds of receiving an HIV test.

Stratified analyses showed that predictors of HIV testing among Black cis women were nearly identical to those reported in the overall sample. Compared to employed Black trans women, unemployed Black trans women had a significantly greater odds of having ever received an HIV test (AOR = 4.72; 95% CI = 1.52,14.66). However, unemployment status was not a significant predictor of HIV testing among Black cis women (AOR = 1.06; 95% CI = 0.98,1.14). The significant relationship between HIV risk and HIV testing among Black trans women suggests that Black trans women who are at risk for HIV are significantly more likely to receive an HIV test compared to Black trans women who are not at risk for HIV (AOR = 15.09; 95% CI = 1.50,151.82).

### *A Moderation Analysis of Sociodemographic Predictors, Gender Identity, and HIV Testing*

In addition to examining main effects of sociodemographic characteristics, we also investigated whether gender identity (e.g., cis or trans) moderated the relationship between the statistically significant sociodemographic. These results are shown in the second block of Table 3. The model revealed a significant interaction between HIV testing and employment status (retired [AOR: 5.43, 95% CI: 1.73, 17.01] and unemployed [AOR: 4.68, 95% CI: 1.42, 15.46]). A simple slope analysis revealed that employed Black cis women had greater odds of receiving an HIV test than their trans peers, while trans women who were unemployed and retired were significantly more likely to receive an HIV test compared to cis women with similar occupations. It is important to note that this interaction effect only included the employment status of 49 Black trans women.

Table 3. Hierarchical regression results with interactions.

Predictor	Block 1		Block 2	
	AOR	95% CI	AOR	95% CI
Gender Identity	1.01	(0.69, 1.47)	0.10*	(0.01, 0.70)
Age				
18-24 years old	--	--	--	--
35-49 years old	1.24***	(1.13, 1.35)	0.86	(0.19, 3.86)
50 years or older	0.30***	(0.28, 0.33)	0.30	(0.09, 1.06)
Income	0.98	(0.95, 1.01)	0.98	(0.95, 1.01)
Education	1.38***	(1.30, 1.46)	0.79	(0.31, 2.00)
Employment Status				
Employed	--	--	--	--
Unemployed	1.06	(0.99, 1.14)	1.06	(0.98, 1.14)
Retired	0.38***	(0.35, 0.40)	0.37***	(0.35, 0.40)
Other	0.66***	(0.59, 0.73)	0.65***	(0.59, 0.73)
Marital Status				
Married/Partnered	--	--	--	--
Not Married	1.30***	(1.22, 1.38)	1.73	(0.65, 4.59)
Widowed	0.76***	(0.70, 0.83)	0.92	(0.23, 3.64)
Metropolitan Status				
Metropolitan	--	--	--	--
Suburban	0.89*	(0.81, 0.97)	0.22	(0.04, 1.13)
Not Metropolitan	0.61***	(0.55, 0.67)	0.42	(0.11, 1.53)
Healthcare	1.03	(0.94, 1.14)	1.03	(0.94, 1.14)
Primary Care Provider	1.26***	(1.16, 1.38)	0.61	(0.19, 2.01)
Delay Care	1.33***	(1.19, 1.48)	1.55	(0.33, 7.24)
Risk	2.05***	(1.69, 2.50)	0.27	(0.03, 2.87)
Gender Identity x Age				
18-34 years old	--	--	--	--
35-49 years old			1.43	(0.32, 6.32)
50 years or older			1.00	(0.29, 3.51)
Gender Identity x Education			1.74	(0.69, 4.39)
Gender Identity x Employment Status				
Employed	--	--	--	--
Unemployed			5.43**	(1.73, 17.01)
Retired			4.68*	(1.42, 15.46)
Other			6.52	(0.97, 44.03)
Group x Marital Status				
Married	--	--	--	--
Not Married			0.75	(0.29, 2.00)
Widowed			0.83	(0.21, 3.25)
Gender Identity x Metropolitan Status				
Metropolitan	--	--	--	--
Suburban			4.08	(0.79, 21.11)
Not Metropolitan			1.46	(0.40, 5.28)
Gender Identity x Delay Care			0.86	(0.19, 3.96)
Gender Identity x Risk			7.33	(0.72, 74.78)

Note. \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$



## Discussion

Guided by an intersectional approach, this study explored HIV testing behaviors of Black trans women and compared them to testing behaviors among Black cis women. For this study, HIV testing behaviors were defined as a person having received an HIV test at least once in their life. Furthermore, the study examined HIV risk as a predictor of HIV testing, while also identifying sociodemographic factors associated with HIV testing behaviors and if they were moderated by gender identity. Our findings generally do not support our hypotheses. Although prior studies suggest that Black trans women are disproportionately affected by a number of structural factors that contribute to increased HIV vulnerability and HIV diagnosis (Clements-Nolle et al., 2001; Herbst et al., 2008), results of this study contradict previous reports on correlates of HIV testing among trans women (Logie et al., 2016; Rutledge et al., 2018). Our identification of HIV risk as a significant predictor of HIV testing is also inconsistent with prior literature on the association between HIV risk and HIV testing which identify HIV risk as a barrier to HIV testing (Dailey et al., 2017; Mills et al., 2011).

The results revealed some interesting information regarding the association between age and HIV testing. The multivariable logistic regression models suggest that older Black trans women and Black cis women were less likely to receive an HIV test compared to Black cis and trans women within the 18-34 year old age range. This result is consistent with previous literature that suggests that older adults are less likely to receive an HIV test (Akers et al., 2008; Wigfall et al., 2011). Findings by other researchers attributed low testing rates among older adults to factors such as limited knowledge, and low self-perceived risk (Guo & Sims, 2017).

Gender identity was not shown as a predictor or moderator of HIV testing, which was anticipated based off of trans women's disproportionate burden of HIV (Baral et al., 2013; Herbst et al., 2008) and their unique vulnerability to HIV (Hwahng & Nuttbrock, 2007; Poteat et al., 2014). Besides HIV risk, unemployment was the only covariate that emerged as a significant predictor of HIV testing among Black trans women. Consistent with previous literature on unemployment and HIV testing (Brown et al., 2007), Black trans women who were unemployed were almost five times more likely to have received an HIV test in their lifetime compared to Black trans women who were employed. The relationship between employment status and receiving an HIV test among cis women indicated that cis women who were retired or had other types of employment (e.g., homemakers or students) were significantly less likely to receive an HIV test relative to employed cis women. It is also worthwhile to note that because some types of self-employment are nontraditional (e.g., sex work), there could be variation in how respondents classified their own employment status. Overall, the association between HIV testing and employment status has been inconsistent in previous literature. On one hand, employment status has not been shown to be a significant predictor among Black people (Benavides-Torres et al., 2012), while other studies suggest that Black people who were employed were more likely to have ever received an HIV test compared to those who were unemployed (Funk et al., 2018).

### *Limitations*

There are several limitations to consider for this study. One major limitation is that all data in this study was self-reported. While the BRFSS has been shown to be a reliable and useful dataset for HIV testing research (Rountree et al., 2009), participants may have reported inaccurate responses due to issues such as recall bias or social desirability. It is also important to note that because the BRFSS collects data via landline and cellular phones, those who do not have access to a landline or cellular phone are not represented in this data (e.g., those who are institutionalized). As previously mentioned, the way that the BRFSS measured HIV risk is also a major limitation. The BRFSS used one item to assess HIV risk, which only asked participants to respond yes or no if they participated in any of the risk behaviors that were stated. This item may not have adequately captured the complex nature of risk. Other studies have found variability in the ways that different types of risk behaviors are associated with HIV risk (Emmanuel & Link to external site, 2019).

Because this was a secondary data analysis, the analysis was limited to the questions that were assessed by BRFSS. Given this, some of the important perspectives that have been shown to greatly influence the well-being of Black women were not captured in this study. For example, the BRFSS did not gather any information on experiences of discrimination in healthcare settings. In addition to conducting bivariate analyses of health outcomes of intersectional groups, gathering information on discrimination has been shown to be an important component of taking an intersectional approach (Bauer & Scheim, 2019). Having information on experiences of discrimination would have been useful for further developing the intersectional grounding of this study.

### **Conclusion**

The results of this study provide information that can help public health practitioners with the development of HIV testing initiatives that address the needs of two historically marginalized populations. The varied number of sociodemographic predictors that emerged as statistically significant predictors of HIV testing suggest that HIV testing interventions should not be “one-size-fits-all”. Public health professionals should consider developing testing interventions that are tailored to the specific needs of Black cis and trans women. These interventions should be guided by an understanding of how different sociodemographic factors are associated with HIV testing. The information provided in this study may help public health professionals in terms of developing resources and providing guidance for vulnerable and diverse populations concerning HIV testing. Furthermore, knowing which sociodemographic groups are not getting tested increases the ability of public health professionals to be able to target these groups. For example, knowing that Black trans women who are employed have lower odds of getting tested compared to those who are unemployed, retired, students, or homemakers may motivate public health practitioners to begin exploring ways to increase testing among employed Black trans women. More research is needed to better understand the interaction between employment, gender identity, and HIV testing.

## References

- Akers, A. Y., Bernstein, L., Doyle, J., & Corbie-Smith, G. (2008). Older Women and HIV Testing: Examining the Relationship Between HIV Testing History, Age, and Lifetime HIV Risk Behaviors. *Sexually Transmitted Diseases*, 35(4), 420–423. <https://doi.org/10.1097/OLQ.0b013e3181644b39>
- Baral, S. D., Poteat, T., Strömdahl, S., Wirtz, A. L., Guadamuz, T. E., & Beyrer, C. (2013). Worldwide burden of HIV in transgender women: A systematic review and meta-analysis. *The Lancet Infectious Diseases*, 13(3), 214–222. [https://doi.org/10.1016/S1473-3099\(12\)70315-8](https://doi.org/10.1016/S1473-3099(12)70315-8)
- Bauer, G. R., & Scheim, A. I. (2019). Methods for analytic intercategorical intersectionality in quantitative research: Discrimination as a mediator of health inequalities. *Social Science & Medicine*, 226, 236–245. <https://doi.org/10.1016/j.socscimed.2018.12.015>
- Becasen, J. S., Denard, C. L., Mullins, M. M., Higa, D. H., & Sipe, T. A. (2018). Estimating the Prevalence of HIV and Sexual Behaviors Among the US Transgender Population: A Systematic Review and Meta-Analysis, 2006–2017. *American Journal of Public Health*, 109(1), e1–e8. <https://doi.org/10.2105/AJPH.2018.304727>
- Benavides-Torres, R. A., Wall, K. M., Núñez Rocha, G. M., Onofre Rodríguez, D. J., & Hopson, L. (2012). Factors Associated with Lifetime HIV Testing in Texas by Race/Ethnicity. *The Open AIDS Journal*, 6, 232–238. <https://doi.org/10.2174/1874613601206010232>
- Bradley, E. L. P. (2019). Disparities in Incidence of Human Immunodeficiency Virus Infection Among Black and White Women—United States, 2010–2016. *MMWR. Morbidity and Mortality Weekly Report*, 68. <https://doi.org/10.15585/mmwr.mm6818a3>
- Brown, N. C., Taylor, E. D., Mulatu, M. S., & Scott, W. (2007). Demographic correlates of HIV testing, high-risk behaviors, and condom/STD consultation among a multi-ethnic sample of women. *Women & Health*, 46(2-3), 59-76.
- Bukowski, L. A., Chandler, C. J., Creasy, S. L., Matthews, D. D., Friedman, M. R., & Stall, R. D. (2018). Characterizing the HIV Care Continuum and Identifying Barriers and Facilitators to HIV Diagnosis and Viral Suppression Among Black Transgender Women in the United States. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 79(4), 413–420. <https://doi.org/10.1097/QAI.0000000000001831>
- Centers for Disease Control and Prevention [CDC](n.d.). About BRFSS. (2019, February 9). Retrieved from <https://www.cdc.gov/brfss/about/index.htm>
- Centers for Disease Control and Prevention. (2018). HIV Surveillance Report 2017. 29, 129.

- Clements-Nolle, K., Marx, R., Guzman, R., & Katz, M. (2001). HIV prevalence, risk behaviors, health care use, and mental health status of transgender persons: Implications for public health intervention. *American Journal of Public Health*, 91(6), 915–921. <https://doi.org/10.2105/ajph.91.6.915>
- Crenshaw, K. (1990). Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. *Stanford Law Review*, 43(6), 1241–1300.
- Dailey, A. F., Hoots, B. E., Hall, H. I., Song, R., Hayes, D., Fulton, P., Prejean, J., Hernandez, A. L., Koenig, L. J., & Valleroy, L. A. (2017). Vital Signs: Human Immunodeficiency Virus Testing and Diagnosis Delays — United States. *MMWR. Morbidity and Mortality Weekly Report*, 66(47), 1300–1306. <https://doi.org/10.15585/mmwr.mm6647e1>
- De Santis, J. P. (2009). HIV Infection Risk Factors Among Male-to-Female Transgender Persons: A Review of the Literature. *Journal of the Association of Nurses in AIDS Care*, 20(5), 362–372. <https://doi.org/10.1016/j.jana.2009.06.005>
- Denson, D. J., Padgett, P. M., Pitts, N., Paz-Bailey, G., Bingham, T., Carlos, J.-A., McCann, P., Prachand, N., Risser, J., & Finlayson, T. (2017). Health Care Use and HIV-Related Behaviors of Black and Latina Transgender Women in 3 US Metropolitan Areas: Results From the Transgender HIV Behavioral Survey. *Journal of Acquired Immune Deficiency Syndromes* (1999), 75(Suppl 3), S268–S275. <https://doi.org/10.1097/QAI.0000000000001402>
- Emmanuel, A. D., & Link to external site, this link will open in a new window. (2019). *Exploring the Relationship between HIV Risk Behaviors and HIV Testing among Youth* [Ph.D., The George Washington University]. <https://search.proquest.com/docview/2203415223/abstract/C907F08EC24E4CCAPQ/1>
- Frye, V., Wilton, L., Hirshfield, S., Chiasson, M. A., Usher, D., Lucy, D., McCrossin, J., Greene, E., & Koblin, B. (2015). “Just Because It’s Out There, People Aren’t Going to Use It.” HIV Self-Testing Among Young, Black MSM, and Transgender Women. *AIDS Patient Care and STDs*, 29(11), 617–624. <https://doi.org/10.1089/apc.2015.0100>
- Funk, A. N., Inungu, J. N., Leveille, E. R., & Minelli, M. (2018). Factors Associated with HIV-Testing among African Americans: Analysis of the 2016 National Health Interview Survey. *European Journal of Environment and Public Health*, 2(1), 03. <https://doi.org/10.20897/ejeph/82621>
- Golub, S. A., & Gamarel, K. E. (2013). The Impact of Anticipated HIV Stigma on Delays in HIV Testing Behaviors: Findings from a Community-Based Sample of Men Who Have Sex with Men and Transgender Women in New York City. *AIDS Patient Care and STDs*, 27(11), 621–627. <https://doi.org/10.1089/apc.2013.0245>

- Guo, Y., & Sims, O. T. (2017). Assessment of recent HIV testing among older adults in the United States. *Social Work in Health Care*, 56(9), 855–864. <https://doi.org/10.1080/00981389.2017.1339762>
- Herbst, J. H., Jacobs, E. D., Finlayson, T. J., McKleroy, V. S., Neumann, M. S., Crepaz, N., & for the HIV/AIDS Prevention Research Synthesis Team. (2008). Estimating HIV Prevalence and Risk Behaviors of Transgender Persons in the United States: A Systematic Review. *AIDS and Behavior*, 12(1), 1–17. <https://doi.org/10.1007/s10461-007-9299-3>
- Hwahng, S. J., & Nuttbrock, L. (2007). Sex workers, fem queens, and cross-dressers: Differential marginalizations and HIV vulnerabilities among three ethnocultural male-to-female transgender communities in New York City. *Sexuality Research & Social Policy*, 4(4), 36. <https://doi.org/10.1525/srsp.2007.4.4.36>
- Logie, C. H., Lacombe-Duncan, A., Wang, Y., Jones, N., Levermore, K., Neil, A., Ellis, T., Bryan, N., Harker, S., Marshall, A., & Newman, P. A. (2016). Prevalence and Correlates of HIV Infection and HIV Testing Among Transgender Women in Jamaica. *AIDS Patient Care and STDs*, 30(9), 416–424. <https://doi.org/10.1089/apc.2016.0145>
- Mills, C. W., Sabharwal, C. J., Udeagu, C.-C., Bocour, A., Bodach, S., Shepard, C., & Begier, E. M. (2011). Barriers to HIV Testing Among HIV/AIDS Concurrently Diagnosed Persons in New York City. *Sexually Transmitted Diseases*, 38(8), 715–721. <https://doi.org/10.1097/OLQ.0b013e31820ead73>
- Muessig, K. E., Baltierra, N. B., Pike, E. C., LeGrand, S., & Hightow-Weidman, L. B. (2014). Achieving HIV risk reduction through HealthMpowerment.org, a user-driven eHealth intervention for young Black men who have sex with men and transgender women who have sex with men. *Digital Culture & Education*, 6(3), 164–182.
- Peterson, J. L., Bakeman, R., Sullivan, P., Millett, G., Rosenberg, E., Salazar, L., Di Clemente, R. J., Cooper, H., Kelley, C. F., Mulligan, M. J., Frew, P., & del Rio, C. (2014). Social Discrimination and Resiliency are not associated with Differences in Prevalent HIV Infection in Black and White Men who have Sex with Men. *Journal of Acquired Immune Deficiency Syndromes (1999)*, 66(5), 538–543. <https://doi.org/10.1097/QAI.0000000000000203>
- Poteat, T., German, D., & Flynn, C. (2016). The conflation of gender and sex: Gaps and opportunities in HIV data among transgender women and MSM. *Global Public Health*, 11(7–8), 835–848. <https://doi.org/10.1080/17441692.2015.1134615>

- Poteat, T., Reisner, S. L., & Radix, A. (2014). HIV Epidemics among Transgender Women. *Current Opinion in HIV and AIDS*, 9(2), 168–173. <https://doi.org/10.1097/COH.0000000000000030>
- Ransome, Y., Kawachi, I., Braunstein, S., & Nash, D. (2016). Structural inequalities drive late HIV diagnosis: The role of black racial concentration, income inequality, socioeconomic deprivation, and HIV testing. *Health & Place*, 42, 148–158. <https://doi.org/10.1016/j.healthplace.2016.09.004>
- Rountree, M. A., Chen, L., Brown, A., & Pomeroy, E. C. (2009). HIV Testing Rates and Testing Locations, by Race and Ethnicity. *Health & Social Work*, 34(4), 247–255. <https://doi.org/10.1093/hsw/34.4.247>
- Rutledge, R., Morozova, O., Gibson, B. A., Altice, F. L., Kamarulzaman, A., & Wickersham, J. A. (2018). Correlates of Recent HIV Testing Among Transgender Women in Greater Kuala Lumpur, Malaysia. *LGBT Health*, 5(8), 484–493. <https://doi.org/10.1089/lgbt.2018.0021>
- Wansom, T., Guadamuz, T. E., & Vasan, S. (n.d.). Transgender populations and HIV: Unique risks, challenges and opportunities. *Journal of Virus Eradication*, 2(2), 87–93.
- Wigfall, L. T., Richter, D. L., Torres, M. E., Annang, L., Lindley, L. L., Swayampakala, K., Sebastian, N., Glover, S. H., & Duffus, W. A. (2011). HIV Testing Among Midlife Women in the Deep South: An Analysis of the 2008 Behavioral Risk Factor Surveillance System Survey Data. *Journal of Women's Health*, 20(6), 933–941. <https://doi.org/10.1089/jwh.2010.2096>
- World Health Organization. (2014). *Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations*. World Health Organization.

# **Leveraging Public and Private Funding to Implement Opt-out HIV Screening Programs in Rural and Urban Emergency Departments in South Carolina Discovered a High Rate of Human Immunodeficiency Virus (HIV) Infection in Black Patients**

**Phillip Moschella, MD PhD**

Department of Emergency Medicine, Prisma Health Upstate Affiliate,  
Greenville SC 29607

**Smith Heavner MS RN**

Department of Emergency Medicine, Prisma Health Upstate Affiliate,  
Greenville SC 29607

**Susan Cordero Romero BS**

Department of Emergency Medicine, Prisma Health Upstate Affiliate,  
Greenville SC 29607

**Jess Knapp MPH**

Department of Emergency Medicine, Prisma Health Upstate Affiliate,  
Greenville SC 29607

**Prerana Roth, MD MPH**

Department of Internal Medicine, Prisma Health Upstate Affiliate,  
Greenville SC 29607

**Alain H Litwin MD MPH**

Department of Internal Medicine, Prisma Health Upstate Affiliate,  
Greenville SC 29607

## **Authors' Note**

This work was supported by funding from the South Carolina Department of Health and Environmental Control and the Frontlines of Communities in the United States (FOCUS) program (Gilead Sciences Inc.). All results are part of an ongoing IRB approved study on the overall seroprevalence of HIV.

## **Abstract**

The new epicenter of the ongoing HIV epidemic in the United States is the South. Specifically, South Carolina (SC) is listed a priority state as part of the CDC's Ending the Epidemic Plan for America. A novel opt-out HIV screening program was implemented in one rural and one urban Emergency Department (ED) within a large SC health system. Leveraging both public

and private funding sources, which made both the testing and linkage processes cost neutral, ED based screening was provided for 2304 Black patients which represents an 44% increase. As part of this screening program a total of 50 individuals were linked to care of which 29 were Black. The rate of HIV positivity for Black patients using this ED based screening program was nearly double that of the baseline health system screening. This program's utilization of the health system electronic health record (EHR) and funding from various sources may provide a model for legislative and public health entities to combat the HIV epidemic in the South.

*Keywords:* Human Immunodeficiency Virus, HIV, South Carolina, Emergency Department, ED

### Introduction

The new epicenter of the Human Immunodeficiency Virus (HIV) epidemic in the United States is the South. The South disproportionately accounts for more than 51% of new HIV cases while only containing about 38% of the total United States population (CDC, 2019). The current HIV epidemic continues to disproportionately affect the underserved and often high-risk Black populations across the United States but especially in the South. The Centers for Disease Control and Prevention (2020) reported on the incidence of HIV infection across the United States. Disturbingly, the incidence of HIV in Blacks/African Americans has remained “stable” since 2014 at 42% of new infections. The South lags far behind the rest of the US in screening, linkage, and retention in care. The South has the highest incidence of HIV infections in the nation at 19.3/100,000 and in 2018 alone accounted for 19,700 new infections (CDC, 2020).

Specifically, South Carolina (SC) is highlighted as a priority area for the CDC Ending the HIV Epidemic: A Plan for America (Fauci et al. 2019). South Carolina unfortunately has a higher rate of, and an increased odds ratio for, late diagnosis of HIV in older, male, non-White patients (Hossain, 2018). The HIV epidemic in SC also has a unique and substantial burden of spread in rural areas (CDC, 2021). The Emergency Department (ED), with universal 24/7 access, delivers a high proportion of care to underserved and high-risk populations and has been published as a key venue to find undiagnosed HIV (Moschella, et al. 2014). The ability of EDs to serve at risk populations is not limited to large urban EDs. The overall impact of EDs in rural areas is magnified secondary to the paucity of healthcare venues and overall lack of social support systems in these areas. Emphasizing this, a recent report showed a dramatic 70% rise in the number of patients seen in rural EDs rising from 16.7 million in 2005 to 28.4 million in 2016 (Greenwood-Ericksen, 2019).

To address the growing HIV epidemic in SC, a novel program was developed to bridge the gap in screening for Black patients in SC in both rural and urban communities. This report describes the results of a novel “Opt-out” HIV screening program instituted in one rural and one urban ED within one health system in SC. This program was created and supported through utilization of funding from both public and private sources including the SC Department of Health and Environmental Control, and the Frontlines of Communities in the United States (FOCUS) program (Gilead Sciences Inc.) respectively.



This program utilized our electronic health record (EHR) to help determine eligibility to guide testing and builds on previous lessons removing impediments to testing (Schnall et al. 2013). Implementation of screening in just two of a possible six total EDs accounted for a rapid 44% increase in the ability to provide screening and linkage to care for Black patients in both rural and urban communities in SC.

This program rapidly increased the number of HIV positive individuals identified, while also achieving an equal linkage to care rate compared to patients screened outside the ED. This program provides an effective model for both legislative and public health entities to emulate to rapidly and effectively increase screening across both rural and urban areas. Furthermore, this model demonstrates, the ability to access various underserved and high-risk communities to ultimately stop the epidemic in the South and reach the CDC's goal of ending the epidemic.

## Methods

As part of our IRB-approved continuous quality improvement program, we evaluated administrative data (May 1, 2020 through April 30, 2021) for all HIV screening results performed across all testing venues within a large South Carolina (SC) hospital system. A novel EHR based universal opt-out HIV screening was instituted at two EDs in SC and compared to baseline testing as part of normal operations within the health system. This new program provided opt-out HIV screening within two divergent EDs which were part of this health system. One ED was a rural tertiary referral hospital in Seneca, SC with an annual census of 67K adult patients/year. The other ED was an urban ED level one trauma center with an embedded emergency medicine residency program located in Greenville, SC with an annual census of 95K adult patients/year. Both EDs are part of a large SC health system that serves around 500K patients a year. They all utilize the same electronic health record (EHR) EPIC® (Madison WI).

### *EHR Screening Protocol*

The opt-out HIV screening program was created to offer screening to all adult patients aged 18–64 years. Eligibility of each adult patient was initially determined using our EHR. Patients were excluded if they had: 1) a documented history of HIV infection, 2) a documented history of a positive HIV test, 3) any HIV treatment medications listed in their medical record, 4) received testing for HIV in the previous year (12 calendar months), 5) not signed their general consent for treatment 6) a documented lack of decision-making capacity, 7) a language barrier or need to use an interpreter, or 8) chosen to opt-out of screening. Patients were also excluded if they did not have any retained blood/serum in the lab obtained as part of their care delivered in the ED. The lab routinely stores all patient blood/serum samples for 48hrs in case any new or confirmation testing is ordered. After 48 hours, the samples are discarded. Lack of decision-making capacity was determined by no reported psychiatric or involuntary hold placed on the patient while in the ED and confirmation of the patient's signed consent for treatment. This health system has adopted universal "opt-out" language as part of

the overall general consent for treatment that all patients sign as part of their ED course of care. This consent has specific language highlighting the opt-out screening for infections including, but not limited to, HIV and HCV. Eligibility, as initially confirmed using this EHR driven process, was used to create an “on-demand” report. This report would be run at least daily but could be run several times a day based on need. This report would be accessed by the linkage to care coordinators who would perform a final compliance check. The final compliance check consisted of confirmation of no reported history of HIV infection or treatment, recent HIV testing in last 12 months, and confirmation of a signed consent for treatment with no charted/ reported “Opt-out” on behalf of the patient. If all above were confirmed, HIV screening was then ordered within the EHR on the retained blood.

### *HIV Laboratory Screening Protocol*

The protocol followed established CDC guidelines (2018) and utilized an initial 4th Generation HIV p24 Ag/HIV Ab combination screening test (Abbott, United States). Positive results were then subjected to confirmation testing using: 1) Geenius HIV-1/HIV-2 assay (BioRad) and 2) Nucleic acid quantification (BioQuest) (CDC, 2018).

### *Notification and Linkage to Care*

All positive 4th generation p24 Ag/HIV Ab results were reported by the lab to SC DHEC and within the EHR to the physician champions (P.M. and P.R.) and the linkage to care coordinators. The linkage to care coordinators are community health workers with either a bachelor's or master's level of education trained to deliver HIV post-test counseling and coordinate overall linkage to care. They assist in all aspects of coordination including notification, appointment scheduling, and transportation assistance. In addition, the lab would make direct phone calls to: 1) a confidential linkage to care coordinator phone line, 2) the ED physician champion (P.M.) and 3) the Infectious Disease physician champion (P.R.). The rapid results were communicated in order to attempt to be able to contact the patient while still in the ED. If the patient was still in the ED or returned to the ED at a later date prior to any other healthcare contact, any of the above team members would provide post-test counseling on results, confirm patient contact information and refer for care or repeat testing. If the patient was discharged from the ED prior to the screening test results, the linkage to care coordinators would confirm final confirmation testing prior to disclosure/post-test counseling. This would be completed initially by phone. If the patient was admitted to the hospital, disclosure/post-test counseling would be conducted in person. All positive results were reported directly to the SC DHEC as per their standard protocols using the SCIONx system in compliance with SC state law on reportable diseases. Linkage to care was defined as direct contact by phone/virtual or in person appointment to an HIV specialty care provider. Linkage to care coordinators assisted patients with connection to various insurance and funding sources (if necessary), various HIV treatment providers both within and outside the health system, and in many cases with direct appointment scheduling within an internal medicine clinic. Overall linkage was performed by direct phone contact and in some cases with text messages after direct phone contact only at the request of the patient.

Results

Overall HIV Screening

As shown in Table 1, a total of 22,319 patients were screened for HIV from May 1,2020 through April 30, 2021. This represents a baseline rate of screening within the health system including all inpatient and outpatient settings (seven hospitals and multiple outpatient clinics minus the testing as part of this new ED opt-out program). The new ED opt-out program as described above implemented in just two of six possible EDs, added 10,894 screening tests (a 49% increase) across the same time period. The overall health system provided 5,183 HIV screening tests for Black patients, while these new ED-based programs increased screening for Black patients by 2,304 tests or 44%.

Table 1. Overall Demographics of HIV Screening, Emergency Department vs Health System

	Emergency Department N (%)	Health System N (%)
Total	10894	22319
Male	5193 (47.7)	5892 (26.4)
Female	5700 (52.3)	16409 (73.5)
Unknown	1 (0.0)	18 (0.1)
Black	2304 (21.1)	5183 (23.2)
Non-Black	8590 (78.9)	17136 (76.8)
Mean Age (SD)	46.7 (17.7)	39.2 (17.6)
Median Age (Interquartile range)	46 (31, 61)	33 (26, 51)

HIV Positivity

With respect to positivity rates, as shown in Table 2, baseline screening throughout the health system found 68 total HIV positive individuals with 37/68 HIV positive Black individuals (~54%). The ED based testing program itself found an additional 54 total HIV positive individuals with 29/54 HIV positive Black individuals (~54%). The ED based testing thus increased the number of overall HIV positive individuals identified by 79% (54+68) and the number of HIV positive Black individuals by 78% (29+37). This new program utilizing the ED, increased overall testing in Black individuals by 44% and simultaneously increased the number of newly diagnosed HIV positive Black individuals by 79%. The overall positivity rate for Black individuals using this ED-based testing program was nearly double that of baseline system-wide testing (29/2304 or 1.3 vs 37/5103 or 0.7 respectively).

Overall mean and median ages for HIV screening in Black patients were higher in the ED based program by 7 and 13 years respectively (Table 1). The HIV positivity rate for

Black individuals using this ED-based testing program was conversely younger by 7 and 11.5 years respectively (Table 2). The linkage to care percentages were equal at ~93% across all testing programs.

Table 2. Demographics of HIV Screening Results, Emergency Department vs Health System

	Emergency Department N (%)	Health System N (%)
Total Positive	54	68
Male	45 (83.3)	46 (67.6)
Female	9 (16.7)	22 (32.4)
Black	29 (53.7)	37 (54.4)
Non-Black	25 (46.3)	31 (45.6)
Mean Age (SD)	37.1 (14)	44.4 (14.1)
Median Age (Interquartile range)	35 (27, 49.5)	46.5 (32, 55.5)
Linkage to Care	50 (92.6)	63 (92.6)

Conclusion

This ED based screening program represented a unique and advantageous venue to rapidly increase HIV screening and linkage to care for Black patients within a large health system in SC. Initial implementation of an EHR supported, ED-based, opt-out HIV screening program was targeted to begin in two of a possible six total EDs within the health system. This program sought to drive screening both in one rural and one urban ED to attack the epidemic across all communities. It is interesting to note that while this new testing program was instituted in only two of six EDs (33%) it increased overall health system testing by 49% and increased the number of newly identified HIV positive Black individuals by ~79% with a positivity rate nearly double that of baseline testing across the health system. This program was not designed to specifically increase screening in Black patients and thus it is not surprising that the overall percentages of screening for Black patients remained similar at ~22% comparing ED based testing and that within the overall health system. It has been published previously that EDs often have a higher percentage of undiscovered HIV positive patients and this data follows this trend (Moschella et al. 2014). It may be that patients who utilize the ED often have several high-risk features and often do not seek care in other healthcare venues. Specifically, within both of these EDs there are between 33-40% of patients that are self-pay or uninsured (data not shown), but we do not have data on whether any of these newly identified HIV positive patients have sought care within the health system at other venues. Often a barrier to increasing testing in high-risk individuals is access. The ED is unique within most health systems in that it is open 24/7 and 365 days a year. Secondary to the Examination and Treatment for Emergency

Medical Conditions and Women in Labor Act of 2010 (2011) (EMTALA), the ED must care for all individuals regardless of their ability to pay. The ED, therefore, is often the first and last access point for individuals with little to no insurance who have limited access and variable health literacy. It is a limitation of this initial report that we did not discuss any recorded patient risk factors and social determinates of health for both patients screened and positive as part of this program. Indeed, further studies are ongoing to better understand the specific high-risk factors within these local communities that are contributing to this rapidly spreading epidemic. Another limitation is our higher screening for females. There are several factors that may be contributing to this gender imbalance in screening. Overall, more females seek care across all venues within our health system (data not shown). This coupled with Medicaid support for pregnant females and the standard practice of universal HIV screening for all pregnant females may be partly responsible for the gender imbalance in screening across our health system. We do not have specific data on gender differences in overall access and/or willingness to access care but these represent future areas of growth and investigation for this ongoing program.

While this program increased the overall percentages of testing and found an increased rate and overall number of HIV positive Black individuals, it was also able to attain the same linkage to care rate as the overall health system (~93%). The fear of not being able to link a newly diagnosed patient to care is often a barrier to implementation of such ED-based programs. Concerns include the inability to contact the patient or to ensure engagement in treatment after being informed of the diagnosis. . This data refutes this stigma/dogma and shows that indeed patients can be contacted, linked and will engage in follow-up care from the ED. This data shows that patients screened from the ED can access follow-up care across both rural and urban communities. To help with post-test counseling and linkage to care, this program utilized two full time linkage to care coordinators and a champion infectious disease physician. This small team was able to match the same linkage to care rate as a multibillion-dollar health system with more than 1000 employed physicians, six hospitals and numerous outpatient clinics. This novel program was specifically implemented in a rural community ED and an urban academic health center to demonstrate that both can be successful and that both are indeed necessary to combat the epidemic in the South, and South Carolina specifically. As noted previously, SC has a higher rate of burden of disease in rural communities (Hossain, 2018).

In addition to various stigmas still surrounding HIV, both practical and regulatory issues also impede universal implementation of ED-based HIV screening programs (Signer et al. 2016). This program benefitted from previous reports that have discussed barriers to large scale implementation and integration into normal workflow with adaptation of the newest testing strategies (Haukoos et al. 2011). Although federal guidance from the CDC supports universal opt-out screening, the ability to perform opt-out screening varies from state to state based on local laws. State laws and institutional regulations regarding all facets of HIV screening, consent, and reimbursement can pose significant challenges (Branson et al. 2006). This inconsistency from state to state and the added complexity prevents broad recommendations on process development and serves as a practical impediment to a nationwide scale-up. In states where opt-out HIV consent is in place (e.g., Texas, South Carolina), reports of more robust scale-up have been published and contributed to this programs' success (Hoxhaj et al. 2011). A few

states (e.g., New York) have enacted legislation that mandates HIV testing be offered, with supported reimbursement. However even with such legislation, the ability to reach the larger ED populations has been challenging where the combination of both legislative and EHR complexities yielded a screening rate of only 10% of their ED population (Schnall et al. 2013).

The last barrier that often exists for widespread screening is cost. The ability to leverage both public and private resources was a major contributing factor in the overall success of this program. The ability to leverage support for testing costs for uninsured patients and the support to fund the linkage to care coordinators allowed for the rapid increase in screening for these underserved and high-risk populations who may only use the ED as their primary source of medical care. Indeed, the fact that this program was initially fully supported by a combination of both public and private funding sources, made implementation easier as the program was cost neutral for the health system. Since the initial implementation however, the health system has recognized the benefits of these coordinators to help guide linkage to care across the entire health system. As such these coordinators have become a central resource for HIV linkage across the health system and now support and guide linkage efforts for both inpatient and outpatient services from surgery to medicine. They have a central role for linkage for complex patients including those that are homeless and have co-occurring substance use disorders. It should be noted that while various staff across all departments were subject to mandatory furlough during the COVID-19 pandemic, none of the linkage to care coordinators as part of this program were at risk. The ability to leverage both public and private funding to implement HIV screening in the ED and utilizing the full potential of our EHR, may serve as a model for other health systems to rapidly increase screening efforts to help combat the HIV epidemic across both urban and rural communities in the United States.

## References

- Branson BM, Handsfield HH, Lampe MA, Janssen RS, Taylor AW, Lyss SB, et al. Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings. *MMWR Recomm Rep*. 2006;55(RR-14):1–17.
- Centers for Disease Control and Prevention and Association of Public Health Laboratories. Laboratory Testing for the Diagnosis of HIV Infection: Updated Recommendations 2018. Available at, <https://doi.org/10.15620/cdc.23447>. Updated January, 2018. [Accessed January 1, 2019].
- Centers for Disease Control and Prevention. National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention: Division of HIV/AIDS Prevention. HIV in the Southern United States. *Issue Brief*. Sept 2019. <https://www.cdc.gov/hiv/pdf/policies/cdc-hiv-in-the-south-issue-brief.pdf> [Last accessed July 21, 2021].
- Centers for Disease Control and Prevention. Estimated HIV incidence and prevalence in the United States, 2014–2018. HIV Surveillance Supplemental Report 2020;25(No. 1). <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Published May 2020. [Last Accessed July 6, 2021].
- Centers for Disease Control and Prevention. Division of HIV/AIDS Prevention. Combined HIV Diagnoses for 2016-2017, United States. *Ending the Epidemics: Jurisdictions*. Reviewed April 1 2021. <https://www.cdc.gov/endhiv/diagnoses-2016-2017.html> [Last accessed July 21, 2021].
- 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. doi:10.1001/jama.2019.1343
- Centers for Disease Control and Prevention/Division of HIV/AIDS Prevention. Combined HIV Diagnoses for 2016-2017, United States. *Ending the Epidemics: Jurisdictions*. Reviewed April 1 2021. <https://www.cdc.gov/endhiv/diagnoses-2016-2017.html> [Last accessed July 21, 2021].
- Greenwood-Ericksen, M. B., & Kocher, K. (2019). Trends in Emergency Department Use by Rural and Urban Populations in the United States. *JAMA network open*, 2(4), e191919. <https://doi.org/10.1001/jamanetworkopen.2019.1919>.
- Haukoos JS, White DA, Lyons MS, Hopkins E, Calderon Y, Kalish B, et al. Operational methods of HIV testing in emergency departments: a systematic review. *Ann Emerg Med*. 2011;58(Suppl 1):96–103.

- Hossain, A., Li, X., Osterman, J., & Chakraborty, H. (2018). Late Diagnosis of HIV in South Carolina: Prevalence, Cause, and Consequences. *Open Forum Infectious Diseases*, 5(Suppl 1), S212. <https://doi.org/10.1093/ofid/ofy210.582>.
- Hoxhaj, S., Davila, J. A., Modi, P., Kachalia, N., Malone, K., Ruggerio, M. C., Miertschin, N., Brock, P., Fisher, A., Mitts, B., & Giordano, T. P. (2011). Using nonrapid HIV technology for routine, opt-out HIV screening in a high-volume urban emergency department. *Annals of emergency medicine*, 58(1 Suppl 1), S79-84. <https://doi.org/10.1016/j.annemergmed.2011.03.030>.
- Moschella, P. C., Hart, K. W., Ruffner, A. H., Lindsell, C. J., Wayne, D. B., Sperling, M. I., Trott, A. T., Fichtenbaum, C. J., & Lyons, M. S. (2014). Prevalence of undiagnosed acute and chronic HIV in a lower-prevalence urban emergency department. *American journal of public health*, 104(9), 1695–1699. <https://doi.org/10.2105/AJPH.2014.301953>.
- Schnall, R., Sperling, J. D., Liu, N., Green, R. A., Clark, S., & Vawdrey, D. K. (2013). The effect of an electronic “hard-stop” alert on HIV testing rates in the emergency department. *Studies in health technology and informatics*, 192, 432–436.
- Signer, D., Peterson, S., Hsieh, Y. H., Haider, S., Saheed, M., Neira, P., Wicken, C., & Rothman, R. E. (2016). Scaling Up HIV Testing in an Academic Emergency Department: An Integrated Testing Model with Rapid Fourth-Generation and Point-of-Care Testing. *Public health reports (Washington, D.C.:1974)*, 131(Suppl 1), 82-89. <https://doi.org/10.1177/00333549161310S110>.



## **We the People: A Black Strategy to End the HIV Epidemic in the United States of America**

**Tenesha J. Lewis, MPH**

Senior Manager, Training and Capacity Building  
Black AIDS Institute  
1833 West Eighth Street  
Los Angeles, California  
Tel: (804) 322-9384  
Email: [TeneshaL@blackaids.org](mailto:TeneshaL@blackaids.org)  
ORCID: <https://orcid.org/0000-0003-0074-8281>

**Maximillian Boykin**

Manager, Policy and Organizing  
Black AIDS Institute  
1833 West Eighth Street  
Los Angeles, California  
Tel: (404) 861-1772  
Email: [MaxxBoykin@gmail.com](mailto:MaxxBoykin@gmail.com)

### **Authors' Note**

This preliminary research was supported in part by grants from the HIV Prevention Trials Network, Gilead Sciences, Inc., and Janssen Pharmaceuticals, Inc. Special thanks to the Black AIDS Institute's President and CEO Raniyah Copeland, as well as Director of National Programs Robert Newells and Special Projects Consultant Michael Isbell for their guidance and insight regarding this article. We also owe a debt of gratitude to the Institute's founder Phill Wilson and all of the staff and community partners who have worked across the decades to make the Institute a valued resource and leader in the fight against the HIV/AIDS epidemic. This material was submitted with institutional review and approval. The authors have no conflicts of interest to disclose. Maximillian Boykin is now with the Center on Budget and Policy Priorities. Correspondence concerning this article should be addressed to Tenesha Lewis, Black AIDS Institute, 1833 West Eighth Street, Los Angeles, CA 90057-4920. Email: [TeneshaL@blackaids.org](mailto:TeneshaL@blackaids.org)

### **Abstract**

The two previous United States presidential administrations implemented efforts to combat HIV/AIDS, recently leading to a plan to end this epidemic by 2030. Although the plan outlines a biomedical framework of key areas to address, it does not prioritize the core systemic and social issues that have caused the disease to devastate Black communities. The Black AIDS Institute (BAI) responded directly to this gap with "We the People: A Black Strategy to End HIV." BAI connected with Black community members across the country and conducted key informant interviews, held town hall meetings, and hosted a community forum in the U.S.

Conference on AIDS. Based on this extensive community-level input, BAI, along with a diverse group of social justice partners, finalized the plan's strategic direction and recommendations. The efforts culminated in the "We the People" framework's four key pillars directly informing all of BAI's policy work, to include radically reimagining housing, health care, and criminalization systems that perpetuate the HIV/AIDS crisis among Black Americans. "We the People" outlines a clear path to engage policymakers and ensure all communities can effectively access and utilize the treatment and prevention advances that have the potential to soon end this epidemic..

*Keywords:* HIV/AIDS epidemic, Black HIV, HIV public policy, systemic oppression, equitable systems, we the people

### Introduction

Since the initial days of HIV/AIDS, remarkable scientific advances have been made. Today's medicines help to prevent the transmission of HIV and reduce its progression. With medical adherence, many people living with HIV (PLWH) can expect lives as long as people who do not live with the virus (Cahill, & Valadéz, 2013), and risk of transmission is often  $\leq 1\%$  (Centers for Disease Control and Prevention, 2021). The future of HIV biomedicine can plausibly include even better treatment and prevention modalities, as well as a vaccine and cure.

However, HIV continues to be a public health crisis in Black America. Constituting 13% of the United States population, Black Americans comprise  $>40\%$  of PLWH, as well as just over 40% of new HIV diagnoses (Centers for Disease Control and Prevention, 2020). The disproportionate effects of HIV are especially apparent among Black gay and bisexual men, as approximately 1 out of every 2 Black gay/bisexual men is estimated to acquire HIV during his/their lifetime (Centers for Disease Control and Prevention, 2017). Of Black PLWH, 85% are aware of their status, but just under half are retained in care (Centers for Disease Control and Prevention, 2017). Black America's unique vulnerability to HIV is rooted in decades of structural oppression following centuries of chattel slavery; the oppression's resultant social and structural issues include poverty, anti-Black racism, homophobia, transphobia, housing and food instability, limited educational and employment opportunities, as well as a diminished quality of mental and physical health (Jeffries & Henny, 2019).

In 2010, the Obama administration established the first National HIV/AIDS strategy, which primarily sought to reduce new infections and deaths (White House Office of National AIDS Policy, 2015). The strategy placed focus on marginalized populations; however, it did not dive deeply into root causes, and the current state of HIV among these populations demonstrates that the plan did not work as anticipated.

In 2019, the Trump administration presented a plan to end HIV in the United States by 2030; Dr. Anthony Fauci then unveiled the rationale for this Ending the HIV Epidemic (EHE) plan that proposed additional funding and biomedical strategies (Fauci et al., 2019). The plan left out important information about intersectionality and stemmed from an administration whose political leaders often touted core features, including racism,

homophobia, and transphobia, that perpetuate the HIV crisis among Black Americans and other disenfranchised populations. While federal initiatives are welcome and federal resources are essential, solely addressing biomedicine will not impact the root causes of Black America's large HIV vulnerability.

The disproportionate impact of HIV on Black Americans is inseparable from historical and present-day anti-Black racism, and it is impossible to solely utilize treatment modalities to end the HIV epidemic without considering root causes for disproportionality. Accordingly, efforts to deliver the latest biomedical tools will fail to significantly impact populations in need if there is little to no consideration of the intersectionality of marginalized populations. The structural and social barriers constricting many Black Americans into poverty, low-quality education and healthcare, housing instability, unemployment, mass incarceration, and voter suppression are also perpetuating high rates of HIV and poor outcomes in Black communities. It is critical to address these systems-level determinants of HIV-related health and to increase access to, and utilization of, biomedical advances that may soon have the ability to eradicate the HIV/AIDS epidemic altogether.

Founded in 1999 as the United States' only unapologetically Black HIV "think and do" tank, the Black AIDS Institute (BAI) is uniquely poised to respond to gaps within national HIV strategies. With this research, BAI seeks to examine ways in which governmental agencies, community organizations, other institutions, and communities themselves can all focus resources and efforts on upstream determinants of health to effect the largest change on downstream incidence and prevalence of HIV among Black Americans.

## Methods

### *Participants*

Participant recruitment was conducted via flyer distribution and notifications within universities, BAI's treatment advocacy network, newspapers, webinars, local health departments, and community-based organizations. From this recruitment effort, 20 key informants and 124 community members from across the United States were invited and consented to participate.

### *Variables*

A semi-structured focus group question guide was created, encouraging storytelling of experiences regarding the HIV workforce, living with HIV, and challenges and opportunities to address the HIV epidemic in Black America.

### *Research Design*

This qualitative study used phenomenology and an inductive approach, with data obtained via community town halls and a focus group.

### *Procedures*

BAI President and CEO Raniyah Copeland convened a meeting with organizational leadership following the Trump administration's February 2019 announced plan to end the HIV/AIDS epidemic. The BAI team acknowledged the federal administration's plan only included a biomedical, location-based approach; further, divisions arising from politically-encouraged racism, homophobia, and transphobia did not create an appropriate environment to effectively eradicate HIV in all American populations, particularly Black communities. Thus, this first meeting served to coordinate a process for assessment and response to the federal plan, and BAI immediately set out to obtain community input.

BAI pursued a community-centered approach in the design of its working framework, "We the People: A Black Strategy to End HIV" (WTP). Consistent with its name, "We the People" was developed through an extensive outreach and consultation process with Black communities, stakeholders, and experts across the country. To inform the strategy for WTP, BAI conducted key informant interviews, held town hall meetings in three southern states, and hosted a community forum at the United States Conference on AIDS (USCA). The Black Treatment Advocates Network (BTAN) was pivotal in linking BAI to community members and experts who could inform the framework. BTAN is BAI's national network of HIV/AIDS stakeholders including service providers, community members and leaders, educators, and PLWH, all of whom mobilize Black communities across the country to confront HIV.

Between February and August 2019, BAI planned and hosted in-person town hall conversations with community members in Houston, TX (n=58); Montgomery, AL (n=22); and Natchez, MS (n=44). Following warm-up introductory conversation, participants were asked open-ended questions to allow free response. Community members provided insight on key action steps and overall strategies to include within a Black plan to end HIV. Field notes were taken during each event and later analyzed by BAI staff and a project consultant to form the initial framework. This initial plan was then piloted for input in September 2019 as "Ending the Epidemic: Our Time for Our Solution" at the USCA and updated accordingly.

In December 2019, 20 key informants joined BAI in Los Angeles for intensive, in-person data collection in the form of a focus group. These key informants included HIV clinicians, community advocates, state and local representatives, PLWH, community organization representatives, members of Black media, human and civil rights organization leaders, as well as criminal justice activists. Similar to the town halls, participants were asked open-ended questions and allowed to respond freely. Field notes were taken and analyzed by BAI staff and a project consultant. For the focus groups, questions also revolved around the plan derived from the town halls and USCA, and the key informants were asked to provide detailed feedback.

The qualitative data from all of the collection events were analyzed for themes, culminating in the clustering of four pillars and supporting components of the final plan. The

framework was promoted nationally in February 2020 and February 2021 to coincide with National Black HIV Awareness Day. During the year between, presentations to the Black community and HIV workforce were conducted. These presentations were carried out through the BTAN and occurred virtually, due to constraints from the Coronavirus Disease 2019 (COVID-19) pandemic.

## Results

The finalized “We the People” framework rests on four pillars of action: 1) Dismantle anti-Black practices, systems, and institutions that endanger the health and wellbeing of Black people and undermine an effective, equitable response to HIV in Black America; 2) Provide resources and services that address the fullness, richness, potential, and expertise of Black people, and mitigate social and structural factors that worsen health outcomes in Black communities; 3) Ensure universal access to, and robust utilization of, high-quality, comprehensive, affordable, and culturally and gender-affirming healthcare to enable Black people to live healthy lives in our full dignity; and 4) Build the capacity and motivation of Black communities to be the change agents for ending HIV. Each pillar includes specific recommendations, interwoven with one another and informed by community members, social justice advocates, and HIV workforce experts.

### *Pillar One: Dismantle Anti-black Practices, Systems, and Institutions that Endanger the Health and Well-being of Black People and Undermine an Effective, Equitable Response to HIV in Black America*

HIV must be addressed as a racial and social justice issue. To dismantle anti-Black entities, local, state, and national anti-racism and social justice coalitions must be established. These situate HIV within a broader context of human rights. Some national movements, such as the creation of the HIV Racial Justice Now coalition, are visible; yet, overall, the efforts remain few, under-resourced, and inadequately mainstreamed across the HIV response.

At the state and local levels, decision-makers must move beyond siloed work, adopting nontraditional and multidimensional strategies for collective impact in dismantling anti-Black institutions, policies, and structural norms. If national, state, and local entities fully embrace HIV as an “upstream” racial and social justice issue, then “downstream” improvement of health outcomes and health equity will be achieved.

BAI tackles national, state, and local engagement and mobilization through the Institute’s flagship BTAN chapters and affiliates, most of which operate in priority EHE jurisdictions. The network currently connects 26 local grassroots chapters and affiliates across 15 states, offering a unique vehicle for assembling broad, multi-sectoral coalitions that center the HIV fight within the broader push for racial and social justice.

### *Mobilize Black Communities, Allies, and Officials to Reform Impeding Laws and Policies*

Removing obstacles to an effective HIV response requires action at the federal, state, and local levels. It is critical to enact laws that recognize the diversity of Blackness and gender identity, as well as prohibit discrimination based on sexual orientation and implement gender-affirming laws, policies, and practices. These laws help create a climate that effectively stifles discrimination against people who identify as Black and/or LGBTQIA+. For urban areas to be more affirming of the LGBTQIA+ community, city ordinances can offer an effective avenue for enacting anti-discrimination and other human rights provisions. However, states can currently act to “preempt” cities’ or counties’ rights to legislate on particular issues, such as anti-discrimination. If this preemption grows in popularity among state legislators, local efforts to pass human rights ordinances will need to cultivate champions and build support among state legislators to reverse these preemption efforts.

Relatedly, states may enact counterproductive laws that criminalize HIV exposure, non-disclosure, and/or transmission in a misguided effort to prevent new HIV infections. This existence of HIV criminalization does not need to be permanent. Instead, states can repeal or reform such laws and commit to grounding their HIV prevention approaches within sound science and evidence-based non-discrimination principles.

Further, on a national level, America’s prison industrial complex and apparent addiction to mass incarceration are commonly understood to be part of a clear and painful legacy of slavery and racism, as the weight of mass incarceration in the United States is known to be largely and disproportionately borne by Black communities (Pettit & Gutierrez, 2018). People living with HIV who undergo incarceration are at great risk of discontinuing critical care, both during that incarceration and upon release (Milloy et al., 2014). Thus, if Black Americans are incarcerated and living with HIV at disproportionately high rates independently, then a logical deduction would be that incarcerated Black PLWH risk continuity of care and negative health outcomes as a result of the disruption caused by a systemically oppressive criminal justice system. A general bipartisan consensus has emerged on the need to reform America’s approach to mass incarceration, whether for moral and/or financial reasons; however, the needed concrete action to dismantle the country’s counterproductive approach to policing and prison has yet to be taken. The United States must eliminate: its costly and ineffective system of mass incarceration, the immunity of law enforcement agents abusive toward Black Americans (e.g., those who are sex workers or misuse substances), and inequitable practices, like cash bail. Simultaneously, concentrated efforts should include improving HIV services for people currently and formerly incarcerated, as well as including care and support for the citizens’ reentry into the community.

### *Advance Accountability Through State and Local Policy Scorecards*

HIV racial and social justice coalitions at the state and local levels should create scorecards to monitor the success of their governments in creating a policy environment that supports an effective HIV response. Not only will these scorecards increase the accountability

of state and local decision-makers, but they will also provide evidence to diverse audiences as to how HIV outcomes are associated with progress on broader racial and social justice issues.

### *Increase Black Voter Turnout to Advance Critical Policies and Systems*

Increased Black voter turnout is vital to elevating the number of elected officials who advance policies and systems critical to Black Americans' wellbeing. The vote should be the most effective means of ushering in the legal and policy reform needed to remove the structural disadvantages that Black communities face. However, when states take steps to curtail Black Americans' ability to exercise their constitutional voting rights, this reform is difficult to realize. States can diminish voting rights by implementing voter identification requirements, restricting opportunities to register to vote, closing voting spaces, or reducing early voting. Further, racial gerrymandering practices can also weaken Black voters' political power. These blatantly unfair and unconstitutional efforts to lessen Black voters have generated an array of initiatives by Black leaders, such as voting rights activist Stacey Abrams and Former United States Attorney General Eric Holder, to fight voter suppression. As evidenced in the way Black people, particularly women, galvanized to support then-candidate Joe Biden in the Democratic primary and presidential elections of 2020, Black communities have the ability to become self-empowered and influence the way they are governed. Further, while working to roll back voter restrictions, these same communities should intensify efforts to register voters and promote consistently robust voter turnout.

### *Ensure Unfettered Access to Comprehensive Sexual and Reproductive Health Services and Education*

It is a person's fundamental human right to make autonomous decisions regarding their own sexual and reproductive health. This right demands that everyone possesses access to medically accurate and person-centered education and counseling, contraception, family planning, and abortion services. Patient-led care is the standard and not the exception. However, a growing number of states have taken steps to undermine the federal guarantee of contraception access in the Affordable Care Act (ACA) and to restrict access to abortion services.

Relatedly, HIV prevention begins as early as childhood sex education. Equipping young people with the skills they need to avoid HIV and to live full and healthy lives if they acquire HIV requires investments in comprehensive, culturally-relevant, and medically-accurate sex education. This education must embrace the myriad of gender identities and the diversity of sexual attraction and expression.

### *Pillar Two: Provide Resources and Services that Address the Fullness, Richness, Potential, and Expertise of Black People and Mitigate Social and Structural Factors that Worsen Health Outcomes in Black Communities*

In the United States, the HIV response has primarily focused on the biomedical advances that can prevent HIV infections, as well as HIV-related illness and death. Given the



multiple social factors that increase Black communities' vulnerability to HIV and affect Black Americans' ability to access and benefit from biomedical services, healthcare for Black people affected by HIV needs to be holistic and personalized in its approach. A person's ability to effectively utilize HIV biomedicine is inevitably influenced by social factors, such as whether they have food security, stable housing, protection from violence, and positive mental health.

### *Ensure Effective Support Services*

Holistic and integrated services can effectively address the lived realities of Black people and meet the needs and expectations of Black communities. Support service professionals must be prepared to provide the culturally-relevant, person-centered services that prevent HIV infection or optimize the wellness of PLWH. Here, cultural relevance includes the integration of trauma-informed practice. Oftentimes, service providers appear to view traumatized clients as "difficult" or "problematic." Instead, it is important to understand the influence that traumatic experiences, whether in childhood or adulthood, have on a person's reception, acceptance, and adherence to support. An individual with a background of trauma may not participate as a partner in HIV service delivery in the way that a provider generally expects; thus, it is critical for the provider to avoid bias and assumptions about how clients participate in their own care. Rather than blame or negatively label clients, service providers and the systems they navigate must prepare appropriate and individualized responses to trauma. Accordingly, resources that integrate peer recovery coaching, peer mentors, community clubhouses, and other person-centered approaches are imperative for the overall health, wellness, and motivation of individuals living with HIV.

Additionally, funding for HIV services needs to include resources for mental health care, to include traditional and nontraditional self-care, positive coping practices, and overall wellness. Positive mental health and wellness are vital to individuals successfully navigating the intersectional layers that accompany preventing, or living with, HIV. Though service providers are pivotal in managing HIV, self-care is equally important for such a chronic condition. Peer-based, community approaches empower, support, and mobilize PLWH; these strategies should be prioritized in the allocation of resources for ending the epidemic.

Similarly, because substance misuse can increase the risk of a person acquiring HIV (Pellowski et al., 2013), as well as reduce the capacity of PLWH to consistently access and engage in HIV care (Kuchinad et al., 2016), an additional layer of mental health support involves integrating harm reduction efforts into all HIV services and promoting evidence-based harm reduction initiatives throughout the Black community. Strategies in the form of needle and syringe exchange services, opioid substitution therapy, and access to behavioral and medical healthcare are all ways to incorporate harm reduction. However, implementing harm reduction strategies is hampered by issues like community stigma and funding restraints, the latter of which can include federal and state prohibitions, as well as siloed funding constraints that separate HIV and substance use treatment services. Overcoming these barriers is essential to addressing the layered health and social needs of people who misuse substances and also are affected by HIV.



Of particular note, certain segments of Black America receive even smaller amounts of elevation and culturally-relevant support services in the field of HIV prevention and treatment. In exemplar, Black cis women are often dismissed, or forgotten altogether, as a population that requires HIV services. Engagement and support are needed to ensure that marginalized communities like these and others within Black America are not overlooked and all have tailored service options.

All in all, achieving comprehensive services demands awareness and action not only at the service provider level but also among governments, as siloed systems and a lack of sufficient and relevant funding are important reasons why these services are so seldom integrated. Social and structural approaches that increase equity in services and empower Black communities are vital to progressing toward the HIV epidemic's end. Few of these socially and structurally-minded services are likely to succeed without the dismantling of America's oppressive systems, to include mass incarceration, education, health care, and housing. Inequitable systems significantly affect service access and utilization for Black families and communities across the country.

### *Promote Prosperity and Economic Development in Black Communities*

Poverty is commonly associated with increases in behaviors that can lead to HIV transmission, but it also reduces the ability of those impacted by HIV to access critical health services (Pellowski et al., 2013). The fight against poverty must coincide with the fight against HIV. New funding investments are needed to accelerate the reduction of HIV incidence and HIV-associated deaths. These investments can increase employment through targeted tax incentives and provide professional development training to build workforce skills. Further, poverty is not a crime, and the United States must eliminate cash bail, incarceration for court-related debts, and police sweeps of homeless populations.

Further, housing insecurity and homelessness make achieving and sustaining viral suppression extremely difficult and, depending on circumstances, even impossible (Aidala et al., 2016). The outcomes from lacking a stable home are interconnected with other social determinants that heavily influence the health of a person living with HIV (Aidala et al., 2016). A federally-led effort to expand housing access and ensure linkage to housing assistance within HIV services is urgently needed, with triaging in the most affected cities and states.

### *Utilize Transformative and Restorative Justice Services to Improve Violence Prevention*

The experience of violence is rooted in structural inequity and is all too common among Black Americans. Validated, evidence-based strategies to prevent violence should be prioritized, accounting for systemic violence, police abuse, gender-based and intimate partner violence, anti-trans violence and community-level violence. Further, as grassroots initiatives like the #MeToo and #SayHerName movements display (Valdivia, 2019), activism has a crucial role in raising public awareness and in preventing violence.

### *Reform Immigration Policies and Practices*

Like millions of Black Americans who constituted the Great Migration from the United States South to the Midwest in the 20th century (Gould, 1991), Black immigrants are frequently targets of “othering” and excluded from basic human services. This pattern of xenophobia has only been intensified with politically-related rhetoric across the country in recent years. Further, proposed changes to immigrant-related policy (e.g., to leverage usage of Medicaid and other assistance programs against citizenship applicants) risk increasing healthcare disparities.

America, the “melting pot” nation of immigrants, must reimagine its immigration policies and resources, and any proposed legislation to discriminate against citizenship applications, based on the applicant’s country of origin or usage of human services should be rejected. Instead, culturally and linguistically relevant services should be available to meet the diversity of America’s immigrants, and dehumanizing detention and deportation processes (including family separation) should be clearly prohibited. These inclusive efforts, should they be implemented, would help meet the needs of the African diaspora and American immigrants, overall.

### *Pillar Three: Ensure Universal Access to, and Robust Utilization of, High-quality, Comprehensive, Affordable, and Culturally and Gender-Affirming Healthcare to Enable Black People to Live Healthy Lives in Our Full Dignity*

Even though advances in biomedicine have provided a real possibility to end the epidemic, we can only realize the full potential of these developments if everyone who needs them is able to use them. Putting these powerful medical tools to use involves two critical steps. First, to have people benefit from this biomedicine means that they must also have unhindered access to affordable healthcare services. Second, alongside access, people who need these biomedical tools require the knowledge and personalized care to effectively and consistently utilize the healthcare services that will deliver the tools.

### *Ensure a Healthcare System Equipped for High-quality Services Among All Black Americans*

Access to high quality, affordable healthcare is a basic human right. This right is one that the United States consistently denies to millions of its people. The United States needs to build upon the Affordable Care Act to achieve universal health coverage, already realized in other major industrialized countries (Vladeck, 2003). There are multiple pathways to achieve this universal coverage; however, one commonality is that, without it, marginalized populations do not have the resources needed to live fully well lives.

However, until the vision for universal health coverage is realized in the United States, all states must expand Medicaid coverage. This ACA-allowed effort fills a gap that, otherwise,

leaves millions of vulnerable people without access to affordable health services (Obama, 2016). Any state that has yet to expand Medicaid must enact steps to do so immediately, and that state's political atmosphere should hold no bearing over the outcome of this expansion.

In addition to expanding health coverage, further policy steps are essential in enhancing the affordability and accessibility of healthcare products. The costs associated with purchasing medication and other pharmaceutical products can only be driven down with policy reform. The more cost-effective it is to purchase pre-exposure prophylaxis (PrEP), for example, the more likely it will be for a person to utilize it (Koechlin et al., 2017). The more a person is likely to utilize PrEP, the lesser instances of HIV transmission are likely to occur. Further, reducing the costs of HIV-related health products is not the only necessity. Instead, it is vital to lower prices for all medical products, as any costly medication can negatively impact individual budgets and influence a person's ability and likelihood of engaging in consistent HIV prevention and treatment.

Further, all stakeholders and interested parties should hold local and state governments accountable for a health system that perpetuates high HIV rates. One such area of advocacy includes encouraging the federal government to require, as a condition for receiving EHE funding, that each EHE jurisdiction conducts regular surveillance of key demographics and HIV-related health outcomes (e.g., new HIV diagnoses, AIDS-related deaths, HIV viral suppression, etc.). Jurisdictions that show racial/ethnic disparities in HIV outcomes should be required to establish a corrective action plan to address these gaps, in order to maintain eligibility for further EHE funding. The federal government should provide capacity-building support and incentivize providers to utilize collected data in improving their service delivery processes' performance and equity.

Lastly, rural counties, particularly in the South where Black America's HIV epidemic is heavily concentrated (Reif et al., 2017), must address hospital closures and any shortage of primary care services, in order to reduce mortality. Strategies to address these closures and shortages can include increased usage of telemedicine and the creation of smaller health centers to deliver health services in areas where hospitals are no longer viable.

### ***Overcome Healthcare Utilization Barriers with Support for Black Experts, Efficient Clinical Environments, and Health Education***

As a society, we must identify, understand, and address the factors that affect people's utilization of healthcare services. In many Black communities, for example, routine use of health services, especially for preventive care, is typically uncommon; this underscores the importance of developing new community norms for seeking care. New and significant investments in implementation science, led by Black researchers, must be made to identify strategies to increase HIV-related access and utilization of services, as well as improve health outcomes in Black communities. Black researchers have lived experience and an unmatched motivation to help increase knowledge in addressing the health needs of Black communities. Accordingly, these scientists are often best equipped to build strong relationships with Black community

organizations, leading to research that not only informs the community but is also informed by the community. Specific, scientific efforts by Black researchers are vital in examining and addressing Black community perceptions about HIV services and biomedical technologies.

In addition to increasing the amount of Black researcher-led science, academic institutions should be incentivized to increase the number of Black enrollees and recipients of clinical degrees (e.g., MDs, RNs, NPs). Steps should also be taken to support Black students seeking education, training, and certification as healthcare professionals; such steps could include student loan relief and personalized outreach initiatives. Oftentimes, Black people encounter the healthcare system and do not see providers who look like them or fully understand their cultural background. Sharing a cultural identity with one's provider is important for many Black Americans to help alleviate stressors related to medical mistrust and a long history of racism and abuse in medical and public health practice (Wells & Gowda, 2020). Medical mistrust negatively impacts Black Americans' ability to seek necessary health care and can lead to further health deterioration, poor prognosis, and missed opportunities for intervention (Wells & Gowda, 2020). Drawn from the communities they serve, an increase in community health workers and other clinical professionals can help a health center overcome the effects of the long-standing medical mistrust in many Black communities.

Additionally, clinical environments that function inefficiently can discourage individuals from seeking the services they need. Thus, it is important to standardize clinic operations that create affirming spaces for Black clients. For example, Black patients who experience significantly longer waiting times for health services than White patients will likely not continue engaging in care at that location, if at all. Focused capacity-building assistance should be provided to help clinics function with more efficiency and compassion. Accordingly, healthcare professionals should be encouraged and/or required to use each client-provider interaction to provide in-depth support, such as inquiring about treatment adherence and associated barriers whenever a prescription is filled. All HIV service providers should have the knowledge and ability to deliver culturally humble and appropriate services to individuals of all racial and ethnic backgrounds. Legislation should mandate regular implicit bias and anti-racism trainings for healthcare professionals in health departments and clinical settings.

Further, if Black people do not possess strong scientific literacy, they may be less likely to assess their risk for HIV acquisition, learn their HIV status, adhere to prescribed treatment regimens, and remain engaged in care (Swenson et al., 2010). Thus, HIV science and treatment literacy must be increased in Black communities, through leveraging advertisement campaigns, social media, and the integration of HIV-related narratives in entertainment and other media platforms. This literacy support is necessary to build the capacity of Black consumers, so that they can serve as competent decision-making partners in their own health care. Community education programs are needed to raise awareness of PrEP and to address persistent misconceptions about the intervention. Healthcare providers must be educated and encouraged to discuss PrEP with their patients in a culturally-relevant manner. To help overcome PrEP-related stigma, delivery channels outside of LGBTQIA+ and HIV-branded sites should be developed.

Relatedly, clinical trials and other work are well underway to develop a preventive vaccine and, ultimately, a cure for HIV. It is plausible that upcoming long-acting antiretrovirals could expand treatment and prevention options and potentially improve treatment adherence rates. However, work is needed now to prepare and educate communities and healthcare systems about any new approach and address concerns, in order to facilitate rapid uptake and positive outcomes for those who desire the treatment. In exemplar, to engage Black communities in prevention and vaccine research and to help prepare them for future prevention breakthroughs, BAI holds a formalized collaboration with the HIV Vaccine Trials Network (HVTN) to develop educational materials and trainings on HIV vaccine and prevention research in areas where HVTN clinical trials are being conducted.

### *Pillar Four: Build the Capacity and Motivation of Black Communities to be the Change Agents for Ending HIV*

Since its founding, BAI's motto has been, "Our People, Our Problem, Our Solution." The Institute recognizes the central role that communities play in addressing complicated health challenges within themselves. If we hope to end the HIV epidemic, a crisis greatly present in Black communities, then Black Americans will need to lead the efforts. This empowerment and leadership demand substantial ownership of the HIV/AIDS fight in Black communities, as well as significant, new resources to support related community-centered efforts.

### *Generate Broad, Enthusiastic Ownership in Black Communities of the Fight to End HIV*

Among its achievements, BAI takes great pride in its work supporting Black organizations and institutions in the development and implementation of community-driven, strategic HIV plans. However, this community leadership has never shown proportionality with the severity of the HIV crisis in Black America; not enough Black organizations and institutions have taken up the mantle to fight HIV. In fact, the concept of prioritizing HIV and its impact on Black Americans is seemingly discussed less each year in newspapers, magazines, the internet, the church pulpit, or among Black celebrities and opinion leaders. To end the HIV epidemic in Black America, we must re-energize our HIV champions and develop relationships with new partners in Black communities. Each aspect of Black America must take part in fighting HIV; this includes elected offices, faith-based organizations, historically Black colleges and universities, civic and fraternal organizations, Black media, Black celebrities, and everyday people who are concerned and desire to make positive change. To renew this HIV coalition, consistent engagement of these influential segments must occur, and HIV must be properly categorized as the racial and social justice issue it is.

With the great influx of social media, we now have new avenues to engage and mobilize Black Americans in an exciting manner. Black people are leveraging social media in activist efforts across the country, and now is the time to make HIV an activism issue once again, but in this new era centered on advocating for the complete wellbeing of Black people. As we work to refocus the attention of Black America on the HIV fight, we should also take steps

to normalize HIV as a health condition like many others, as well as reduce related stigma and concentrate attention on HIV testing and accessing prevention and treatment services. Further, within Black families and communities, we need to engage in intergenerational conversations that move toward a real culture change and openly address the fullness, wholeness, and diversity of Black Americans. Across all of our efforts to reignite Black communities' drive to eliminate the HIV epidemic, we must promote the voices and stories of Black PLWH, to include young leaders, people who identify as LGBTQIA+, sex workers, and people who were formerly incarcerated.

### *Allocate Sufficient Financial Resources for Black Communities to Lead Efforts to End HIV*

An influx of new EHE funding, particularly from the Biden Administration, while welcome, should be understood only as a “down payment” on the planning and implementation resources that will be needed to end HIV. To truly end HIV and tackle the aforementioned systemic and structural issues, a substantial amount of additional funding is required, particularly in EHE jurisdictions where a comparatively limited tax base exists. EHE financial resources need to be directed toward communities of color, particularly as EHE funding borrows heavily from the Minority AIDS Initiative (<https://www.hiv.gov/federal-response/smaif/overview>).

Specifically, because of the HIV disproportionality in Black communities, by 2025, at least 60% of EHE funding should be earmarked for Black-led organizations. That is, these organizations are where Black Americans comprise the highest levels of primarily leadership (e.g., chief executive officer and executive director) and overall governance (e.g., board of directors, senior leadership team). In these next four years, the federal government should move toward this 60% earmark by using the funding for the large, Black-serving (but not Black-led) organizations to intimately collaborate with Black-led organizations in building necessary and sustainable infrastructure (e.g., processes and networks for grant-writing, donor engagement, human resources, finance management, administration, etc.). These intimate collaborations would serve as a “bridge,” with funding gradually and fully shifting to the Black-led organizations between years 1 and 4. These infrastructure-building contracts should be performance-based and should include clear milestones toward the empowerment and self-sufficiency of Black-led organizations to lead efforts to end the HIV epidemic. Further, as the federal government's EHE plan envisions a key role for federally qualified health centers (FQHCs) in reaching the most vulnerable populations, FQHCs must be expanded and diversified to include more smaller, Black-led organizations.

Focused investments across the public and private sector and toward Black leadership development are required to appropriately address the breadth of the needed HIV response. For example, in reimagining funding for Black-led organizations and initiatives in the HIV response, foundations and pharmaceutical/biotech companies should prioritize new funds, with the pharmaceutical and biotech companies earmarking a percentage of their profits for unrestricted granting in these efforts. These investments should ensure that Black-led and Black-serving organizations are prepared to optimize their performance to improve their communities' HIV

and broader health outcomes. While energy and commitment within grassroots efforts will remain vital to the Black response to HIV, it is essential to move beyond unpaid volunteerism and low paid work as the primary sources, or the backbone, of much of the response. Alternatively, strong fiscal pathways are essential to building the sustainable community infrastructure that is needed.

All told, elected officials and community leaders must engage Black community members and each other in EHE planning and implementation. Further, all agencies and organizations that receive federal EHE funding must have clear and significant processes in place to receive culturally-based feedback from Black communities; the processes could be in the form of recurrent community town halls and evaluations. These agencies and organizations must also utilize the information obtained through these community processes to inform and guide service delivery.

## Discussion

The approach detailed here, while ambitious, is derived from a background of scientific evidence, as well as over 40 years of experience among BAI's staff, expert affiliates, and community partners working in the fight against the HIV/AIDS epidemic. For more than 20 of those years, BAI itself has served as the only national Black HIV "think and do" tank and supports the findings presented. To some, the idea of implementing this framework and encountering inevitable challenges or setbacks may be daunting. In fact, the HIV crisis is a complex and multifaceted problem; there will be no simple solution. On the contrary, the real solutions are layered and intricately intertwined with one another. Thus, if Americans desire to eradicate the HIV/AIDS epidemic, we must address the structural and social challenges that increase vulnerability to HIV, as well as hinder people's ability to access and benefit from valuable and effective biomedical tools. The "We the People" framework reflects this complexity, where several pillar components are interrelated and less distinct from pillar to pillar; addressing them would heavily advance the major solutions that the four pillars identify. Ultimately, because this crisis is so complex and disproportionately prevalent in Black communities, efforts must be driven by the lived experience and energetic leadership of Black Americans, with support from all levels of government and industry expertise.

### *Implementing the We the People Vision and Framework*

"We the People" is a plan beyond the capacity of any single organization or agency. Black leaders, organizations, grassroots activists, and diverse stakeholders can use this set of strategies to restructure their fight against HIV and to prioritize their contributions toward ending the epidemic. The Black AIDS institute has committed to reorienting all of its work toward implementing this framework, as well as monitoring and regularly reporting on progress.

Over the past year, BAI has worked with its BTAN and other partners across the country to host WTP-related community town halls and meetings to develop jurisdiction-specific recommendations to end the HIV epidemic within these communities. BAI has



also leveraged the WTP framework in working to support focused efforts to move key suggestions from local communities forward, culminating in the creation of implementation recommendations for the federal, state, and local levels.

### *Governmental Implementation of the “We the People” Framework*

Recommended priorities at the national level center on expanding access to, and financial support for, HIV prevention and treatment modalities. Access to PrEP and other prevention methods must be increased, and information campaigns should be run to educate the public. Specifically, PrEP services should be prioritized for segments of the Black American population not often elevated, including Black cisgender women (Sophus & Mitchell, 2020). Support for treatment modalities can include the monthly injectable regimen recently approved by the Food and Drug Administration (U.S. Food and Drug Administration, 2021). Further, the federal government must prioritize the Undetectable=Untransmittable (U=U) “treatment as prevention” ideology as the target for all HIV-related programs that serve Black Americans.

Additionally, the federal government must acknowledge the impact that generations of racism and anti-Black policies have had on medical mistrust and health disparities. Because racism is, in fact, a public health emergency (Centers for Disease Control and Prevention, 2021), the federal government must reevaluate priority public health and HIV programs to include the race-related experiences of Black Americans. Stigmas against Black and LGBTQIA+ people, as well as against HIV, must be introduced as national behavioral indicators and measured across HIV programs. Further, funding for Black-centric HIV programming and outreach must be prioritized, and the federal government must actively work to ensure a representative percentage of Black Americans are included in clinical trials for HIV, sexually transmitted infections (STIs), and COVID-19.

Both federal and state governments must prioritize issues that are currently, and unnecessarily, stigmatized and politicized. Voting access, particularly across southern states where many Black Americans live and are heavily affected by HIV, must be expanded and uncomplicated. Additionally, comprehensive sexual health education, including LGBTQIA+ awareness and stigma reduction, should be guaranteed to all young people. Further, federal and state governments need to ensure that people living in states without expanded Medicaid eligibility are able to access necessary care, and new funding should be provided to support and incentivize states that expand Medicaid eligibility.

Across all levels of government, Black Americans should comprise the majority of HIV decision-making leadership, with the remaining leaders being installed following input from Black Americans. Additionally, Black health experts and clinical researchers at all career development stages must be elevated and provided growth opportunities in leadership spaces, as well as spheres of program management and budgetary control. Federal, state, and local governments should partner with Black-led training and capacity building programs to increase the culturally-relevant knowledge of the HIV workforce. These governments should also invest in marketing and community-led programming that centers Black queer, non-binary, and



PLWH-relevant resources and experiences; they should also prioritize county/neighborhood partnership-building upon Black-centric initiatives that are led by individuals who represent the local community. Finally, federal, state, and local governments should increase policy reform and investments in affordable housing to expand access for everyone, particularly PLWH and homeless LBGTWIA+ youth.

### *Limitations and Considerations*

As with many other efforts to assess and act upon structural and social determinants of health, this research is subject to several limitations. While participants from diverse disciplines, lived experiences, and backgrounds provided feedback in all of the community and expert forums, selection bias could be present. Black Americans are not monolithic, and the participants who gave feedback may not entirely represent the views, knowledge, or even the geographic scope of every Black person in the HIV workforce or living with HIV; methods could have been bolstered with additional town hall meetings across more states. Additionally, the techniques used to collect the data were qualitative in nature and did not use standardized surveys; this could have contributed to a limited ability to conduct a thorough data analysis, and future research may warrant either a quantitative approach or a more formalized qualitative approach. Further, data for this research was collected during a transition period for BAI, whereby the new leadership was becoming established and navigating new organizational processes; thus, time constraints in balancing this research with a new organizational structure could have played some role.

Large-scale change, such as that proposed in WTP, occurs in multiple domains, and no one individual or organizational entity can accomplish everything alone. This framework calls for collaboration across public and private sectors, and this process could be slowed if one party from a collaborating group is not yet fully in agreement with all pillars and pathways. Because the outlined strategies address large, systemic issues, they are broad with the potential for challenges and setbacks caused by a variety of confounding factors. Clear indicators will certainly help assess progress made regarding any pillar and systemic oppression, overall.

### *Next Steps*

Despite any limitations, “We the People” has the opportunity to positively influence advocacy and comprehensive policy to eradicate the HIV epidemic. This framework leverages community input to identify key areas where local, state, federal, and private entities can focus monetary and human resources. From this information, robust and culturally-relevant programming and policy recommendations have been derived, and it is recommended that entities enhance and reimagine HIV prevention, treatment, and eradication. Future research could benefit from additional studies addressing the tangible impact of implementing this framework across localities, states, and the nation. To that end, a better understanding of the impact from the WTP implementation could soon be apparent, as BAI is actively designing indicators of progress and developing action steps for specific national, state, and local entities,

to include federal agencies, HIV-specific organizations, community groups, and those supporting the HIV workforce. From these indicators and entity-specific steps, BAI will be able to provide technical assistance to create reasonable timelines and support the actualization of WTP.

### Conclusion

Research consistently demonstrates that addressing systems-level underlying causes is the key to ending HIV (Jeffries & Henny, 2019). “We the People” is a strategy for America, as viewed through an unapologetically Black lens. The Black AIDS Institute works to stimulate investment and engagement across the breadth of government, private entities, and Black America. Thus, BAI uses the WTP framework with its 26 BTAN chapters and affiliates for action at the local and state levels. In addition to outlining action steps to end the HIV epidemic, this article also includes intersectional ways to elevate people already responding to HIV in their communities. This reflects the very core of “We the People.” If Black communities are empowered and resourced, it will be possible to end this epidemic. There is extraordinary potential in Black communities across the nation, which must be free to lead the way toward ultimate victory in our long struggle against HIV/AIDS.

“We the People” is significantly more than a theory; it is the community-informed strategy we can all use to make meaningful progress toward ending the HIV/AIDS epidemic in Black America, and the country, overall. Those within the HIV workforce and those with the desire to make sustainable change must own this fight and break the historically ineffective patterns of our national HIV response, where Black Americans have been left behind at each step. If we hope to finally end this epidemic, Black communities must be positioned at the forefront of the fight with resources and a plan for action. “We the People” provides the blueprint.

## References

- Aidala, A. A., Wilson, M. G., Shubert, V., Gogolishvili, D., Globberman, J., Rueda, S., ... & Rourke, S. B. (2016). Housing status, medical care, and health outcomes among people living with HIV/AIDS: A systematic review. *American Journal of Public Health, 106*(1), e1-e23.
- Cahill, S., & Valadéz, R. (2013). Growing older with HIV/AIDS: New public health challenges. *American Journal of Public Health, 103*(3), e7-e15. <https://doi.org/10.2105/AJPH.2012.301161>
- Centers for Disease Control and Prevention. (2017, February 2). *CDC Fact Sheet: HIV Among African Americans*. <https://www.cdc.gov/nchhsp/newsroom/docs/factsheets/cdc-hiv-aa-508.pdf>
- Centers for Disease Control and Prevention. (2020, May). *HIV Surveillance Report, 2018 (Updated)*, Vol. 31. <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>
- Centers for Disease Control and Prevention. (2021, February 22). *HIV Treatment as Prevention*. <https://www.cdc.gov/hiv/risk/art/index.html>
- Centers for Disease Control and Prevention. (2021, April 8). *Media Statement from CDC Director Rochelle P. Walensky, MD, MPH, on Racism and Health*. <https://www.cdc.gov/media/releases/2021/s0408-racism-health.html>
- Fauci, A. S., Redfield, R. R., Sigounas, G., Weahkee, M. D., & Giroir, B. P. (2019). Ending the HIV epidemic: A plan for the United States. *JAMA, 321*(9), 844-845.
- Gould, L. L. (1991). *The Great Migration in historical perspective: New dimensions of race, class, and gender* (Vol. 669). Indiana University Press.
- Jeffries, W. L., & Henny, K. D. (2019). From epidemiology to action: The case for addressing social determinants of health to end HIV in the southern United States. *AIDS and Behavior, 23*(3), 340-346.
- Koechlin, F. M., Fonner, V. A., Dalglish, S. L., O'Reilly, K. R., Baggaley, R., Grant, R. M., ... & Kennedy, C. E. (2017). Values and preferences on the use of oral pre-exposure prophylaxis (PrEP) for HIV prevention among multiple populations: A systematic review of the literature. *AIDS and Behavior, 21*(5), 1325-1335.
- Kuchinad, K. E., Hutton, H. E., Monroe, A. K., Anderson, G., Moore, R. D., & Chander, G. (2016). A qualitative study of barriers to and facilitators of optimal engagement in care among PLWH and substance use/misuse. *BMC research notes, 9*(1), 1-11.

- Milloy, M. J., Montaner, J. S., & Wood, E. (2014). Incarceration of people living with HIV/AIDS: Implications for treatment-as-prevention. *Current HIV/AIDS Reports*, 11(3), 308-316.
- Obama, B. (2016). United States health care reform: progress to date and next steps. *JAMA*, 316(5), 525-532.
- Pellowski, J. A., Kalichman, S. C., Matthews, K. A., & Adler, N. (2013). A pandemic of the poor: Social disadvantage and the US HIV epidemic. *American Psychologist*, 68(4), 197.
- Pettit, B., & Gutierrez, C. (2018). Mass incarceration and racial inequality. *American Journal of Economics and Sociology*, 77(3-4), 1153-1182.
- Reif, S., Safley, D., McAllaster, C., Wilson, E., & Whetten, K. (2017). State of HIV in the US Deep South. *Journal of Community Health*, 42(5), 844-853.
- Sophus, A. I., & Mitchell, J. W. (2020). Reducing HIV risk behaviors among Black women living with and without HIV/AIDS in the US: A systematic review. *AIDS and Behavior*, 1-16.
- Swenson, R. R., Rizzo, C. J., Brown, L. K., Venable, P. A., Carey, M. P., Valois, R. F., DiClemente, R. J., & Romer, D. (2010). HIV knowledge and its contribution to sexual health behaviors of low-income African American adolescents. *Journal of the National Medical Association*, 102(12), 1173-1182. [https://doi.org/10.1016/s0027-9684\(15\)30772-0](https://doi.org/10.1016/s0027-9684(15)30772-0)
- U.S. Food and Drug Administration. (2021, January 21). *FDA Approves First Extended-Release, Injectable Drug Regimen for Adults Living with HIV*. <https://www.fda.gov/news-events/press-announcements/fda-approves-first-extended-release-injectable-drug-regimen-adults-living-hiv>
- Valdivia, A. N. (2019). # IntersectionalActivism: Tales of origin and intersectional negotiations. *Interactions: Studies in Communication & Culture*, 10(3).
- Vladeck, B. (2003). Universal health insurance in the United States: Reflections on the past, the present, and the future.
- Wells, L., & Gowda, A. (2020). A legacy of mistrust: African Americans and the US healthcare system. *Proceedings of UCLA Health*, 24.
- White House Office of National AIDS Policy. (2015, July). *National HIV/AIDS Strategy for the United States: Updated to 2020*. [https://obamawhitehouse.archives.gov/sites/default/files/docs/national\\_hiv\\_aids\\_strategy\\_update\\_2020.pdf](https://obamawhitehouse.archives.gov/sites/default/files/docs/national_hiv_aids_strategy_update_2020.pdf)

# Health Care Reform: Exploring Health-Related Quality of Life of HIV/AIDS Patients in Baltimore Post Implementation of the Affordable Care Act

**Francesca Weeks, DrPH, MS, MCHES**

The Genevieve Strategy Group  
thegenestrategygroup@gmail.com

## Background

There is an ongoing political debate in the United States regarding whether access to health care is a financial necessity or a luxury (Getzen, 2000). The United States government has been attempting to create a more efficient and uniform health care system for over five decades. Although there has been some movement towards an improved healthcare system over the years, in general, the U.S. healthcare system is woeful when compared to the systems of other industrialized countries.

Through the current implementation of health care reform, the Affordable Care Act (ACA) – contains policies mandating that healthcare coverage must be available and accessible for every citizen, including those with pre-existing conditions. Whether or not the ACA delivers the improved access to healthcare that its policies promise is a question of great concern to health policy administrators, particularly regarding at-risk populations

There is a need for exploration studies that examine existing healthcare laws that have been implemented and the impact of the laws on chronic disease populations. Qualitative studies provide narrative perspectives that detail the barriers to access, knowledge of health insurance, and quality of life for those with chronic diseases, such as HIV/AIDS patients. The aim of this study was to understand better health outcomes for HIV/AIDS that result from legislation that permits patients to improve their healthcare outcomes. The existing literature provides little research that examines the HRQOL through the lens of health reform for HIV/AIDS patients.

The Ryan White HIV/AIDS Program (RWHAP) is a special program that provides services to low-income individuals living with HIV who have no health care coverage (public or private), insufficient health care coverage, or lack of financial resources to get the care and treatment they need. In 2015, of the 531,816 RWHAP clients who reported gender, 71.3% were male, 27.6% were female, and 1.1% were transgender. It was reported that nearly eighty percent of RWHAP clients had some form of health care coverage during the same year. Among all RWHAP clients in 2015, 32.7% were covered by Medicaid, Medicare-covered 10.4%, and another 36.2% had another or multiple sources of coverage. One-fifth (20.7%) of RWHAP clients had no health care coverage in 2015. According to the ACA, all individuals must obtain a primary health insurance source or be subject to a fine and be ineligible to apply for other health subsidy programs (HRSA, 2013). The purpose of this study is to understand the relationship between access and utilization of health insurance under the ACA for HIV/AIDS patients and their health-related quality of life (HRQOL).

This exploratory study investigated the efficacy of the ACA by examining its effect (or lack thereof) on members of a community with a pre-existing condition. Specifically, this study focused on individuals who had contracted the Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) previous to implementing the ACA. This group was selected because chronic disease patients, such as those with HIV/AIDS, were projected to be a health impaired group that would be highly impacted by the passing and implementation of the ACA.

### Research Question(s)

1. What have been the HRQOL experiences for Ryan White participants who enrolled in ACA's access to health care provision (Medicaid expansion or Exchange) in Baltimore City?
2. What have been the HRQOL experiences for Ryan White Participants compared to their counterparts in other Ryan White Programs?

### Literature Review

Wilson and Cleary (1995) describe a theoretical model (Figure 4) of HRQOL consisting of five different levels: biological, symptom status; functional health; general health perceptions; and overall quality of life (QoL). Studies of cancer, arthritis, Parkinson's disease, HIV, and other chronic diseases have applied this model to describe non-clinical factors that determine health outcomes. The model is based on a linear domino process of biological variables - symptom status - functional health - general health perceptions - overall QoL.

The intentions of this study were to review articles on HRQOL that explore non-clinical outcomes for HIV/AIDS patients that have examined their lifestyle and social components of quality of life while living with HIV. The most recent published studies on HRQOL and those living with HIV have examined their clinical outcomes related to other biological and social HRQOL measures. Between 2005- 2018, a few of these notable studies include a research investigation by McManus et al. (2016). In 2013-2014, they compared viral load suppression in relationship with access to the Aids Drug Assistance program, reviewing the Affordable Care Act's added benefits. In their comparison between Medicaid expansion and non-expansion states under the ACA provisions, they reviewed the new insurance access opportunities' contributions to the increased rates of viral suppression (McManus et al., 2016).

Physical factors include energy and fatigue, pain and discomfort, sleep and rest, mobility, daily living activities, and dependence on medicinal substances and medical aids. HIV is no longer a death sentence or even an early terminal disease (i.e., death before standard life expectancy) with ART therapy. Rather, HIV has become a manageable chronic disease for which we have developed survival techniques and measurements. ART therapy has succeeded in protecting patients from and decreasing the risks of infections, improving survival, and maintaining patients' QoL (Marins, 2003).

Psychological factors include body image and appearance, negative feelings, positive feelings, self-esteem, memory, concentration, the ability to learn and think clearly. Coping, *A Psychology that Works* is a book by C.R. Snyder (1999) that discusses day-to-day mechanisms for coping with life's pressures. In this book, Snyder defines "coping" as a fundamental psychological process that allows individuals to build on their strengths. For HIV/AIDS patients, this can be an uphill battle of fighting the multiple issues associated with having HIV/AIDS. Many patients attempt to cope by avoidance and disengagement, which often increases their health-related stress (Schmitz, 2000).

Social factors include personal relationships, social support, and sexual activity. Social interactions for HIV/AIDS patients are often limited due to stigma and ignorance about how the disease is transmitted. This distancing is associated with HIV/AIDS patients exhibiting poor social functioning through withdrawal and avoidance. Isolation from their communities often increases stress and depression (Fleishman, 2000). In two studies conducted on HIV/AIDS-infected women in southern states, spirituality was a quality-of-life variable that reflected social support. The role of social support for HIV/AIDS patients was critical in coping with the HIV cascade and continuum of care process (Sowell, 1998).

Environmental factors include financial resources (income), freedom, physical safety and security, health and social care; accessibility and quality; home environment; opportunities for acquiring new information and skills; participation in and opportunities for recreation/leisure; physical environment (pollution/noise/traffic/climate) and transportation.

## Methods

This study used a phenomenological research design to measure and explore the relationship between access and using the healthcare system for Ryan White HIV/AIDS (RWHAP) patients post ACA implementation and their health-related quality of life status. The data for this study was provided by using the established grant-funded Ryan White HIV/AIDS Programs at the Baltimore City Health Department (BCHD). The Ryan White Service Report (RSR) is HRSA's reporting system that requires client-level data reports that include dates of services and visits on all clients served by RWHAP funds. The Baltimore City RWHAP has a Clinical Quality Improvement Program (CQIP) that addresses improving the clinical quality for HIV/AIDS patients enrolled in the program. Sub-grantees of the Baltimore City Health Department RWHAP were emailed an inquiry by the Principal Investigator to participate in the study voluntarily. For each site, accommodations were attempted to be made based on their Ryan White clients' existing meetings, transportation, schedule, and time frame of the study. The sub-grantee sites that agreed to participate were Total Healthcare, Chase Brexton, Sisters Together and Reaching. Purposive sampling was conducted for this study and directed through the critical case sampling model. A purposive sample is a non-probability sample that is selected based on the characteristics of a population and the objective of the study.

The participants in this study were HIV/AIDS patients enrolled in the BCHD RWHAP for at least six months. To be considered eligible for this study, participants had to

live within one of the 22 zip codes of Baltimore City. Eligible participants also had to be at least 18 years of age, with no hearing, speaking, or cognitive difficulties, and could hear, speak, and comprehend English. Participants were available in summer 2019 for two (2) hour focus groups or one-hour one-on-one interviews. Using the above parameters, participants were randomly selected by their case managers and Ryan White coordinators to participate in focus groups and/or one on one interviews. The desired sample size for the focus groups included five to seven individuals and six (6) individuals for the interviews.

Topic areas for focus groups were: Physical Factors, Psychological Factors. Physical Factors included energy and fatigue, pain and discomfort, sleep and rest, mobility, daily living activities, and dependence on medicinal substances and medical aids.

Psychological Factors include body image and appearance, negative feelings, positive feelings, self-esteem, memory, concentration, and the ability to learn and think clearly. Social Factors included personal relationships, social support, and sexual activity. Social interactions for HIV/AIDS patients are often limited due to stigma and ignorance about how the disease is transmitted.

Environmental factors included financial resources (income), freedom, physical safety and security, health and social care: accessibility and quality, home environment, opportunities for acquiring new information and skills, participation in and opportunities for recreation/leisure, physical environment (pollution/noise/traffic/climate), and transportation are all environmental factors equated into measuring health-related quality of life.

The data was collected at four out of the eighteen (18) RWHAP sub-grantee centers in Baltimore City. The collection took place from June 2019-August 2019. Three focus groups were recruited, with one additional focus group scheduled as make-up to ensure desired participation numbers were met. The focus groups were composed of participants who meet eligibility criteria. A make-up focus group was scheduled of individuals from all sub-grantee locations but did not occur. Confidentiality was addressed by conducting the focus groups and interviews as Healthy Love Parties. Individuals were allowed to use an alter ego name for the session, and their demographics (gender, age, geographic location) were not reviewed and connected to them.

## Results

Primary qualitative data was collected to explore the lived experiences of RWHAP health-related quality of life since the Affordable Care Act implementation. Given that limited studies exist around the topic, this phenomenological approach was selected to add additional insight into the factors that influence HIV/AIDS patients' health behaviors in the Ryan White Program. The research included twenty-three (N=23) participants total from three different locations. The locations were: Sister Together and Reaching, Inc. (STAR) (Southeast Baltimore), Chase Brexton Health Care (Southwest Baltimore), New Vision House of Hope (NVHOH) (East Baltimore), from three focus groups and one set of six, one on one



interviews (8= STAR/ 5= Chase Brexton/ 6 = New Vision House/4=STAR). A summary of the relevant findings from data generated at these focus groups in Baltimore City follows.

*Table 1. Data Collection Summary*

Data Collection Location	Data Collection Method	Section of Baltimore	Group Type	Age Range	Number of Participants
Group 1: Sister Together and Reaching, Inc.	Focus Group	Southeast	Homogeneous Females	51-68	8
Group 2: Chase Brexton Heath Care	Focus Groups	West Baltimore	Heterogeneous Males & Females	36-56	5
Group 3: Sister Together and Reaching, Inc.	Focus Groups	Southeast	Homogeneous Males	58-65	4
Group 4: New Vision House of Hope	Interviews	Southwest Baltimore	Heterogeneous Males & Females	28-53	6

### *Theme 1: Knowledge of HealthCare Reform*

As noted in Table 3, participants' knowledge of health care reform was informed by their definition of health care reform, sources of knowledge, added benefits, the significance of health care reform, and knowledge of health care reform agencies. Their definitions of health reform participants did not know that the Affordable Care Act, Obamacare, and Patient Protection Act (PPA), were the same policy. Most commonly, they had heard of Obamacare and how it was associated with everyone being eligible for health insurance. One participant stated that "ACA allows people to get insurance through an exchange and they cannot be discriminated against based on preexisting illnesses."

Another key subtheme that emerged from participant discussions was the source(s) of knowledge gained. In the second focus group session, a participant replied that a Chase Brexton employee was his healthcare reform information source. When asked about what has changed in health care or what health care reform was, many participants did not understand what health reform entailed. However, a few connected the conversation with Obamacare and health insurance coverage. Most participants admitted that they did not know much about exchanges, PPA, and Medicaid other than receiving Medical Assistance. Among study participants, there was a common misunderstanding between Medical Assistance and Medicaid, not fully understanding that the immediate Medical Assistance for HIV/AIDS patients is Medicaid. Across groups, the media outlet news and the Maryland Health Exchange commercials were the

most common source of where they had heard information about healthcare reform, followed by their Ryan White providers and primary care provider centers.

Another key subtheme contributing to participants' knowledge of Health Care reforms was the benefits and significance. The majority of study participants felt they benefited most from access to different HIV/AIDS medication options since Medical Assistance has increased the approval for payment under the healthcare reform. Participants noted that they received a better quality of medications over the past decade and paid less for their medications. One group indicated that having the option to get better medications resulting in taking less medication was an important benefit from health care reform. For HIV patients, healthcare reform was most significant because of healthcare services and health insurance eligibility changes. Participants indicated this change meant HIV clients did not have to pay as much for medications and services and reduced the burden from finances removing emotional constraints.

The participants were asked for specific locations where they obtained the information, they knew about health care reform. A participant knowing where to obtain information on the health care reform contributed to the participant's overall knowledge of health care reform. Many participants acknowledged similar key agencies that they would go to for more information. These agencies were the Health Department, Community Organizations that were Ryan White Providers, and Primary Care Provider centers. Clarification had to be provided several times when asking questions about being specific with their answers to Healthcare Reform, Affordable Care Act, and Ryan White services to not have them tied into the same category or connected. Participants also acknowledged that they felt like the Ryan White HIV/AIDS program was the service that covered most of their services.

### *Theme 2: HIV/AIDS Initial Diagnosis*

Subthemes that informed Theme 2 across focus group sites were: (a) guidance after diagnosis, (b) life changes since diagnosis, and (c) substance abuse. After being diagnosed, participants recalled their medical providers' instructions to begin their treatment and lifestyle of living with HIV. Many participants admitted that they do not remember the initial conversation and instructions on how to begin their journey of living with HIV due to the diagnosis and disbelief's initial shock.

The key theme was that all participants were given guidance on how to begin their regime and routine of medications, doctors' visits, lifestyle changes, and changing their risky behavior lifestyles. The majority of the group noted they were given this guidance, but they did not adhere to the guidance because they were still battling mental health and/or substance abuse user issues with addiction. Participants felt as though they were given the proper guidance. However, due to the nature of the lack of cultural sensitivity, competence, unaddressed co-founding behaviors, and/or the medical providers' comprehension in the early stages of the HIV epidemic, they were not open to addressing the forward-moving process of their health status.

Participants remembered from their initial diagnosis that they were made aware of resources and services through Medical Assistance and the Ryan White Program. However, they

did not understand which resources paid for specific services or all the readily available services. Many acknowledged that from the beginning, they have received privacy and explanation of benefits documents in the mail but have never viewed these documents to see which services and medications were being paid out of specific resources. Participants stated they learned more about various options they had for medical treatment, medications, and therapies to address their new diagnosis from fellow HIV patients who willingly guided and connected them to services. When Ryan White Programs began being available through community organizations, participants could be walked through the services later in their journey.

There were conversations among participants during the focus groups where they reflected on the medications from the 1980s, and 1990's remarking that they were low quality but were the only medications paid for by Medical Assistance, and they made many of them ill. A few participants mentioned that through clinical trials and grant-funded programs, they could try better quality medications, but often the funding for those programs eventually ended, and they had to return to medications that Medical Assistance covered and the Ryan White Program would supplement.

Although the participants stated they all had known about the severity of HIV/AIDS, they admitted that at initial diagnosis, attending to their health status was not a priority in their life at that time. Overall, they did not feel they had major life changes in their relationships, social life, love life, health care status, and personal health care behaviors.

A recurring theme was that the changes in their life were necessary for them to break the cycle of bad behaviors that they had in their lives, including relationships with those who participated in risky behaviors. The section highlights were how they were presented with the information that they had HIV/AIDS and their initial reactions. All noted that they were not in a good mental health position to hear that they were HIV/AIDS positive but hearing the news further sent their mental health into a lower state.

The leading sub-theme in diagnosis was their discussion on their lifestyle and behaviors at the time of diagnosis. Ninety percent of the group admitted to being addicted to a substance and a substance abuse user before and at the time of their diagnosis. This sub-theme was the group's overarching voice throughout the sessions, where they acknowledged that their addiction prevented them from immediately processing the news that they had heard. Those on substances said they felt nothing or had no realization of the effects until they became sober and clean (many years later). Once off substances, they had feelings of punishment, shame, and disappointment in their lifestyles and behaviors associated with contracting the virus.

### *Theme 3: Perceptions of Healthcare System Pre & Post Diagnosis*

Theme 3 was informed by pre-diagnosis health status, using health care services, and health care status maintenance. Although many participants reported having hypertension and diabetes, they remained adamant that they considered themselves very healthy before being diagnosed with HIV/AIDS. Substance abuse users noted that they had poor health due to not being aware of the harmful patterns, lifestyles, and lasting effects. Due to lack of access and

affordability to care, the participants remarked that using healthcare services was not a part of their lifestyle before being diagnosed unless they became severely ill. They did not use the available resources, and many did not know healthcare resources (dental, eye, specialist). The services that all mentioned that they routinely used were the free needle exchange program and free clinic. The sub-theme was that they knew there were health care resources there before being diagnosed, including drug treatment programs, but they were not interested in being a part of them or tried and did not like the programs.

Once they became diagnosed, they acknowledged that it took them a few years to start fully using the services, but once they were in recovery, they could better focus and adhere to their HIV/AIDS treatment. Years after diagnosis now, they feel like they have a better healthcare status than before diagnosis. The sub-theme was that they thought there were beneficial services there before, but they were unsure of the quality of the services due to their unwillingness to activate any of them for themselves. The participants explained that the resource options that they have now specific to HIV/AIDS patients are better than the access and affordability options for health care before they were diagnosed. They mentioned that they use healthcare services at least once a week compared to almost non-existing before they were diagnosed. Ultimately, they feel like the HIV/AIDS services are better than the services for non-HIV/AIDS patients and are satisfied with the resources that they receive now.

### *Theme 4: Health-Related Quality of Life*

Lastly, the subthemes that informed Theme 4 were (a) impact of HIV; (b) social support; (c) mental health; and (d) medical services. The participants gave praise to their HIV diagnosis, not in approval of contracting it but highlighting HIV for the impact that it has had on changing their lifestyle and changing their risky behaviors. This recurring sub-theme from them led to them honoring how HIV/AIDS saved their lives. The ability to walk, wash dishes, or do laundry was repeated often as they listed tasks that limited their day-to-day functionalities. Many mentioned that they were more intentional about being active and finding activities that fit their level.

The underlying theme for social support is that most of them have good friends, family, and other social support, but most of their friends are from their HIV/AIDS circle. They did lose people after being diagnosed, but it was more due to removing people who were still practicing unhealthy risky behaviors and could negatively influence. They often felt lonely during the journey and feel disappointed in themselves for allowing themselves to be in the situation. Due to stigma, they felt isolated in certain areas and felt like their presence was a burden to specific scenes and audiences.

Mental health was a major theme throughout the entire focus group, from pre-diagnosis, diagnosis, post-diagnosis, and current journey mental health. The individual viewed themselves as a leading cause of their behaviors and how they felt like they valued themselves. Several participants noted they were clinically diagnosed with a mental disease and thought they were not in good mental health. After diagnosis, their mental health has improved. Depression was a term that almost every participant used, stating that they currently still have spells of

manic depression. Most participants said the diagnosis did not lead them to suicidal thoughts but rather to thoughts about changing their lives and living a full life. They all mentioned that daily they have to fight negative thoughts.

They currently seek out medical services when needed and are impressed with the different resources as Ryan White and HIV/AIDS patients. The majority are satisfied with their treatment. Medicaid and Medicare are their primary insurances, with the addition of Ryan White and MDAP. They all feel like they have good medical providers and receive the best care available to them. Overall, they all feel like they have better health now, resources, medical service and opportunities, and quality of life than before they were diagnosed with HIV/AIDS.

## Conclusion

The purpose of this study is to understand the relationship between access and utilization of health insurance under the ACA for HIV/AIDS patients and their health-related quality of life (HRQOL). Derived from the Wilson and Cleary (1995) model, the Basavaraj et al. (2010) HRQOL modified model was developed specifically for HIV/AIDS patients' quality of life. The modified Health-Related Quality of Life model examined four different PLWH lives: physical, psychological, social, and environmental. Through a qualitative process of focus groups and interviews, participants discussed their knowledge, attitudes, and practices regarding health care reform. Secondly, they were asked questions about their Health-Related Quality of Life before being diagnosed, once diagnosed, and living with HIV. The participants were given educational handouts to fill in healthcare reform gaps, specifically the ACA.

Most of the focus groups and interview participants did not know the Affordable Care Act and its implementation. For example, how ACA directly impacted healthcare coverage, access, and affordability but knew general information about Health Care Reform and ACA. It was great to hear that the media, Ryan White Program Providers, and medical providers are continuing conversations about Obamacare with patients. However, it was also apparent that they have been given more information than how the ACA applies to HIV/AIDS patients and their healthcare rights and benefits. The participants were told about the resources but not about the best way to use the resources from their given information. Therefore, the participants not being able to relate the ACA provisions to the resources they have been able to receive through their disease's progression were indirectly provided through them discussing their HRQOL experiences as a person living with HIV over the years. Below you will find an analysis of how the HRQOL components have been present in Ryan White Program participants' lives.

The Affordable Care Act was enacted to improve health care accessibility, cost, and services for all Americans. The initial ACA has been amended over 1500 times, bringing it to its current structure. Health Care Reform in this country will continue to be a debate that continuously divides the country. We must remain focused on the impact that health care laws, policies, and implementation have on the wellbeing of all that reside in the United States. For public health practitioners, the goal is to keep pushing back until the necessary changes are made in law and policy arenas to ensure that we create and maintain positive impacts for our

Table 2. Themes, Subthemes, and Quotes Across All Four Focus Group Sites

Themes	Subthemes	Sample Quotes
Theme 1: Knowledge of Health Care Reform	1.1Definitions of Health	“ Initiated by Obama for everyone to get free health insurance.”
	1.2 Source of Knowledge Gained	“I have to apply for Medicaid because I get Social Security and Social Services informed me.”
	1.3 Benefits and Significance of Health Care Reform	“Medications ( better medication, less medications)”
	1.4 Healthcare Reform Agencies	“Confused what is going on with the services, and I do not see how things are getting better.”
Theme 2: HIV/AIDS Diagnosis	2.1 Guidance after diagnosis	“The health department.” “Yes-Set up with case manager, and bring information, set up with PC.”
	2.2 Life Changes Since Diagnosis	“more accepting from society and family, education is the key.”
	2.3 Substance Abuse	“substance abuse user, was on substance----accepting and adjusting to the situation.”
Theme 3: Perceptions of Health Care System	3.1 Pre-Diagnosis Health Status	“very healthy.”

communities. For those laws and policies that are not making an impact, it is our duty to review them, question their existence, and request them to be removed or amended.

The Ryan White Program has proven to be a successful policy that positively impacts HIV/AIDS patients. Public Health Practitioners owe it to HIV/AIDS patients to give all our energy to protect the laws. As the Health Reform movement continues to develop, we must be mindful of existing policies, such as Ryan White, that improve populations' health care outcomes. It would be counterproductive to cause conflict or confusion about which laws or policies provide specific services and non-duplicating services and are needed for our communities. The turnover that we see year to year from programs and resources being eliminated is from the lack of tracking of these programs' effectiveness to renew fiscal notes that support these policies being continued.

Most importantly, we must listen to those in the community on how we serve them. We can no longer make policies off of adjusted quantitative data alone, which are not delivering the outcomes that we need in our communities. The ACA has started us on the right path, and we must keep the momentum going.

Over the past ten years of healthcare reform, the ACA has had a major impact on chronic disease populations. Ryan White Program patients are among the few chronic disease populations followed for health insurance obtainment, status, and utilization because of the program's federal mandates. Although knowledge from the Ryan White Program study participants is low on ACA and its provisions that impact their population, they have obtained the basic knowledge of knowing that it impacts health insurance on a national scale. Obamacare is recognized more as a political and news topic than a healthcare implementation needs among communities that are most impacted by the ACA's provisions. We need local agencies to begin discussing and educating all chronic disease populations about their rights and responsibilities as consumers and how to utilize the resources that were implemented from the ACA.

The stories of those who have lived with HIV/AIDS need to be heard, and every advocate, health care executive, and politician needs to know their needs and what is not working to improve their quality of life through policies.

Disturbingly, it became clear that the HIV/AIDS patients' prior risky behaviors were continuing because of the lack of service to intervene before they got to the stage where HIV/AIDS diagnosis was the endgame that forced them to change their health behaviors and lifestyle. It brings into question if the policies, implementations, and resources that we provide for low-income, substance abuse users, and other chronic disease populations are insufficient to receive the help they need to recover before they get infected. In retrospect, we are improving the quality of life for HIV/AIDS patients, but there should have been policies to help them with their health care before they reached the point of contracting an infectious disease. HIV/AIDS can be a life-changing, path redirecting diagnosis, but we need to make sure that we are making policies to improve the longevity of life and the quality of their lives.

# Wisdom Matters: Honoring the Wisdom and Assessing the Health Literacy of Black Women Living with HIV

**Ndidiamaka Amutah-Onukagha, PhD, MPH, CHES**

Nathanaelle Ibeziako, MA, BA

Celsea Tibbitt, BSN, RN

LeAnn Louis, BS

Aishwarya Amarnath

ndidiamaka.amutah\_onukagha@tufts.edu

## Authors' Note

Ndidiamaka Amutah-Onukagha, PhD, MPH is an Associate Professor, Tufts University School of Medicine, Boston, MA. Nathanaelle Ibeziako, MA, BA is a fourth year MD student, Tufts University School of Medicine, Boston, MA. Celsea Tibbitt, BSN, RN is a PhD candidate, Northeastern University, Boston, MA. LeAnn Louis, BS is a fourth year MD/MPH student, Tufts University School of Medicine. Aishwarya Amarnath is a third-year undergraduate student, Tufts University School of Arts & Sciences.

The authors report no real or perceived vested interests that relate to this article that could be construed as a conflict of interest.

*Acknowledgments:* The Tisch College of Civic Engagement, Tufts University School of Medicine

*Keywords:* Health literacy, community health, living with HIV, civic engagement, Black women, African American women

## Abstract

Low literacy levels in Black women with HIV (WWH) have been shown to amplify pre-existing health disparities and sequelae of non-adherence to health-related guidance. Wisdom Matters is a community-based participatory research program with an aim of improving health literacy in populations of Black WWH and assessing the existing knowledge, attitudes, and beliefs surrounding HIV care delivery and psychosocial barriers in these populations. Our research was conducted in Boston, MA, where 17 Black WWH were recruited to complete a 6-week curriculum designed to provide a thorough and cohesive path to empowerment, both individually and collectively, pertaining to living with HIV. Data collection was augmented through pre- and posttest data as well as qualitative data collected via focus groups. Content and narrative analyses of these qualitative data demonstrate individual and group improvement in the areas of nutrition, medication adherence, stress management, and disclosure of HIV status after participation in the Wisdom Matters program. The study demonstrates the feasibility and acceptability of health literacy interventions based within community settings and addresses gaps in literacy that healthcare workers can prioritize in the education of their patients.



## Introduction

Black Americans account for a higher proportion of new HIV diagnoses, as well as a higher proportion of people with HIV (PWH), than any other race and ethnicity in the US (CDC, 2018). In the most recent national data from 2018, Black Americans accounted for 13% of the US population, yet 42% (16,002) of the 37,968 new HIV diagnoses in the United States. Among Black Americans living with HIV in 2018, an estimated 85% were aware of their infection (CDC, 2018).

Black women in particular experience heightened cases of HIV and its related adversities, despite advances in care and increased availability of pre-exposure prophylaxis (PrEP) to the general population. In 2018, Black women accounted for 13% of the general female population but made up 58% percent of HIV diagnoses in the female population. Of these new cases in the Black women with HIV (WWH) population, 92% contracted HIV through heterosexual contact, 8% through injection drug use, and 1% through another mechanism (CDC, 2018).

The disproportionate number of Black WWH coupled with the myriad of psychosocio economic barriers creates complexities for HIV management in this population. Factors such as structural racism and a subsequent distrust in American healthcare, sexual oppression and exploitation, poverty, and other such social determinants can individually and collectively act as barriers to adequate treatment of an HIV diagnosis. Of such social inequities, poor health literacy and a subsequent reduction in shared decision making and health-promoting behaviors act as some of the greatest social barriers to accessing healthcare services and appropriate disease management among patients living with HIV (Palumbo, 2015). As a result of these psychosocio economic barriers, Black WWH are more likely to die from HIV-related diseases and are less likely to be virally suppressed than white women, notwithstanding advances in care and increased availability of pre-exposure prophylaxis to the general population (McFall et al., 2013). First-hand accounts from a study conducted by Amutah-Onukagha et al in 2012 among 10 African American women in an HIV support group demonstrated that Black WWH do not receive care due to deeply internalized stigmas and discriminations heightened by their race (Amutah, N. N., 2012). Another intervention-based study conducted by Amutah-Onukagha et al in 2018 entitled Project THANKS resulted in the 31 Black WWH participants citing lack of good healthcare provider relationships, poor mental health, and lack of social support as barriers to proper care, all factors related to racial and cultural factors left unacknowledged by healthcare systems (Amutah-Onukagha et al., 2018).

In order to combat the disproportionate effects of HIV in Black female populations, we must carefully address the aforementioned barriers; specifically: lack of health literacy, reluctance to disclose HIV status, stigmas, and difficulty managing HIV along with comorbidities, as detailed below.

### *Health Literacy:*

Health literacy is “a complex phenomenon involving access to and skillful use of health-related information to inform and improve health decision making, behaviors, and

outcomes” (Perazzo et al., 2017). Health literacy has been found to have a significant association with antiretroviral medication adherence, as examined by a literature review on health literacy as an impact on PWH (Wawrzyniak et al., 2013). A study within this review conducted by Ownby et al. in 2012 utilized the Test of Functional Health Literacy in Adults (TOFHLA) to measure knowledge about HIV and appropriate usage of HIV medication before and after exposure to a computer-delivered intervention, designed in part to provide disease-specific education, and reported a significant increase in this knowledge post-intervention within the 118 participants studied. This study demonstrated the impact of dynamic disease-specific education based on the health literacy level leveraging visual and technological resources to increase the intensity and efficacy of patient education (Ownby et al., 2012).

### *Disclosure:*

Literature consistently suggests that women of all races are reluctant to disclose their HIV status (Grodensky et al., 2015) because of the potential consequence of HIV-related stigma, isolation, and discrimination. Disclosure can result in support, but it can also make an HIV-positive woman susceptible to stigmatization and discrimination (Fletcher et al., 2017).

Within a study conducted with 48 Black WWH who were also primary caretakers of young children, Black and Miles (2002) describe the “calculus of disclosure” that Black WWH experience when deciding to whom they will disclose their status. For the Black WWH participating in their study, the calculus of disclosure included determining the risks of HIV-related stigma from individuals and groups in their social world. Their calculation of risk was derived from both indirect, observed societal stigma and from direct, personal experiences with stigma (Black et al., 2002). This research ascribes significance to differences in disclosure calculation according to race in America and considers the need to understand how women are impacted after disclosure depending on their race. Another 2020 study conducted in South Africa with a sample of 406 mothers with HIV further delves into the forces that prevent mothers from disclosing their HIV status with their children, as introduced by Black and Miles. Data collected in this study indicated that only 11.6% of WWH disclosed their HIV status to their young children, listing reasons such as “age [appropriateness]” and other such causes related to stigma surrounding HIV status; results also demonstrated that mothers who did disclose status to their children reported significantly more emotional support and family closeness than those who did not (Visser & Hlungwani, 2020). Further research is needed to gain a more complete understanding of the impacts of disclosure on relationships for Black WWH.

Recent research also reveals that fear of HIV disclosure, criminalization, rejection, and loneliness can push women to stay in or return to abusive relationships. Concurrent with violence and abuse, many women fear that after HIV disclosure, their partners might disclose their status without consent to others (Krusi, 2018).

### *Stigma and Medical Adherence:*

In 2018, a qualitative study was conducted that sought to understand the perceptions of intersectional HIV-related stigma among diverse women living with HIV in the United States (Rice et al., 2018). The women participating in the study perceived these interrelated

forms of social marginalization from multiple sources: their communities, interpersonal interactions, and within systems and structures.

Sweeny & Venable conducted a systematic review and synthesis of the literature and found substantial evidence to indicate that stigma contributes to medication adherence difficulties among PWH. The similarities in findings across studies assessing single or multiple factors generating HIV-related stigma is significant given that the studies included diverse patient populations with samples from countries composed of different social, economic, and political contexts, as well as different experiences of the HIV epidemic. Their findings indicate plausible commonalities in the impacts of HIV-related stigma adherence across different socio-cultural contexts (Sweeny & Venable, 2016).

The National Institutes of Health have recently identified HIV-related stigma as a research priority, citing reasons such as the aforementioned intersections between HIV stigma and “stigma and discrimination due to their race/ethnicity, gender identity, sexual orientation, substance use, engagement in sex work, among other identities and positions (Greenwood et al., 2020),” and the demonstrated correlation between stigma reception and low uptake of HIV testing and prevention methods, such as pre-exposure prophylaxis and antiretroviral therapy (Greenwood et al., 2020).

### *Comorbidities:*

A constant comparison analysis published in 2014 looking at Black WWH with comorbidities revealed that HIV management and the management of their co-morbidities are linked. The study reports that diabetes and hypertension were perceived to be more difficult to manage than HIV among the women included in the study. Warren-Jeanpiere et al suggest that in order to enhance Black women’s self-management strategies, researchers need to consider how cultural factors uniquely intersect (Warren-Jeanpiere et al., 2014).

According to qualitative research conducted by Amutah-Onukagha and team, investigators discovered that although participants recognized the importance of taking care of their overall health, the majority of participants were more concerned with the treatment of their comorbidities (Amutah-Onukagha et al., 2018). Their study utilized a mixed-methods intervention to increase the adoption of healthy behaviors in Black American WWH with substance abuse. They found that in addition to HIV, many participants reported struggling to manage various comorbidities, such as cholesterol, hypertension, poor mental health, kidney failure, diabetes, heart disease, and Alzheimer’s disease, seizures, and arthritis. Participants directly suggested the need for strategies to highlight management of HIV and managing common HIV related chronic illnesses (Amutah-Onukagha et al., 2018).

The purpose of this article is to describe a community-based health literacy intervention in Black American WWH while also addressing issues of disclosure, HIV-related stigma, medication adherence, and management of concurrent co-morbidities. Given the findings of past literature surrounding health literacy among Black WWH, our findings seek to disseminate evidence that improving health literacy is pivotal to respectively improving

HIV health outcomes. The intervention, titled Wisdom Matters, addressed barriers presented in literature that led to non-health-promoting behaviors, and sought to educate participants in order to increase resolve to stay in treatment for HIV and chronic diseases. The program components were selected and developed based on the review of current literature on the socio-ecological barriers to care in Black American WWH. Components of the curriculum include: understanding and defining comorbidities, pathophysiology and management of diabetes, hypertension and heart disease, HIV pre-exposure prophylaxis and indication, medication adherence, nutrition and social components of HIV including stigma and disclosure. Addressing the key components of our curriculum have been shown to increase advocacy for Black WWH and the greater community in healthcare settings, ultimately resulting in improved health outcomes for HIV and comorbid chronic diseases and reductions in healthcare costs.

### Methods

#### *Program Design and Setting:*

We designed the protocol as a 6-week curriculum to increase health literacy and empower Black WWH to take control of their health and educate others on HIV and metabolic disease prevention. The sample size was two groups of Black WWH (N= 17) at The Dimock Center in Jamaica Plain, MA. The intervention included lectures conducted on a weekly basis over the course of a 2-hour session, which encompassed topics that would in turn enable the participants to increase their literacy levels and confidence in advocating for themselves in healthcare settings.

Prior to recruitment, IRB approval was granted. Participants were recruited from the Dimock Center, a community health center geared towards providing caring specifically to the underserved. This center primarily targets the predominantly Black/African American and Latino population living in the Roxbury, Dorchester, Mattapan, and Jamaica Plain communities surrounding Boston, MA. In addition to primary care, the center also offers HIV management and behavioral health care. Convenience sampling was used, as participants were contacted and recruited directly from a longstanding women's-only HIV support group at the center. Members of this group were asked to participate verbally, through use of flyers, and through contact with case managers. All participants were fully informed about the purpose of the study, as well as compensation. They were ensured that lack of participation would not have any impact on the services being provided to them by the Dimock Center.

#### *Goals and Objectives:*

The goals of our intervention were to ask and answer questions regarding differing access to healthcare resources, increase health literacy in the subjects presented in the lecture materials, educate participants about relevant health disparities and their effects on participants' personal experiences, and mobilize her family and community to act against these disparities and to engage in action to change healthcare access in her neighborhood. We sought to achieve the following outcomes: (1) provide WWH with hands-on experience in engaging their communities around issues related to HIV risk, (2) teach WWH the value of

civic engagement, (3) create a health literacy intervention that community organizations and healthcare professionals engaging directly with this patient population can replicate beyond our intervention and encourage further dialogue about the impact of HIV on communities of color. Additionally, our project highlights the intersection of health literacy and health disparities and empowers WWH to focus on how they can impact change in their environment using their newfound framework of intersectionality.

### *Inclusion and Exclusion Criteria:*

Eligible participants were: (a) Black American women (ethnicity identified by self-report and inclusive of African and Caribbean women); (b) HIV positive with verification from clinical data; (c) have an adolescent daughter residing with them at least 50% of the time (relevant to the study of disclosure & stigma, how the mother-daughter relationship is affected by HIV status); (d) currently residing in Boston, MA or the surrounding areas; e) English speaking; and (f) over the age of 18. The subjects were recruited through seropositive female support groups held at the Dimock Center. Women were also presented details about the study by their Infectious Disease care providers at the Dimock Center.

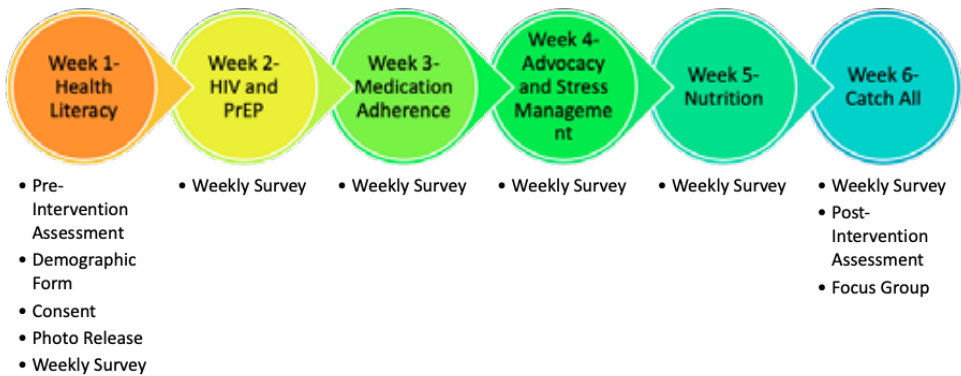
### *Procedures:*

The lectures were delivered sequentially and built on topics to improve subjective health literacy levels. Due to varying levels of literacy in our study population, a 2nd grade reading level was used to develop the lectures and was adjusted throughout the intervention relative to the women's literacy levels. In addition to the lecture material, pretest, posttest, and focus group assessments (i.e., health literacy, increase in knowledge, attitudes, and beliefs about HIV, increase in medication adherence - topics which were derived through deductive reasoning) for each of the groups were collected. The lectures took place on Saturdays and followed the described schedule starting with our opening poem, followed by the lecture for the week and ending with the weekly survey. Participants were provided with a nutritious breakfast during each session, as well as a \$20 cash incentive for their time and to aid with transportation costs. Participants were also given a folder of curriculum handouts and a notebook. Individual unstructured interviews and group discussions with women about the impact of their participation on their feelings of self-efficacy and confidence to advocate for themselves in a healthcare setting were conducted regularly. At the conclusion of the six-week lecture series, a celebratory graduation dinner was held to acknowledge the accomplishments of the participants and to share the celebration with their friends and family.

### *Lecture Content and Creation Process:*

A lecture-based curriculum developed to increase health literacy in WWH was administered through in-person lectures over the course of six weeks. The topics covered through our curriculum included: HIV and opportunistic infection basics, PrEP and PEP, medication adherence, nutrition, comorbidities, and advocacy. We reserved the final week lecture for a topic chosen by our participants, and participants requested disclosure as the topic. Figure 1 describes the lecture schedule in addition to the materials distributed each session.

Figure 1. Curriculum Plan and Materials Collected by Lecturers



Lecture topics and general focuses of our intervention were selected based on the findings of Amutah-Onukagha et al, where qualitative studies revealed needs and concerns of Black WWH to include: deficits in knowledge on medication adherence, stress management and HIV-related stigma, and HIV and modes of transmission. Additional non-lecture-based intervention components such as the opening poem on the power of wisdom and free-structured interview targeted additional findings of Amutah-Onukagha et al of stigma and diminished feelings of self-worth and efficacy, which has substantial impacts on mental health in WWH (Amutah-Onukagha et al., 2018; Amutah-Onukagha et al., 2020; Mahadevan et al., 2014).

The general frameworks for lecture content and structure were derived from Project THANKS and the CDC Sister to Sister initiative ((Amutah-Onukagha et al., 2018; Amutah-Onukagha et al., 2020; Mahadevan et al., 2014). Key differences in our novel intervention stem from the clinical focus of the lecture content. Core lecture content was generated using core nursing and medical school curriculum on the pathophysiology and management of HIV (including PrEP and opportunistic infections), nutrition and chronic disease.

## Measures & Data Analysis

At the start of the lecture series, participants completed a pre-test derived from BEHKA-HIV, direct content from lecture materials and qualitative assessment questions derived from the findings of Amutah-Onukagha et al in Project THANKS. The BEHKA-HIV is a psychometrically sound tool for assessing health knowledge and action regarding HIV treatment and predicting non-adherence to HIV medications (Osborn et al., 2010). The BEHKA-HIV is a brief and simple measure of patients' understanding and ability to take action in a specific health care context, and is a strong, independent predictor of HIV medication adherence (Osborn et al., 2010). Participants were required to complete the post-test with the same BEHKA-HIV-derived questions for comparison. The modified BEHKA-HIV included seven questions assessing participants' ideas pertaining to health and health management behaviors, five assessment questions pertaining to HIV and proper disease management, and five questions directly pertaining to lecture-based topics (Osborn et al., 2010).

During the initial session, participants completed a demographic form collecting information pertaining to race, age, education, relationship status, living arrangements, employment status, income level, and HIV diagnosis-related information. HIV diagnosis-related information included length of time with diagnosis, interactions with the healthcare system after diagnosis, HIV-centered support groups, viral load, antiretroviral usage, and presence of co-morbidities (i.e. diabetes, hypertension, heart disease, arthritis, depression, etc.). Participants were given weekly post-lecture surveys in which they reported satisfaction and impact using a 5 item Likert scale. In addition, participants were also asked to qualitatively report what they learned, their confidence in discussing lecture topics and areas for improvement. During the final session of each cohort, we also conducted a focus group with the participants. To collect qualitative data, focus groups were chosen over individual interviews due to the advantage of these groups having a prior repertoire through their HIV support group history, as well as the diminished sense of reservation. The focus groups were recorded, transcribed verbatim, and verified by the team of researchers. These transcriptions were then inductively coded to organize overarching themes using an Excel spreadsheet, which contained a data dictionary of themes, their codes, and theme descriptions. Some examples of codes used include Family Dynamics (FAMD), Concepts Learned (CONL), Acceptance of Status (AOS), and Comorbidities (COM). Content and narrative analysis were both being conducted with these focus groups, as the qualitative data collected was categorized and utilized to identify key patterns and themes of participants' experiences as well as structured to represent the general narrative as told by Black WWH.

## Results

Qualitative results were derived primarily from the focus group as well as free-structured interviews conducted throughout the program. Using the intervention format of Project THANKS, participants were asked a variety of questions based on lecture materials and recurrent themes that presented during the intervention (Amutah-Onukagha et al, 2018). Focus group topics included the following themes: nutrition, PrEP usage and indications, medication adherence, barriers and solutions to HIV and chronic disease care and management, HIV-related stigma, disclosure of HIV status, and guilt. The results are outlined below.

The Wisdom Matters curriculum and intervention incorporated themes from Table 1 in discussion and lecture material. Our efforts were directed towards identifying ways in which negative themes could be eradicated and positive themes could be integrated into the healthcare system and community engagement efforts. Highly prevalent themes that arose included: health literacy, nutrition, pre-exposure prophylaxis, medication adherence, retention in healthcare, disclosure, stigma, and guilt.

### *Health Literacy:*

Study participants routinely sought health-related information prior to the onset of our intervention for the purposes of learning how to improve their overall well-being. Unfortunately, many women expressed feelings of hopelessness regarding their ability to obtain



Table 1. Summary Focus Group Themes

<b>The focus group revealed several themes impacting health care and contributing to the outcomes present for Black WWH. The themes include:</b>
Availability of health care providers and multidisciplinary care
Ongoing pursuit of education
Social support
HIV-related stigma
Disclosure of HIV status
Guilt
Stress and mental health
Supplemental nutritional counseling
Advocacy
Self-efficacy
Optimization of the role of “Community Matriarch” to strengthen pre-existing health-promoting systems.

accurate information pertaining to their health from their healthcare providers and had little knowledge on how to obtain such. Given the focus of our intervention, a formal discussion assessing the attitudes of Black WWH on health literacy was warranted. Many women expressed feelings of bewilderment upon recalling their misunderstandings of HIV when first diagnosed.

*“When I was diagnosed, I didn’t know what HIV was. When my doctor explained to me I said, ‘is this for gay people, lesbian, bisexual’? He said no, even straight people get it too. I didn’t understand that. So I [tried to] learn.”*

It is important to highlight the efforts of many of the participants to obtain HIV-related information and the effects of their successes. Women commonly found success in their pursuit of knowledge when networking and interacting with other PWH.

*“It was hard for me too, but as I was learning about HIV when I was first diagnosed. Like moving around and seeing other people that have it, like I’m not alone. And plus I went to conferences and stuff.”*

The direct correlation between health literacy and health outcomes was understood by the women and fueled their desires to seek knowledge, ultimately leading to their involvement in the intervention. Generally, women within the intervention who had prior access to a network of outside resources to obtain information pertaining to HIV, displayed higher levels of literacy and inquisition throughout the intervention. Use of pre-existing support groups to



teach and share HIV and health-related knowledge represents an under-utilized modality of increasing health literacy in Black WWH and focus group data supports its efficacy.

### **Nutrition:**

Nutrition proved to be a popular topic amongst the women, particularly because many had diagnoses of metabolically responsive chronic diseases. A common narrative included a woman first diagnosed with diabetes, hypertension, or high cholesterol, then subsequently counseled by their health care provider about “healthy” foods and behaviors to mitigate the downstream effects of their disease. Prior to the intervention, interactions between nutrition and disease processes were barely understood by the women. Discussions included general topics such as defining macro and micronutrients riddled down to assessing the biochemical differences between trans and saturated fats and their metabolism.

*“Everything was very, very informative to me. I learned a lot that I didn’t even know, I knew I didn’t know. That had gone as far as like the nutrition and fixing my diabetes, hypertension, um, and it was just very, very educational. Very educational for me in this. And, you know, I’ll just, I just wanna keep being educated on this, on nutrition and my illnesses.”*

Women were also deeply interested in dietary modifications that could be made in response to the weight changes caused by certain HIV medications.

*“I never had any children. I’m not pregnant. But saying to them, it’s the medication. I don’t like it. They give me too many medication, make you gain all that weight, it make my stomach look big. I don’t like it when it’s like that. I don’t like the way my body changed too much. I don’t like that. I want to go back to the way it was. My stomach used to be flat. But on the medication it blew up. What can I do to fix that with my food?”*

This clear interest in dietary modifications demonstrates a need for increased research and compilation of information regarding the effects of HIV medication on nutrition and weight changes and subsequent relaying of this information to women diagnosed with and being medicated for HIV. Providing such information to WWH would increase quality of life, empowering WWH to maintain control of certain aspects of their lives and bodies and sustain or develop overall confidence in the midst of a holistically life-altering diagnosis.

### **Pre-Exposure Prophylaxis (PrEP):**

Many within the field of infectious disease have discussed means of increasing the usage of PrEP amongst vulnerable populations. Given that study participants were all PWH, discussion of usage of PrEP within this population was not done. However, many participants expressed connections with at-risk populations and had little knowledge pertaining to the indications for PrEP usage. During the intervention, women were taught what PrEP was, its mechanism of action, and its indications. After achieving a basic understanding of PrEP, they were given examples of how to teach this information and advocate for others in clinical settings. During the final focus group, one woman in particular expressed a recent clinical encounter where she advocated for her significant other for the first time.

*“Well, for me, it was just advocating for him. Bringing him to the hospital, talking, sitting down, talking to his doctors, and letting his doctors what type of relationship he’s in, and we talked about the PrEP.”*

Encounters such as this, depict the impact of education and its direct translation to actions that reduce adverse health outcomes in at-risk populations. Women frequently commented on discussions with their children, extended family, and friends where they encouraged them to consider PrEP. A prominent theme women expressed was misinformation on transmission of HIV within people they interacted with. Many expressed that they were not only able to educate others using materials from the intervention, but also teach about the benefits of utilizing PrEP. Black women are central to communal foundations and utilizing their networking capabilities to educate and spread information pertaining to PrEP can prove to be a successful mode of increasing PrEP usage in vulnerable populations.

### **Medication Adherence:**

Medication adherence has been cited frequently as a large contributor to health outcomes making it a target of outreach initiatives. The barriers to medication adherence in PWH have been widely explored and inadequate education has been found to be one of the most prominent causal factors. Lectures on medication adherence during our intervention primarily focused on understanding the indications for HIV and chronic disease medications, discussion of side effects and the concept of different side effects associated with different medications and lastly understanding the nomenclature and labeling on post-visit instructions, prescriptions, and pill bottles. Discussions pertaining to barriers to taking medications highlighted factors primarily surrounding adverse effects pertaining to weight gain and loss. The majority of the women attested to the difficulties of consistently taking antiretrovirals, especially in the presence of others not required to take daily medications.

*“They don’t know. We get sick and they don’t know what we’re going through taking that medication. We’re always getting sick. Sometimes you don’t want to be sick all the time, you want to stay healthy. People don’t know what we’re going through taking that medication every day. It’s hard. It’s very hard to do that.”*

Many women stressed the importance of a good provider and were inspired by their consistency and encouragement.

*“Well, my doctor- she used to call me a lot. She’d always say, ‘You always take your medication, every day. You never miss a day.’ When it comes to me, she’s a great doctor. She knows I take my medicine. I know I do. But I’m not going to stop because of that. I’m trying to stay healthy and stay positive.”*

### **Retention in Healthcare:**

Retention in healthcare was a major theme that recurred throughout the intervention. The women expressed many occasions in which they have left care because of what they believed

was inadequate treatment. Many of the reasons they listed centered around the availability and their perception of the investment of their provider in their health and well-being. A common narrative surrounding the transfer of care to another provider depicted a visit in which the provider did not engage the patient, spent little time teaching, and was dismissive of patient concerns.

*"I wasn't happy with my HIV doctor, and I got a new one you know. Because all she did was look at the computer. And my visit was done. Here's your prescription, your blood work, here's your slip, go get your blood, see you in three months."*

Successes in the retention of study participants within medical care included multidisciplinary efforts with some form of social support. Black WWH face unique psychosocial challenges to retention in care as a result of racism, HIV-related stigma and discrimination and the myriad of roles they play within their communities. According to demographic data, the majority of study participants had incomes below \$35,000. Many reported informally that they currently support their children and grandchildren, unofficially putting them below the poverty line. Simultaneously, Black WWH face isolation from their families and communities and find difficulty maintaining healthy romantic relationships. Additionally, many of the women had experienced homelessness, substance abuse, prostitution and carry trauma and mental illness as a result. These stressors are then compounded with marginalization resultant from living under the constructs of racism and the consequent health, unstable housing, resource and economic disparities. The presence of an involved healthcare team proved to be one of the most impactful interventions leading to consistent retention in healthcare in Black WWH.

*"My team is so open, and so concerned, especially my HIV team, if I make it a doctor's appointment, and I don't show up. I'll never forget this, my doctor, I missed an appointment. My doctor and my social worker came to my house."*

Many women spoke to the impact of social workers in their medical care and their support.

*"I have my support mainly from my social worker, who has had my back from the beginning of this HIV battle. Um, and I have to say I love my social worker because if it wasn't for her I probably be either in a nuthouse, or probably dead. Um, being accepted, you know, she's always, always supported me and that's my biggest support. When it comes with living with this HIV. "*

"Having a good case manager, because that's the good thing, because they call you and stuff like that. Because I remember when I first got HIV, it was very hard for me. My case manager would come to my house, pick me up, bring me here and sometimes take me back home. Things like that was really helpful for me, so having a good case manager that has your back, I don't know. I don't know what else to say."

### **Disclosure:**

The topic of safely and effectively disclosing HIV status and the emotional burden associated was a recurrent topic throughout the intervention. Many women expressed fear

surrounding disclosure and worried about its impact on their relationships with family, friends and significant others.

*"I think we all are scared of rejection. All it takes is you to tell one person."*

Particular experiences disclosing to family members revealed rejection linked to misunderstanding of HIV transmission.

*"And when I tried to tell some other group, I mean family members, you know, they say things like 'That's one thing about me, I don't like having people in my house that got multiple diseases and then I gotta buy new furniture and all that.' And right there that shut me down."*

*"There's some people that are very ignorant. They think they can disrespect you, you know? They don't know nothing about you."*

The following quote demonstrates the fear Black WWH have specifically surrounding romantic relationships. Fear of rejection strongly influenced how women perceived other's capacity to love and care for them within relationships.

*"And to piggyback on that, that was my fear. I mean, this man came into my life, and he treated me like the queen that I am, and I was afraid. You know? Um that one he found out, he was gonna be gone out the door, and ... I just ... Listen, I don't want to be lying to you, but I just want you to know I'm HIV positive."*

Finally, it is important to highlight difficulties in disclosure as a result of shame felt due to mode of HIV transmission.

*"I feel shame, when it comes down to me disclosing myself. Because sometimes I be wanting to lie. I be wanting to lie. You know, 'How did you catch it?' Uh, sometimes I want to be, 'Oh, from a blood test.' Because I don't want people to know that I've worked the streets."*

### **Stigma:**

Discrimination and stigma were recurrent themes throughout the intervention and in all portions of the focus group. Women expressed that stigma surrounding HIV was experienced in all realms of their lives. This stigma impacted their abilities to form and maintain relationships. Stigma was also experienced in health care settings. One of the prevalent themes associated with stigma was lack of education. Many women believed that the ostracization they experienced stemmed from the little and many times incorrect knowledge surrounding HIV.

*"Like some of them they are very ignorant. So I don't even have to tell them, to disclose myself. Everywhere I go they just point fingers. If I finish to talk to someone, and then they go like, 'Oh, this girl, you know she has HIV? Her baby died with HIV, blah blah blah.'"*

**Guilt:**

Many of the women spoke about the feelings of guilt from losing their children, when they were in the street, or when they were battling addiction. Many women expressed feeling inadequate as mothers and all expressed an occasion in which they were forced to relinquish childcare responsibilities to another.

*“When I had my kids, you know, I started ... I didn’t use with my girls, but I used with my son. My son was born with crack cocaine in his system. It stopped his growth. He’s four something, probably four two, four three. It stopped his growth. He’s a very angry. And that’s all because of me using. And I feel bad that my son had to go through this. I feel bad that every time I go on Facebook, I see my son on Facebook fighting somebody and talking about beating them up. I feel bad, you know what I’m saying?”*

One quote in particular exhibited the stressed relationship between the women and their children.

*“I’m going to make it short. When I was 15 years old, I abandoned my older son. Oh god give me grace [...] He didn’t talk to me for over thirty-something years. You know what I’m saying? Every time he sees me he bangs me over the head with it.”*

## Discussion

The Wisdom Matters health literacy intervention was developed and implemented to equip women with the knowledge needed to advocate for themselves and their communities in healthcare settings as well as examine the attitudes and trends around pressing issues impacting health disparities in Black WWH. An evaluation of systems in place and communal networks conducted revealed ways in which pre-existing systems can be utilized to increase shared decision making and socio-political action. It is important to continually evaluate the barriers to care present for Black WWH in order to eradicate disparities that disproportionately impact Black women and empower them to have active roles in their healthcare.

The targets of our intervention, although not exhaustive, sought to address commonly misunderstood or expressed barriers to care and medication adherence in Black WWH. Sixteen Black WWH, split between two cohorts, underwent a 6-week health literacy intervention to improve HIV and chronic disease-related knowledge, health outcomes and ultimately empower them to increase perceptions of self-efficacy in all realms of their lives. Health literacy endpoints were achieved when women expressed increased confidence in discussions, advocacy, and decision-making pertaining to their health and that of their families and surrounding communities.

All women showed improvements and increased confidence in discussing all lecture subjects. Women had at least one comorbidity in addition to HIV and expressed satisfaction in their level of understanding after learning about the management of these diseases. Across the board, women discussed future goals to pursue community level advocacy and subsequent to the

completion of the intervention, sought to serve as liaisons for future interventions. Advocacy was a major marker of the success of our initiative. At the completion of the intervention, all women had either advocated for themselves or others in a healthcare setting to amplify their voices during instances of shared decision making.

Our intervention additionally sought to provide a framework for future HIV-centered community based participatory research. In community-based participatory research (CBPR), there is a large emphasis on the marriage of the research process and community involvement reducing health disparities in marginalized populations. In our intervention, the following characteristics of CBPR were addressed: recognizing community (PWH), building on strengths and resources of the community (usage of the health center and a pre-formed HIV support group for women), promoting co-learning among research partners, and emphasizing the relevance of community-defined problems (Holkup et. al, 2004).

Bryun et al. described six metrics that can be used to determine adequacy of CBPR, thus increasing a study's credibility. The six metrics are as follows: time, place, social circumstances, language, intimacy, and consensus (Bryun et al., 1966). In terms of time, six five-hour sessions were conducted totaling 30 in-person hours with the participants. The Wisdom Matters intervention took place at a local health Center, where the participants received their medical care and participated in support groups. During lectures, participants were seated at a round table and were allowed to interject lectures with questions or commentary. The comfort of the participants was observed during their liberal speech during focus group sessions. Based on this validated measure of CBPR credibility, the structure of the Wisdom Matter's intervention is adequate for effective community engagement and should be replicated on a larger scale to address needs in more women.

In conjunction with the structure of our intervention, themes that arose during focus groups may be used to center future research efforts and bridge gaps in existing research surrounding HIV and Black WWH. The major themes as presented in results--health literacy, nutrition, pre-exposure prophylaxis, medication adherence, retention in healthcare, disclosure, stigma, and guilt--demonstrate which facets of Black WWH's experiences with HIV have been gravely overlooked or improperly studied and learned by the greater public. Health literacy,

Themes reflecting components of HIV treatment, such as nutrition, pre-exposure prophylaxis, and medication, are closely tied to the overarching theme of health literacy and the importance of informing WWH about each component of HIV and how their bodies and other parts of self will be affected by medical treatments. Dialogue from focus groups surrounding the desire to know more about HIV status & treatment and every way in which they affect the individual can be tied to the findings of Wawrzyniak et al., which demonstrated significant correlations between health literacy interventions and an increased uptake/retention of care (Wawrzyniak et al., 2013). Retention in healthcare, another theme that came up in focus groups, highlights the inadequacy of care for Black women specifically in the treatment of HIV status. Finally, the themes of disclosure, stigma, and guilt reflect literature findings about the

persistent prevalence of stigma, and how stigma and guilt can prevent Black WWH from feeling comfortable or safe enough to disclose their status even with close family members, despite the studied correlation between disclosure to family members and an increased reception of emotional and other support (Visser & Hlungwani, 2020). Breaking down stigmas can be crucial to the health and treatment of Black WWH, as it would empower them to seek proper treatment and care for their conditions and receive support from family and peers.

### *Future Directions:*

Our intervention sought to teach material about HIV as well as additional comorbidities Black WWH commonly navigate. Our findings indicated the need for multidisciplinary care. Two areas in which women expressed either a desire for more education or information pertaining to services and resources were nutrition and mental health.

The study of mental health within Black WWH has generally focused on empowerment interventions to increase self-efficacy and to decrease risky sexual behaviors. Recent studies have shown positive results with the usage of cognitive behavioral therapy specifically addressing psychosocial trauma and HIV-related racism to promote medication adherence (Dale et al., 2018). In future interventions, a licensed mental health worker will be incorporated into sessions and will provide individualized counseling to participants. Future iterations of our intervention will also incorporate a licensed nutritionist to provide individualized counseling to women.

The structure of the intervention will be expanded to include three cohorts of 10 women each. Additionally, pre-intervention surveys will be adjusted to obtain information pertaining to antiretrovirals used by participants and lectures will be expanded to teach and discuss side effects of interest.

### *Limitations:*

Wisdom Matters primarily targeted Black women and finding may not be representative of WWH of other races. The average age of women in both cohorts was 55, and therefore our findings cannot be generalized WWH of different age groups. Women were sampled from an urban community and their thoughts and attitudes may not represent those of Black WWH in other communities. All women were from low socioeconomic status and attitudes and barriers due to this cannot be generalized to WWH of other socioeconomic backgrounds. The social nature of our program also introduces selection bias, as the group of participants chosen are restricted to those who are comfortable in or enthusiastic about social, group-style meetings. Lastly, information-seeking behavior acts as a bias, as participants may have attended our program solely for increase of knowledge. Although our study has limitations, findings are still useful for informing future interventions, community engagement and medical care in Black WWH.

### Conclusion

In conclusion, Wisdom Matters is a health literacy initiative that aims to train Black WWH with an aim of shifting them from lower rates of health literacy to a place of subjective health literacy. Nurses and other healthcare professionals in HIV care can be instrumental in ensuring that their patients have health literacy to adequately understand their treatment plans in order for patients to be active participants in their health. Nurses and other healthcare professionals should also recognize the stress and strain on mental health surrounding feelings of guilt, stigma, and navigating disclosure.

Our study shows the feasibility and acceptability of health literacy interventions based within community settings. The potential benefits of our intervention and others similar can be optimized by broader inclusion of HIV, mental health, and morbidity related topics. A closer look at the intervention execution process as well as in data collection and assessment of health literacy may highlight additional mechanisms to reduce disparities in Black WWH within community settings.



## References

- Amutah, N. N. (2012). African American Women: The Face of HIV/AIDS in Washington, DC. *Qualitative Report*, 17, 92.
- Amutah-Onukagha, N., Mahadevan, M., Opara, I., Rodriguez, M., Trusdell, M., & Kelly, J. (2018). Project THANKS: Examining HIV/AIDS-Related Barriers and Facilitators to Care in African American Women: A Community Perspective. *AIDS patient care and STDs*, 32(4), 119–128. <https://doi.org/10.1089/apc.2017.0215>
- Amutah-Onukagha, N., Mahadevan, M., Opara, I., Rodriguez, M., Baxter, A., Trusdell, M., & Kelly, J. (2020). Comment on Project THANKS: Examining HIV/AIDS-Related Barriers and Facilitators to Care in African American Women: A Community Perspective. *Journal of the International Association of Providers of AIDS Care*, 19, 2325958220936406. <https://doi.org/10.1177/2325958220936406>
- Auerbach, J. D., Kinsky, S., Brown, G., & Charles, V. (2015). Knowledge, Attitudes, and Likelihood of Pre-Exposure Prophylaxis (PrEP) Use Among US Women at Risk of Acquiring HIV. *AIDS Patient Care & STDs*, 29(2), 102–110. <https://doi.org/10.1089/apc.2014.0142>
- Brody, L. R., Jack, D. C., Bruck-Segal, D. L., Ruffing, E. G., Firpo-Perretti, Y. M., Dale, S. K., & Weber, K. M. (2016). Life Lessons from Women with HIV: Mutuality, Self-Awareness, and Self-Efficacy. *AIDS Patient Care & STDs*, 30(6), 261–273. <https://doi.org/10.1089/apc.2016.0031>
- Bruyn, S. T. (1966). 1966 The Human Perspective in Sociology. The Methodology of Participant Observation. Englewood Cliffs, New Jersey: Prentice-Hall.
- Calabrese, S. K., Dovidio, J. F., Tekeste, M., Taggart, T., Galvao, R. W., Safon, C. B., Willie, T. C., Caldwell, A. M., Kaplan, C. M., & Kershaw, T. S. (2018). HIV Pre-Exposure Prophylaxis Stigma as a Multidimensional Barrier to Uptake Among Women Who Attend Planned Parenthood. [Miscellaneous Article]. *Journal of Acquired Immune Deficiency Syndromes*, 79(1), 46–53. <https://doi.org/10.1097/QAI.0000000000001762>
- Dale, S. K., & Safren, S. A. (2018). Striving Towards Empowerment and Medication Adherence (STEP-AD): A Tailored Cognitive Behavioral Treatment Approach for Black Women Living With HIV. *Cognitive and Behavioral Practice*, 25(3), 361–376. <https://doi.org/10.1016/j.cbpra.2017.10.004>
- Greenwood GL, Wilson A, Bansal GP, et al. HIV-Related Stigma Research as a Priority at the National Institutes of Health [published online ahead of print, 2021 Apr 22]. *AIDS Behav*. 2021;1-22. doi:10.1007/s10461-021-03260-6

- Haider, S., Fletcher, F., Ott, E., Wishart, M., Terlikowski, J., & Johnson, A. (2018). Examining knowledge of and attitudes toward preexposure prophylaxis (PrEP) among HIV-vulnerable women in a Chicago-based family planning clinic. *Contraception*, 98(4), 369. <https://doi.org/10.1016/j.contraception.2018.07.122>
- Hartman, T. J., McCarthy, P. R., Park, R. J., Schuster, E., & Kushi, L. H. (1994). Focus group responses of potential participants in a nutrition education program for individuals with limited literacy skills. *Journal of the American Dietetic Association*, 94(7), 744–748. [https://doi-org.ezproxy.library.tufts.edu/10.1016/0002-8223\(94\)91940-2](https://doi-org.ezproxy.library.tufts.edu/10.1016/0002-8223(94)91940-2)
- Holkup, P. A., Tripp-Reimer, T., Salois, E. M., & Weinert, C. (2004). Community-based participatory research: an approach to intervention research with a Native American community. *ANS. Advances in nursing science*, 27(3), 162. <https://doi.org/10.1097/00012272-200407000-00002>
- James, D. C., Harville, C., Efunbumi, O., & Martin, M. Y. (2015). Health literacy issues surrounding weight management among African American women: a mixed methods study. *Journal of human nutrition and dietetics: the official journal of the British Dietetic Association*, 28 Suppl 2, 41–49. <https://doi-org.ezproxy.library.tufts.edu/10.1111/jhn.12239>
- Jayakumaran, J. S., Aaron, E., Gracely, E. J., Schriver, E., & Szep, Z. (2016). Knowledge, Attitudes, and Acceptability of Pre-Exposure Prophylaxis among Individuals Living with HIV in an Urban HIV Clinic. *PLOS ONE*, 11(2), e0145670. <https://doi.org/10.1371/journal.pone.0145670>
- Kwakwa, H. A., Bessias, S., Sturgis, D., Mvula, N., Wahome, R., Coyle, C., & Flanigan, T. P. (2016). Attitudes Toward HIV Pre-Exposure Prophylaxis in a United States Urban Clinic Population. *AIDS and Behavior*, 20(7), 1443–1450. <https://doi.org/10.1007/s10461-016-1407-9>
- Lambert, C. C., Mugavero, M. J., Najjar, Y. S., Enah, C., & Guthrie, B. J. (2018). The State of Adherence to HIV Care in Black Women. *Journal of the Association of Nurses in AIDS Care*, 29(4), 487–503. <https://doi.org/10.1016/j.jana.2018.02.008>
- McFall, A. M., Dowdy, D. W., Zelaya, C. E., Murphy, K., Wilson, T. E., Young, M. A., Gandhi, M., Cohen, M. H., Golub, E. T., Althoff, K. N., & Women's Interagency HIV Study (2013). Understanding the disparity: predictors of virologic failure in women using highly active antiretroviral therapy vary by race and/or ethnicity. *Journal of acquired immune deficiency syndromes (1999)*, 64(3), 289–298. <https://doi-org.ezproxy.library.tufts.edu/10.1097/QAI.0b013e3182a095e9>

- National Center for Health Statistics, & Centers for Disease Control and Prevention. (2018). HIV and Women. Retrieved from <https://www.cdc.gov/hiv/group/gender/women/index.html>
- Okoro, O., & Odedina, F. T. (2016). Improving medication adherence in African American women living with HIV/AIDS: Leveraging the provider role and peer involvement. *AIDS Care*, 28(2), 179–185. <https://doi.org/10.1080/09540121.2015.1071771>
- Osborn, C. Y., Davis, T. C., Bailey, S. C., & Wolf, M. S. (2010). Health Literacy in the Context of HIV Treatment: Introducing the Brief Estimate of Health Knowledge and Action (BEHKA)—HIV Version. *AIDS and Behavior*, 14(1), 181–188. <https://doi.org/10.1007/s10461-008-9484-z>
- Palacio, H., Kahn, J. G., Richards, T. A., & Morin, S. F. (2002). Effect of Race and/or Ethnicity in Use of Antiretrovirals and Prophylaxis for Opportunistic Infection: A Review of the Literature. *Public Health Reports (1974-)*, 117(3), 233–251. JSTOR.
- Pellowski, J. A., & Kalichman, S. C. (2016). Health behavior predictors of medication adherence among low health literacy people living with HIV/AIDS. *Journal of Health Psychology*, 21(9), 1981–1991. <https://doi.org/10.1177/1359105315569617>
- Perazzo, J., Reyes, D., & Webel, A. (2017). A Systematic Review of Health Literacy Interventions for People Living with HIV. *AIDS and Behavior*, 21(3), 812–821. <https://doi.org/10.1007/s10461-016-1329-6>
- Reynolds, R., Smoller, S., Allen, A., & Nicholas, P. K. (2019). Health Literacy and Health Outcomes in Persons Living with HIV Disease: A Systematic Review. *AIDS and Behavior*, 23(11), 3024–3043. <https://doi.org/10.1007/s10461-019-02432-9>
- Rice, W. S., Logie, C. H., Napoles, T. M., Walcott, M., Batchelder, A. W., Kempf, M.-C., Wingood, G. M., Konkle-Parker, D. J., Turan, B., Wilson, T. E., Johnson, M. O., Weiser, S. D., & Turan, J. M. (2018). Perceptions of intersectional stigma among diverse women living with HIV in the United States. *Social Science & Medicine*, 208, 9–17. <https://doi.org/10.1016/j.socscimed.2018.05.001>
- Sweeney, S. M., & Vanable, P. A. (2016). The Association of HIV-Related Stigma to HIV Medication Adherence: A Systematic Review and Synthesis of the Literature. *AIDS and Behavior*, 20(1), 29–50. <https://doi.org/10.1007/s10461-015-1164-1>

- Turan, B., Smith, W., Cohen, M. H., Wilson, T. E., Adimora, A. A., Merenstein, D., Adedimeji, A., Wentz, E. L., Foster, A. G. N., Metsch, L., Tien, P. C., Weiser, S. D. M., & Turan, J. M. (2016). Mechanisms for the Negative Effects of Internalized HIV-Related Stigma on Antiretroviral Therapy Adherence in Women: The Mediating Roles of Social Isolation and Depression. [Miscellaneous Article]. *Journal of Acquired Immune Deficiency Syndromes*, 72(2), 198–205. <https://doi.org/10.1097/QAI.0000000000000948>
- Visser M, Hlungwani AJ. Maternal HIV status disclosure to young uninfected children: psychological variables of the mother. *Afr J AIDS Res*. 2020 Mar;19(1):48-56. doi: 10.2989/16085906.2019.1681481. Epub 2020 Mar 10. PMID: 32153231.
- Warren-Jeanpiere, L., Dillaway, H., Hamilton, P., Young, M., & Goparaju, L. (2014). Taking It One Day at a Time: African American Women Aging with HIV and Co-Morbidities. *AIDS Patient Care & STDs*, 28(7), 372–380. <https://doi.org/10.1089/apc.2014.0024>
- Wawrzyniak, A. J., Ownby, R. L., McCoy, K., & Waldrop-Valverde, D. (2013). Health Literacy: Impact on the Health of HIV-Infected Individuals. *Current HIV/AIDS Reports*, 10(4), 295–304. <https://doi.org/10.1007/s11904-013-0178-4>
- Zuniga, J. A., Wright, C., Fordyce, J., West Ohueri, C., & Garcíá, A. A. (2018). Self-Management of HIV and Diabetes in African American Women: A Systematic Review of Qualitative Literature. *The Diabetes Educator*, 44(5), 419–434. <https://doi.org/10.1177/0145721718794879>

## **The Increased Risk for HIV and Other Sexually Transmitted Infections Among Substance-Using and Depressed Women in the Legal System**

**Karen Johnson, PhD**

University of Alabama, Little Hall,  
670 Judy Bonner Drive, Tuscaloosa, AL 35401  
ph: (718) 709-1907, fax: 205-348-9419  
kjohnson38@ua.edu

**Angela Pretz, PhD student**

University of Alabama, Little Hall  
670 Judy Bonner Drive, Tuscaloosa, AL 35401  
(563) 593-0759, fax: 205-348-9419  
ajpretz@crimson.ua.edu

**Winne Chu, MSW**

Columbia University School of Social Work  
wwc2116@columbia.edu, ph: 630-303-7709

**Catherine Isabel West, MSW**

Columbia University School of Social Work  
ciw2112@columbia.edu, ph: 424-610-5639

**Mingway P. Chang**

Columbia University School of Social Work, Social Intervention Group  
1255 Amsterdam Avenue, Rm 819A, Mail Code 4600  
ph: 212-851-2105; fax: 212-851-2126

**Akansha Anand, PhD candidate**

Fordham University, Graduate School of Social Service  
aa3387@columbia.edu, ph: 917-683-9344

**Benjamin P. Chapman, PhD MPH MS**

Associate Professor, Departments of Psychiatry and Public Health Sciences, Director  
Psychiatry Quantitative Methods Core  
University of Rochester School of Medicine and Dentistry  
300 Crittenden, Rochester, NY 14642  
Ben\_Chapman@urmc.rochester.edu, ph: 585-275-9431, fax: 585-273-1082

**Dawn Goddard-Eckrich, EdD**

Columbia University Teacher's College, School of Social Work, Social Intervention Group,  
3280 Broadway, Rm 802L1255 Amsterdam Ave, 8 th Floor,  
Mail Code: 4600, NY, NY 10027  
(212) 851 5660, fax: 212.851-2126 dg2121@columbia.edu

**Timothy Hunt, PhD**

Columbia University School of Social Work, Social Intervention Group  
1255 Amsterdam Avenue, Mail Code 4600, NY, NY 10027  
(212) 851-2110, fax: 212.851-2126, th2258@columbia.edu

**Elwin Wu, PhD**

Columbia University School of Social Work, Social Intervention Group  
1255, Amsterdam Avenue, Rm 814, Mail Code: 4600, NY, NY 10027  
(212) 851 2397, fax: 212.851-2126, elwin.wu@columbia.edu

**Louisa Gilbert, PhD**

Columbia University School of Social Work, Social Intervention Group  
1255 Amsterdam Avenue, Rm 813, Mail Code: 4600, NY, NY 10027  
(212) 851 2395, fax: 212.851-2126, lg123@columbia.edu

**Nabila El-Bassel, PhD**

Columbia University School of Social Work, Social Intervention Group  
1255 Amsterdam Avenue, Rm 814, Mail Code: 4600, NY, NY 10027  
(212) 851 2391, fax: 212.851-2126, ne5@columbia.edu

### Authors' Note

The only intervention of its kind, the Women on the Road to Health intervention is highly efficacious in preventing HIV and other sexually transmitted infections among women in community corrections engaged in high levels of drug and sexual behaviors (primary outcomes). Earlier analyses of the data used for this current study identified rates of HIV/STIs among Black participants (208 out of a total of 306 participants), 65% of whom were depressed, comparable to rates in sub-Saharan Africa. WORTH is not however designed to treat depression. This secondary data analysis utilizes 12-month longitudinal data from the 2009 WORTH trial and investigates a potential moderating effect of depression on the intervention effect. Two hypotheses were examined. Namely, depression at baseline significantly moderates WORTH intervention effects on 1) sexual risk behaviors ( $H_1$ ): and 2) drug risk behaviors ( $H_2$ ) among participants assigned to the WORTH intervention conditions as compared with those assigned to an active control. The first hypothesis was supported at the 3- and/or 6-month mark. Results points to an urgent public health need to develop integrative HIV/STI and depression prevention interventions for women in community corrections to decrease sexual risk behaviors among those who are depressed.

### Abstract

This study was conducted in Alabama's Black Belt Counties to examine the association between household food insecurity and self-reported health status. Data were collected from 400 households to measure household food insecurity and self-reported general health status using the U.S. Food Security Module. In bivariate analyses, household food insecurity was

Policy changes to increase economic resources and access to federal food programs are needed to reduce household food insecurity in this region. Gendered experiences in the context of consequences of poverty should not be ignored.

**Keywords:** Community Corrections, Depression, Evidence-based interventions, HIV prevention, Moderation, Parole, Probation, Sexually transmitted infections

## Introduction

Decades of targeted HIV research and prevention interventions notwithstanding, low-income, cis-gender, women in U.S.' community corrections system (e.g. probation, parole, etc..) remain among the most vulnerable of all at-risk women to HIV and other sexually transmitted infections (STIs) (El-Bassel et al., 2014; Gilbert et al., 2021), with their Black women peers facing the most concentrated risks (Gilbert et al., 2021; Johnson et al., 2018). Although a leading cause of overall health and HIV disability domestically and worldwide (Friedrich, 2017), surprisingly little empirical data exists examining depressive pathways of HIV/STI risks faced by this population as a whole, much less those who are Black. Rates of depression among women in community corrections have been found to be as high as 25%, as compared with 7.1% of US adults who report having had at least one major depressive episode (Malcome et al., 2019). In addition, as high as 58% have reported the use of an illicit substance in the past two years (Golder et al., 2014). Among Black women on probation and parole specifically, these risks are perniciously and disproportionately high. Rates of depression have been identified as high as 50% (Malcome et al., 2019). In addition, depending on the form of substance endorsed, rates of substance use among Black female probationers and parolees range between 60% and as high as 85-90% (Gilbert et al., 2021). These statistics are particularly troubling since separately, depression and substance misuse has been found to 1) drive HIV/STI drug and sexual risk behaviors (Benton 2008; Defechereux 2016); 2) decrease treatment engagement (Ye, J., Shim, R., & Rust, G. 2012); and 3) curtail PrEP utilization (Gonzalez JS, Batchelder AW, Psaros C, & Safren SA 2014; Mendez, N. A., Mayo, D., & Safren, S. A. 2021).

Further exacerbating these risks, depression and the misuse of substances oftentimes co-occur. Although the preponderance of studies examining relationships between these risk variables have leveraged cross-sectional data, it has been found that women in the criminal legal system are nearly twice as likely as men to experience co-occurring substance use and depression (Messina et al., 2007). Depression and substance use co-morbidity is particularly salient for women on probation, parole and other mandated forms of community corrections sentences given the close proximity in which they live to adverse and exacerbating micro- (i.e. intimate partner violence, sex trading) and macro- (i.e. homelessness, unemployment, over policing, systemic racism) level conditions (Aholou T.M., Murray A., & Sutton M.Y. 2016). Experienced disproportionately by Black women in community corrections specifically, depression and substance misuse comorbidity has been identified as a significant pathway of HIV/STI risk, and bidirectionally associated with disproportionately high levels of structural and system risks (Mugavero et al., 2009). Literature also points to syndemic-like synergistic

interactions that occur between these co-occurring epidemics, associated with both a worsening of depression and substance misuse (Nydegger, L. A., & Claborn, K. R. 2020), and an even higher risk of HIV and STI transmission \* Thomas, K., 2011, Bhardwaj, A., & Kohrt, B. A. 2020).

Depression has also been identified as a moderator of the effectiveness of evidence-based HIV interventions. Specifically, results to date point to 1) a muting of the effectiveness of a telephone-administered motivational interviewing intervention targeting HIV positive individuals in reducing episodes of non-condom-protected anal and vaginal intercourse (Lovejoy TI, & Heckman TG 2014) ); and 2) a moderation of the effectiveness of a guided internet-based self-help cognitive behavioral intervention aimed at reducing depressive symptomology among HIV positive men (van Luenen et al., 2020). Although only two such manuscripts have been identified, neither focused on important within group differences related to 1) gender; 2) race; 3) HIV positivity status; and 4) criminal legal system involvement. Perhaps due to this disturbing inattention in literature, there is currently no evidence-based HIV/STI prevention intervention that concurrently targets depression designed for women in community corrections as a whole, or Black female probationers/parolees specifically (National Center for HIV/AIDS, N.D.)

This gap is surprising given numerous requests for proposals over the past three decades calling for the development of HIV and depression prevention interventions targeting highly vulnerable populations such as those who are forensically involved (U.S. Department of Health and Human Services, N.D. Further underscoring this urgency, the overall number of women on probation, parole, etc... has increased significantly during the same time period such that there are currently 4.5 times more women in U.S.' community corrections system than those who are incarcerated (The Pew Charitable Trusts, N.D., Nellis & Mendel, 2020). The percentage of Black women in community corrections is especially high. Despite representing only 13% of the U.S. population, cis-gender Black women account for 19% of women in the nation's state and federal prisons population, and 30% of those under community supervision (Catalyst, 2021).

The current study addresses this critical gap. In it, findings from a secondary data analysis of Women on the Road to Health (WORTH) data collected between 2009 and 2012 (NIDA R01DA025878) are presented. WORTH is the only HIV/STI prevention intervention designed specifically for low-income, women under community supervision who misuse substances (El Bassel et al., 2014). Included in the Centers for Disease Control compendium of evidence-based interventions (National Center for HIV/AIDS, N.D.), WORTH has also been culturally adapted for Black women in community corrections who use drugs (Johnson et al., 2018) and women recently released from jails and prisons. WORTH (and the adapted WORTH interventions) stands alone in its ability to stem the tide of new HIV/STI transmissions among this population variously at risk for HIV. Despite its tremendous impact to date however, WORTH is not designed to treat depression. Instead, women participating in the 2009 trial who articulated a need for mental health support were provided with behavioral health referrals, services, and support.



Building on prior findings, the present study leverages longitudinal data from the WORTH study to examine a potential moderating effect of depression on HIV/STI drug and sexual risk behaviors (main study outcomes). At baseline, 77% of all study participants ( $n = 306$ ) reported unprotected vaginal or anal sex ( $n = 237$ ) and 63% ( $n = 194$ ) had multiple sex partners. Sixty-eight percent of participants ( $n = 208$ ) self-identified as Black (El Bassel et al., 2014). Baseline rates of HIV and STIs found among the Black sample specifically were significantly higher than the already disproportionately high rates identified among all participants combined and likened to rates found in sub-Saharan Africa. Two hypotheses were examined: 1) among those assigned to the WORTH intervention conditions, depression at baseline significantly moderates WORTH intervention effects on 1) sexual risk reduction behaviors (primary outcome): a) decreasing the number of self-reported unprotected sex acts; b) increasing the proportion of protected sex; and c) increasing consistent condom use; and similarly as compared with participants assigned to the active control arm (H1); 2) drug risk reduction behaviors (primary outcome): a) heroin use in the past 90 days; b) crack cocaine use in the past 90 days; c) marijuana use in the past 90 days; d) illicit drug use in the past 90 days; e) injection drug use in the past 90 days; f) heavy drinking in the past 90 days; g) drug treatment in the past 90 days as compared with those assigned to the active control arm. (H2). Clinical implications, study limitations and suggestions for future research are also presented.

## Methods

### *Participants and Trial Design*

The 2009 WORTH study aimed to decrease HIV and other STIs (primary aim), increase condom use, reduce drug use, increase participation in drug treatment, connection to HIV care, and decrease partner violence and recidivism in the justice system among women who misuse substances on parole, probation and other forms of community corrections. Information on study participants and trial design, inclusion criteria, randomization, procedures, statistical methods, and measures have been described in the outcome paper (El Bassel et al., 2014). This secondary data analysis uses cross-sectional and longitudinal data collected from 2009 to 2012.

A brief summary of the methods used for the original study is included in the sections that follow.

### *Recruitment and Incentives*

Women were recruited by trained retention staff from community corrections and other alternatives to incarceration programs in New York City. Participants received a \$30 incentive for completing a baseline self-interview and biological testing.

### *Inclusion/Exclusion Criteria*

Women were eligible to participate if they were 18 and older, engaged in a community supervision program, were on probation or parole, enrolled in drug treatment court supervision

within 90 days, self-reported illicit drug use or binge drinking within six months, had condomless sex within 90 days, and were HIV positive or had at least one risk factor for HIV/STI within six months. HIV/STI risks included having more than one sexual partner, history of injecting drugs, an STI diagnosis, or had condomless sex with a partner who had HIV or one of the identified risk factors.

Individuals were ineligible to participate if they had a psychiatric or cognitive impairment that impeded their ability to consent. Women with depression were eligible to consent. Women were also excluded if they could not speak English or were attempting to conceive, as condom use was a focus of the intervention. Women who could not provide a mailing address or lived outside of New York City were also excluded.

### *Data Collection*

Demographics and responses about risk behavior were collected at baseline, and three-months, six-months and 12-months after treatment. At the completion of the study, 29% of participants reported having been arrested and 35% reported having been incarcerated at some point during the 12-month follow up period.

### *Randomization and Masking*

Participants were randomly assigned to one of three study conditions: traditional WORTH, multimedia WORTH, and Wellness Promotion. Investigators were masked to random assignment of each participant until data collection was completed.

### *Procedures*

Traditional WORTH involved four weekly, in-person, 90 minute group sessions, with curriculum designed to address HIV/STI knowledge, risk reduction problem-solving and negotiation skills, condom use, self-efficacy, partner abuse, safety planning, social support, identification of service needs and linkage to services, and risk reduction goal setting.

Multimedia WORTH involved the same number of group meetings and identical educational components as traditional WORTH, but was converted into interactive computerized games, video enhancements, web-connected case management tools, and interactive visual tools, including support and risk mapping. Unlike traditional WORTH, group participants used individual laptops to view video vignettes and complete skill-building activities, leaving facilitators with a less active role. Participants could complete self-paced activities independently or a facilitator-guided group-based intervention (El Bassel et al., 2014).

The Wellness Promotion assignment was also delivered in a facilitator-guided group setting, with core components of maintaining a healthy diet, promoting fitness in daily routines, addressing tobacco use risk, learning stress-reduction exercises such as guided meditation, and setting and following up on personal health goals (El Bassel et al., 2014; El Bassel et al., 2010).

## Measures

### *Behavioral Endpoints*

Participants completed a 1.5-hour computer-assisted self-interview at baseline and follow up assessments. Data was analyzed for sexual behaviors with primary partners, non-paying casual partners, and paying partners within the past 90 days (Napper, Fisher, Reynolds & Johnson, 2010), including the number of condomless sex acts, the number of sex acts with condom use, and whether participants had multiple male sex partners.

### *Biological Endpoints*

Data collection included both self-reported data and biological assays. Biological assays were used to detect HIV and three STIs (chlamydia, gonorrhea, and trichomoniasis). Women provided a self-collected vaginal swab specimen at both baseline and 12-month follow up. Oral swabs were collected from participants to test for the presence of HIV ½ antibodies using the OraQuick ADVANCE Rapid HIV Test.

### *Socio-demographic Variables*

Self-reported information was collected to capture gender, age, ethnicity, marital status, years of education, employment, monthly income, and homelessness, defined as not having a consistent place to sleep over the past 90 days.

### *History of Incarceration*

Incarceration was measured using the number of times the participant had been arrested and/or incarcerated, with distinction noted when arrests were drug-related.

### *Current and Past Substance Use*

The Risk Behavior Assessment (Booth et al., 2004) measured HIV risk behaviors and drug use within 90 days. Specifically, it assessed if participants had smoked heroin, crack/cocaine, marijuana, or methamphetamines. Participants were also asked to report if they consumed four or more alcoholic drinks within a six-hour period within 90 days.

### *Depression*

Depression symptoms were assessed using the Brief Symptom Inventory 4-item subscale (Derogatis & Melisaratos, 1983). The BSI had nine subscales designed to assess individual symptom groups, including depression (i.e., feeling no interest in things; Cronbach's  $\alpha = .84$ ). Items endorsed a 5-level Likert-type scale ranging from 0 = not at all to 4 = extremely, with higher scores indicative of increased levels of symptoms.

## Statistical Methods

### *Depression Prevalence at Baseline*

Scores from the 4 items were summed into a total score (max of 12) and then converted into a t-score with a mean of 50 and standard deviation of 10. A cutoff of 63 or above indicated

depressive symptoms, consistent with prior research (Michalopoulos, Jiwatram-Negrón & Choo *et al*, 2016). BSI scores were transformed into a T-scores using the sum from the 4 questions on BSI Depression subscale (min=0; max=12). The mean and standard deviation were then calculated and the z-score obtained (mean=3.389; standard deviation=3.411). The z-score indicates how many standard deviations the score is from the mean. The t-score takes an individual score and transform it into a standardized form, which helps to compare scores. In psychometric testing, t-score has a mean of 50 and standard deviation of 10. A cutoff of 63 on the t-score is used to indicate women who are depressed.

Two chi-square tests of independence were performed examining 1) the relationship between race and depression endorsed at baseline among the entire sample (n = 306); and 2) race/ethnicity and intervention assignment at baseline among the depressed sub-sample only at baseline (n = 49).

A two-way analysis of variance (ANOVA) test was also conducted to compare mean differences in baseline depression scores by race/ethnicity. A type I error probability of <0.05 was used to determine statistical significance.

### *Depression Moderation*

As indicated in the original outcome paper, intention-to-treat analyses were used to estimate the effects in the main study. Intervention and modality effects were obtained by applying generalized linear models with random effects for repeated measures in the multiple imputed data. Random-effects negative binomial regressions were used to estimate effects of the intervention and modality on the number of unprotected sex acts; corresponding effect estimates are reported as incident rate ratios (IRR) and 95% confidence intervals (CIs). Random-effects linear regressions were used to estimate effects on proportion of protected sex acts; corresponding effect estimates are reported as mean difference (b) and 95% CIs. Random-effects logistic regression models were used to estimate effects on consistent condom use and having multiple partners; for these effect estimates, odds ratios and 95% CIs are reported. (See paper for additional details on models created to test intervention and modality and the effects for each follow-up assessment (El-Bassel *et al.*, 2014).

For the secondary data analyses presented in this manuscript, depression at baseline, modeled as a continuous variable on intervention effects on self-reported HIV/STI drug and sexual risk behaviors (main study outcomes) collected at 3-, 6- and 12-months. Analysis

was of (1) the “intervention effect” of assignment to the active treatment conditions of the WORTH intervention (a multimedia version of the WORTH intervention or a traditional paper-based version) versus assignment to the control arm (Wellness Promotion); and (2) within those assigned to the active treatment condition, the “modality effect” of the delivery method (multimedia versus traditional). To estimate depression moderation on the “intervention effect” and the “modality effect” at the 3-, 6-, and 12-month time periods, 5 interaction terms were created using the baseline depression variable and the following variables from the original analysis: 1) the intervention effect (depression\*interv); 2) the modality effect (depression\*modal); 3) the 3month, 6month and 12-month time period variables (i.e. depression\*month\_3m); 4) the intervention\*3month, 6month and 12-month time period variables (i.e. depression\*intervx3m); and 5) the 3month, 6month and 12-month time period variables (i.e. depression\*modalx3m). 3-, 6- and 12-month regression models were then created and ran separately on original study sexual and drug outcome variables.

Due to sample size limitations, depression moderation on sexual and drug behaviors by race/ethnicity was not separately analyzed.

Statistical analyses were performed using STATA 15.1.

## Results

### *Participant Race/Ethnicity and Intervention Assignment*

As noted in the main outcome paper (El-Bassel et al., 2014), a total of 306 women were enrolled and randomized with 103 assigned to multimedia WORTH, 101 to traditional WORTH, and 102 to Wellness Promotion. Retention rates at each follow-up, which were 87% or higher for all three follow-up assessments, did not significantly differ by condition. Attrition analyses, which compared the socio-demographic characteristics of those who completed all follow-up assessments (completers) versus those who missed one or more follow-up assessments (non-completers) identified that completers on average were older (42 vs. 39 years) and less likely to report homelessness (8% vs. 18%). Of the 306 participants, 208 (68%) were Black, 47 (15%) Hispanic/Latinx, and 51 (17%) met the criteria for “Other”. (Women classified as “Other” self-identified as white, Native American, Asian, multi-racial/ethnicity, and other not specified.)

### *Sample Characteristics: Depression*

*Table 1. Depressed and Non-Depressed by Race/Ethnicity. All Participants.*

Race / Ethnicity	Total (306)	Depression (n=49)	Non-Depression (n = 257)
Black	208 (68%)	32 (65.306%)	176 (68.482%)
Other (white, mixed race)	51 (17%)	12 (24.489%)	39 (15.175%)
Hispanic/Latinx	47 (15%)	5 (10.204%)	42 (16.342%)

Table 1 presents the numbers of women by racial/ethnic designation who did and did not exhibit depressive symptomology. As indicated, forty-nine (16%) of the total sample endorsed depression at baseline. Thirty-two (65%) of the depressed sub-sample were Black, as compared with 10% (n = 5) and 24% (n = 12) who identified as Hispanic/Latinx and Other respectively. In comparison, 57% (n = 176) of the non-depressed sample identified as Black, followed by 13.7% (n = 42) and 12.7% (n = 39) who were Hispanic/Latinx and Other respectively. The chi-square statistic confirmed no significant differences between race/ethnicity and depression at baseline ( $p < .05$ ). ( $X^2 (2, N = 306) = 3.213, p = .200586$ ).

Table 2. Depressed Participants by Race/Ethnicity and Intervention Assignments

Race / Ethnicity	Total (N=49)	Wellness (n= 19)	Traditional + Mul- timedia (n= 30)
Black	32 (65.306%)	12 (63%)	20 (50%)
Other (white, mixed race)	12 (24.489%)	5 (26%)	7 (31%)
Hispanic/Latinx	5 (10.204%)	2 (11%)	3 (19%)

Table 2 presents intervention assignment by race. As reflected, among the 49 participants who endorsed depression, 19, 16, and 14 respectively were assigned to the Wellness, Traditional and Multimedia conditions. Proportionately, depressed Black women were assigned to the Wellness, Traditional, Multimedia WORTH conditions at greater amounts at 12 (63%), 8 (50%) and 12 (86%) respectively, followed by depressed women identified as “Other” and Hispanic/Latinx. Here as well, chi-square tests confirmed no significant differences between race/ethnicity and intervention assignment at baseline ( $p < .05$ ). ( $X^2 (2, N = 49) = 0.0673, p = .966891$ ). (Since there were no Hispanic/Latinx participants assigned to Multimedia WORTH, the Traditional and Multimedia arms were combined when conducting the chi-square test.)

The two-way ANOVA test identified no significant differences in depression scores and racial/ethnic identities ( $p = .5566$ ).

Additional socio-demographic characteristics, history of criminal legal involvement, drug history, and biological assay results at the baseline assessment for the sample are reported in the outcome paper. As was reported in that paper, over 90% of participants had a history of using heroin, crack/cocaine, or marijuana. One-quarter had injected drugs. At baseline, 14% of women tested positive for HIV and 26% tested positive for an STI.

Depression Moderation on Sexual Risk Behaviors Intervention Effect

Table 3. Summary of Baseline Depression Moderation on Sexual Risk Behaviors at Baseline, 3-Month, 6-Month and 12-Month Follow-up Assessments: Means/percentages and 95% Confidence Intervals.

Within 90 Days	Comparison	Entire Follow-up Main Effect	3-Month Main Effect	6-Month Main Effect	12-Month Main Effect
Number of unprotected vaginal and anal sex with primary partner	Intervention (MM+TD vs. WP)	0.23*	0.06**	0.16*	0.99
		[0.06, 0.86] (p=0.029)	[0.01, 0.40] (p=0.003)	[0.04, 0.65] (p=0.011)	[0.16, 6.16] (p=0.989)
	Modality (MM vs. TD)	2.35	2.38	2.34	3.40
		[0.54, 10.19] (p=0.255)	[0.28, 19.91] (p=0.424)	[0.54, 10.12] (p=0.257)	[0.51, 22.47] (p=0.205)
Proportion of protected vaginal and anal sex with primary partner	Intervention (MM+TD vs. WP)	0.22*	0.51**	0.33**	-0.06
		[0.05, 0.40] (p=0.011)	[0.25, 0.78] (p=0.000)	[0.14, 0.51] (p=0.001)	[-0.31, 0.20] (p=0.667)
	Modality (MM vs. TD)		-0.02	0.02	0.03
		[-0.19, 0.20] (p=0.962)	[-0.32, 0.27] (p=0.878)	[-0.18, 0.22] (p=0.856)	[-0.22, 0.29] (p=0.793)
Consistent condom use during vaginal and anal sex with primary partner	Intervention (MM+TD vs. WP)	17.10	876.67*	83.05*	1.47
		[0.84, 347.49] (p=0.065)	[1.13, 678446.1] (p=0.046)	[1.16, 5948.80] (p=0.043)	[0.03, 71.25] (p=0.846)
	Modality (MM vs. TD)	0.29	0.04	0.22	0.33
		[0.01, 5.54] (p=0.409)	[0, 16.84] (p=0.291)	[0.01, 7.98] (p=0.412)	[0.01, 21.40] (p=0.605)

Number of unprotected vaginal and anal sex with all partners	<i>Intervention (MM+TD vs. WP)</i>	0.43	0.12*	0.27	1.57
		[0.13, 1.44] (p=0.171)	[0.02, 0.85] (p=0.033)	[0.07, 1.07] (p=0.063)	[0.29, 8.57] (p=0.602)
	<i>Modality (MM vs. TD)</i>	1.57	1.18	1.57	1.76
		[0.39, 6.41] (p=0.530)	[0.14, 10.13] (p=0.877)	[0.38, 6.42] (p=0.530)	[0.31, 10.01] (p=0.523)
Proportion of protected vaginal and anal sex with all partners	<i>Intervention (MM+TD vs. WP)</i>	0.18*	0.51**	0.30**	-0.13
		[0.02, 0.35] (p=0.030)	[0.26, 0.76] (p=0.000)	[0.12, 0.47] (p=0.001)	[-0.37, 0.11] (p=0.300)
	<i>Modality (MM vs. TD)</i>	0.02	0.06	0.04	-0.01
		[-0.17, 0.21] (p=0.857)	[-0.21, 0.33] (p=0.662)	[-0.15, 0.24] (p=0.651)	[-0.25, 0.23] (p=0.952)
Number of unprotected vaginal sex with primary partner	<i>Intervention (MM+TD vs. WP)</i>	0.24*	0.05**	0.15**	1.37
		[0.06, 0.91] (p=0.035)	[0.01, 0.32] (p=0.002)	[0.04, 0.61] (p=0.008)	[0.21, 8.72] (p=0.740)
	<i>Modality (MM vs. TD)</i>	1.77	1.54	1.69	2.52
		[0.40, 7.81] (p=0.451)	[0.17, 14.02] (p=0.703)	[0.38, 7.48] (p=0.487)	[0.38, 16.58] (p=0.335)



Proportion of protected vaginal sex with primary partner	<i>Intervention (MM+TD vs. WP)</i>	0.22* [0.05, 0.39] (p=0.013)	0.51** [0.24, 0.77] (p=0.000)	0.32** [0.14, 0.51] (p=0.001)	-0.06 [-0.32, 0.20] (p=0.628)
	<i>Modality (MM vs. TD)</i>	0.00 [-0.20, 0.20] (p=0.973)	-0.03 [-0.33, 0.26] (p=0.823)	0.01 [-0.19, 0.21] (p=0.928)	0.02 [-0.24, 0.28] (p=0.856)
Consistent condom use during vaginal sex with primary partner	<i>Intervention (MM+TD vs. WP)</i>	17.94 [0.97, 333.45] (p=0.053)	606.65* [2.12, 173304.2] (p=0.026)	69.06 [1.50, 3188.08] (p=0.030)	1.17 [0.03, 40.20] (p=0.931)
	<i>Modality (MM vs. TD)</i>	0.38 [0.02, 6.60] (p=0.503)	0.14 [0, 21.89] (p=0.445)	0.38 [0.02, 9.04] (p=0.553)	0.38 [0.01, 15.74] (p=0.609)
Number of unprotected vaginal sex with all partners	<i>Intervention (MM+TD vs. WP)</i>	0.42 [0.13, 1.32] (p=0.136)	0.08** [0.01, 0.47] (p=0.005)	0.23* [0.07, 0.82] (p=0.024)	2.21 [0.41, 12.11] (p=0.359)
	<i>Modality (MM vs. TD)</i>	1.56 [0.41 5.96] (p=0.518)	0.91 [0.10, 8.09] (p=0.930)	1.53 [0.39, 6.00] (p=0.540)	2.18 [0.37, 12.71] (p=0.388)
Proportion of protected vaginal sex with all partners	<i>Intervention (MM+TD vs. WP)</i>	0.19* [0.02, 0.35] (p=0.025)	0.52** [0.27, 0.76] (p=0.000)	0.30** [0.13, 0.48] (p=0.001)	-0.13 [-0.37, 0.11] (p=0.277)
	<i>Modality (MM vs. TD)</i>	-0.01 [-0.20, 0.18] (p=0.952)	0.03 [-0.24, 0.30] (p=0.812)	0.02 [-0.17, 0.21] (p=0.823)	-0.03 [-0.27, 0.21] (p=0.801)

Consistent condom use during vaginal sex with all partners	<i>Intervention (MM+TD vs. WP)</i>	32.99 [0.04, 25011.86] (p=0.301)	17763.25** [13.84, 2.28e+07] (p=0.007)	468.33* [3.79, 57936.53] (p=0.012)	0.15 [0, 21.20] (p=0.453)
	<i>Modality (MM vs. TD)</i>	0.30 [0.01, 18.18] (p=0.569)	0.28 [0, 300.09] (p=0.718)	0.34 [0, 35.76] (p=0.649)	0.06 [0, 24.82] (p=0.362)

Table 3 presents results from random-effects generalized linear models created to examine depression moderation on the effects of the intervention (multimedia and traditional WORTH jointly vs. Wellness Promotion) with respect to sexual risk behavior outcomes (H1). A significant moderation effect of depression was identified on seven out of nine related sexual risk indications presented in the original findings: 1) Number of unprotected vaginal and anal sex with primary partner; 2) Proportion of protected vaginal and anal sex with primary partner; 3) Number of unprotected vaginal and anal sex with all partners; 4) Proportion of protected vaginal and anal sex with all partners; 5) Number of unprotected vaginal sex with primary partner; 6) Proportion of protected vaginal sex with primary partner; and 7) Number of unprotected vaginal sex with all partners.

Over the 12-month follow-up period (“entire follow up on main effect”), women with depressive symptomology in the intervention arms were 23% and 22% less likely to experience a reduction in the number (IRR=0.23; 95% CI=0.06–0.86) and proportion (IRR=0.22; 95% CI=0.05–0.40) of unprotected vaginal and anal sex (condomless) with their primary sexual partner as compared to those assigned to the Wellness condition. These effects were significant at the three- (IRR=0.06; 95% CI=0.01–0.40; IRR=0.51; 95% CI=0.25–0.78) and six-month (IRR=0.16; 95% CI=0.04–0.65; IRR=0.33; 95% CI=0.14–0.51) follow up periods, but no longer indicated significance at 12-month follow up assessment (IRR=0.99; 95% CI=0.16–6.16; IRR=-0.06; 95% CI=-0.31–0.20).

Likewise, over the 12-month follow-up period, women with depressive symptomology in the intervention arms were 43% and 18% less likely to experience a reduction in both the number (IRR=0.43; 95% CI=0.13–1.44) and proportion (IRR=0.18; 95% CI=0.02–0.35) of unprotected (condomless) vaginal and anal sex with all partners as compared to those assigned to the control condition respectively. For the number of unprotected (condomless) vaginal and anal sex with all partners, these effects were significant at the three-month mark (IRR=0.12; 95% CI=0.02-0.85), but no longer significant at the six-month (IRR=0.27; 95% CI=0.07–1.07), and 12-month follow up periods (IRR=1.57; 95% CI=0.29–8.57). Whereas, for the proportion of unprotected (condomless) vaginal and anal sex with all partners, these

effects were significant at the three- (IRR=0.51; 95% CI=0.26–0.76), and six-month marks (IRR=0.30; 95% CI=0.12–0.47); but not at the 12-month follow up period (IRR=-.13; 95% CI=-0.37–0.11).

This finding remained true when measuring the proportion protected vaginal sex (sex with condoms) with primary and all sexual partners. Specifically, depressed participants in the WORTH arms were 22% and 19% significantly less likely to use condoms consistently as compared to those assigned to the Wellness promotion arm when having vaginal sex during the entire follow up period (IRR=0.22; 95% CI=0.05–0.39; IRR=0.19; 95% CI=0.02–0.35), as well as at the three (IRR=0.51; 95% CI=0.24–0.77; IRR=0.52; 95% CI=0.27–0.72) and six-month follow up periods (IRR=0.32; 95% CI=0.14–0.51; IRR=0.30; 95% CI=0.13–0.48). (Consistent condom use was defined as having protected vaginal and/or anal sex during each penetrative sexual act).

A depression moderation intervention effect was also observed on unprotected vaginal sex with primary and all partners. When compared with the Wellness control condition, depressed participants assigned to the WORTH intervention arms were 24% less likely to see a reduction in the number of unprotected vaginal sex with their primary partners over the 12-month follow-up period (IRR=0.24; 95% CI=0.06–0.91) and at the three- (IRR=0.05; 95% CI=0.01–0.32) and the 6-month follow up period (IRR=0.15; 95% CI=0.04–0.61). Lastly, a significant intervention effect was identified at the three- (IRR=0.08; 95% CI=0.01–0.47) and the six-month follow-up assessment periods (IRR=0.23; 95% CI=0.07–0.82). for the number of unprotected vaginal sex with all partners.

### *Depression Moderation on Drug Risk Behaviors Intervention Effect*

Table 4 presents results from random-effects generalized linear models examining depression moderation on the effects of the intervention (multimedia and traditional WORTH jointly vs. Wellness Promotion) with respect to drug behavior outcomes (H<sub>2</sub>). A trend over the entire follow up period was observed related to a decreased ability to reduce illicit drug use in the past 90 days (IRR=0.39; 95% CI=0.16–0.98) among depressed participants in the Traditional and Multimedia WORTH arms, as compared to those who participated in the Wellness Promotion arm. No similar significant effect was observed at any of the follow up marks suggesting that this finding was not significant at any of the follow up time periods examined. As noted, associations between race and the identified depression moderation on the intervention effect could not be assessed due to sample size limitations.

## Discussion

Study findings provide strong support for integrating evidence-based depression treatment into efficacious HIV/STI prevention interventions that target women on probation and parole to increase intervention effects on sexual risk behaviors engaged in by participants who are depressed. This priority is consistent with ones identified in extant peer-reviewed

Table 4. Summary of Baseline Depression Moderation on Drug Risk Behaviors at Baseline, 3-Month, 6-Month and 12-Month Follow-up Assessments: Means/percentages and 95% Confidence Intervals.

Within 90 Days	Comparison	Entire Follow-up Main Effect	3-Month Main Effect	6-Month Main Effect	12-Month Main Effect
<u>heroin90</u> heroin use in the past 90 days	<i>Intervention</i>	3.28 [0.24, 44.81] (p=0.374)	4.62 [0, 6577.76] (p=0.680)	2164.54 [0, 6.66e+10] (p=0.383)	36800000.00 [9.35e-13, 1.45e+27] (p=0.449)
	<i>Modality</i>	6.61 [0.41, 107.29] (p=0.184)	1.07 [0, 2666.96] (p=0.987)	1434927 [115.79, 1.78e+10] (p=0.003)**	11700000000000000 [485674.1, 2.83e+26] (p=0.002)**
	<i>Intervention</i>	0.39 [0.16, 0.98] (p=0.046)*	0.34 [0.08, 1.41] (p=0.137)	0.3827807† [0.14, 1.03] (p=0.058)	0.34 [0.06, 1.85] (p=0.212)
	<i>Modality</i>	1.42 [0.51, 3.95] (p=0.503)	0.58 [0.11, 2.93] (p=0.507)	1.11 [0.38, 3.27] (p=0.846)	1.54 [0.26, 9.02] (p=0.634)
<u>crack90</u> crack cocaine use in the past 90 days	<i>Intervention</i>	0.96 [0.35, 2.67] (p=0.943)	0.97 [0.19, 5.05] (p=0.974)	1.02 [0.33, 3.15] (p=0.971)	0.95 [0.21, 4.37] (p=0.947)
	<i>Modality</i>	0.42 [0.12, 1.46] (p=0.172)	0.18 [0.02, 1.47] (p=0.110)	0.37 [0.01, 1.40] (p=0.143)	0.64 [0.13, 3.27] (p=0.592)
	<i>Intervention</i>	0.62 [0.20, 1.89] (p=0.401)	1.46 [0.21, 10.07] (p=0.701)	0.92 [0.24, 3.54] (p=0.899)	0.34 [0.06, 1.85] (p=0.212)
	<i>Modality</i>	1.35 [0.36, 5.12] (p=0.659)	0.72 [0.10, 5.07] (p=0.738)	1.19 [0.30, 4.67] (p=0.805)	1.54 [0.26, 9.02] (p=0.634)

<u>injdrg90</u> Injection drug use in the past 90 days	<i>Interven- tion</i>	2.19 [0.27, 17.44] (p=0.461)	2.55 [0.11, 58.98] (p=0.559)	0.00 [0, .] (p=0.997)	2.93E-71 [2.90e-73, 2.96e-69] (p=0.000)**
	<i>Modality</i>	3.81 [0.37, 38.71] (p=0.259)	1.16 [0.04, 33.68] (p=0.932)	1.97E+54 [0, .] (p=0.997)	1.1E+144 [. , .] (p=.)
	<i>Interven- tion</i>	0.63 [0.12, 3.36] (p=0.584)	2.42 [0.17, 34.19] (p=0.513)	1.06 [0.18, 6.16] (p=0.950)	0.21 [0.02, 2.19] (p=0.191)
	<i>Modality</i>	0.59 [0.08, 4.38] (p=0.602)	0.27 [0.02, 3.78] (p=0.332)	0.55 [0.09, 3.56] (p=0.534)	2.65 [0.21, 33.29] (p=0.451)
<u>crack90</u> crack cocaine use in the past 90 days	<i>Interven- tion</i>	0.96 [0.35, 2.67] (p=0.943)	0.97 [0.19, 5.05] (p=0.974)	1.02 [0.33, 3.15] (p=0.971)	0.95 [0.21, 4.37] (p=0.947)
	<i>Modality</i>	0.42 [0.12, 1.46] (p=0.172)	0.18 [0.02, 1.47] (p=0.110)	0.37 [0.01, 1.40] (p=0.143)	0.64 [0.13, 3.27] (p=0.592)
	<i>Interven- tion</i>				
	<i>Modality</i>				

literature (Azhar, S., Berringer & Epperson 2014; Sherr et al., 2011) and the Ending the HIV Epidemic initiative (Office of Infectious Disease and HIV/AIDS Policy, 2021) aimed at leveraging and tailoring proven interventions and targeting highly vulnerable populations. Moreover, current calls by the National Institutes of Health point to continuing “gaps in understanding how to best address mental health comorbidities in the context of HIV prevention and treatment” and the need to combine ‘effective HIV prevention and care interventions with efficacious mental health treatment to maximally improve mental health and HIV outcomes’ (U.S. Department of Health and Human Services, N.D.)

Specifically, results provided support for the first study hypothesis only (H<sub>1</sub>).

*H<sub>1</sub>: Depression at baseline significantly moderates the intervention effect on sexual risk reduction behaviors engaged in, as compared to the active control arm.*

As indicated, depressed participants assigned to WORTH intervention arms were significantly less likely to demonstrate a decrease the number of self-reported unprotected sex acts, and an increase in the proportion of protected sex and consistent condom use but only

within the first 3-6 months of intervention exposure. Across all areas of sexual risks examined, this effect dissipated before the 12-month mark. Findings point to a possible 'window of heightened sexual risk' may exist for women in community corrections who misuse substances, triggered by depression. This is consistent with prior findings that suggests that reducing sexual risk behaviors engaged in by women who have been convicted of crimes is intimately tied to a reduction of psychological risk factors (Azhar, Berringer & Epperson 2014).

While it was not possible to separately examine how depression may similarly or differently moderate sexual risk behaviors among African American participants in WORTH due to sample size limitations, the disproportionately high rates of depression and HIV/STIs identified are of significant concern and warrants further exploration. The importance of additional research is further underscored by earlier findings identifying disproportionately higher rates of depression among Black women in the criminal legal system (Williams et al., 2007; Malcome et al., 2019) and significant associations between depression and an increase in sexual risk behaviors engaged in by depressed African American and Mexican female participants (n= 477) in a behavioral/cognitive intervention designed to reduce sexual risk behavior and sexually transmitted infections ( Holden et al., 2008). In the latter study, depression and increased risk sexual behaviors were both associated with an inability to 1) process information, 2) identify risk, and 3) modify risky behaviors. Here as well, acute risks appeared to dissipate over time providing further evidence of a possible within of heightened sexual risk.

It will be crucial therefore for future research to examine how depression and HIV sexual risk behaviors intersect to decrease HIV/STI evidence intervention effects on sexual risk behaviors and consequently increase the risk of HIV/STIs among highly vulnerable women such as those on probation and parole and/or from traditionally underrepresented and systemically oppressed racial groups. It is possible that the disproportionately high rates of HIV and other sexually transmitted infections identified in Black 2009 WORTH participants may be associated, at least in part, with the triadic relationship between these variables. Additional research is also needed regarding if and how the moderating impact of depression may be further associated with an accumulation of other comorbid risks such as intimate partner violence, PTSD and trauma. Given findings that the identified moderation occurs within 3-6 months of intervention exposure, it will also be important to better understand the 'risk window' itself (e.g. its duration and factors associated with it opening and closing).

*H2: Depression at baseline significantly moderates the intervention effect on drug risk reduction behaviors engaged in, as compared to the active control arm.*

As indicated, the second hypothesis was not supported. The lack of significant moderation identified between depression and drug risk intervention outcomes also warrants further examination. Prior findings have identified a strong positive association between depression and an increased likelihood of illicit drug use and risky-sexual behaviors (Taniguchi et al., 2014). Since this is the first study that examines this association through the lens of the effects of a HIV/STI prevention intervention, additional research is needed that unpacks this

relationship. It will be important, for example, to determine if the lack of moderation on this intervention effect was attributed to intervention content itself or a biobehavioral process associated with substance misuse addiction. If the latter, it would be expected that there would be some variability in terms of the forms of substances endorsed (e.g. marijuana vs. illicit substances). It will be important for future research to examine how depression moderation on intervention effects may differently associated with severity of substance misuse and polysubstance use.

Despite the partial support received for the study hypotheses, the results from this study are highly instructive and provides added nuance to continuing efforts to close all remaining HIV risk pathways experienced by this already vulnerable population. Prior research suggests that the risks for acquiring HIV associated with depression co-morbidity increases 4:10 fold (Remien ET AL., 2019). In view of this concentrated risk, the depression modification on intervention effects identified in this current study may help to explain the disproportionately high rates of HIV and other sexually transmitted infections experienced by women on probation and parole. Given the aforementioned disproportionately high rates of depression and co-occurring systemic risks experienced by Black women in community corrections specifically (El Bassel et al., 2014), these risks may be significantly attenuated by race and possible synergistic interactions that may occur between HIV and depression, substance misuse, sexual risk behaviors, and other comorbidities.

Although sobering, study findings are also promising. If in fact a ‘window of heightened sexual risk’ exists, as is suggested by study findings, it is possible that a ‘window of heightened opportunity’ may also exist during which depression treatment may be optimally applied to maximize intervention effects of such a highly efficacious HIV/STI prevention intervention like WORTH. Given these findings, the results from this study can serve to sharpen prevention strategies directed at women in community corrections. Interpreted in tandem with earlier research that suggests that treating depression alone is insufficient in preventing new HIV transmissions among highly vulnerable populations (Tsai et al., 2013), the depression moderation identified in this study provides urgent support for the need to incorporate depression treatment into highly efficacious interventions like WORTH. As an important next step, additional research is needed that explores optimal approaches for integrating depression treatment into evidence-based intervention targeting women in community corrections like WORTH, and across the spectrum of criminal legal system involvement. Cultural and other forms of acculturation should also be proactively considered alongside additional research examining the possible impact of race.

There were several limitations that should also be enumerated. Due to sample size limitations, findings related to a possible drug-related risk depression moderation should be interpreted cautiously. Additional research is needed, with larger sample sizes, to further explore if there are indeed distinct windows of ‘heightened sexual risks’ and ‘heightened drug risks’ triggered by depression. In addition, since results suggest that the onset of these windows risk may differ with the period of heightened sexual risks occurring ‘3- to 6-months’ post intervention versus a ‘6- to 12-months’ window during which depressed participants may engage

in 'heightened drug risks', future studies would do well to examine these temporal differences. Also due to sample size limitations, the impact of race could not be separately examined. As also noted however, rates of HIV/STIs among Black participants were disproportionately high. Using larger datasets, additional research is needed that explores the possible impact of these within-group differences on depression moderation, as well as the alluded to potential synergism of risks.

Self-reported behavioral data was utilized. Self-reported data has proven reliable in research studies however (Johnson & Turner, 2003) and respondents in research studies have demonstrated high recall for HIV, homelessness, and other repeated and/or traumatic events (Short et al., 2009).

### Conclusions

This study is the first to examine the moderating effect of depression on the primary study outcomes of a highly efficacious HIV/STI prevention intervention targeting low-income women in community corrections who engage in high levels of drug and sexual risk behaviors. Study findings point to a significant depression moderation on sexual risk behaviors among depressed intervention participants, 65% of whom were Black. Findings identify a strong public health need for integrated HIV/STI prevention and depression interventions that target sexual risk behaviors among this highly vulnerable population who also endorse depression. Given the disproportionately high percentage of Black women on probation and parole with depressive symptomology, cultural acculturation considerations are salient. To guide intervention development/tailoring, additional research with larger sample sizes is needed to examine within-group differences related to race, depression and substance misuse severity, comorbidity, and possible mediated moderated pathways.



## Author's Notes

**Authorship and contributor acknowledgments:** KJ and AP drafted the manuscript. WC, CIW, AA, MC and BPC conducted the analyses and/or provided statistical oversight. All other authors provided critical review of the completed manuscript.

**IRB review and approval:** IRB approval was granted by the Columbia University (Morningside) Institutional Review Board (Protocol ID: IRB-AAAD5608; dates of approval: \_\_\_\_\_) and the Center for Court Innovation IRB for community supervision sites (Protocol ID: \_\_\_\_\_; dates of approval: \_\_\_\_\_).

**Acknowledgements:** The authors wish to thank the women of Project WORTH for bravely and openly sharing their stories as well as the New York City Department of Probation for their assistance in carrying out this project.

**Financial conflicts of interest or Competing interests:** The authors have declared that no competing interests exists.

**Funding and Financial contributors:** The study was funded by the National Institute of Drug Abuse (NIDA) to NE (R01DA025878). The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

**Data Availability:** The authors confirm that all data underlying the findings are fully available without restriction. Data supporting this manuscript have been deposited in Academic Commons (<http://academiccommons.columbia.edu/>), Columbia University's institutional research repository. The permanent URL is <http://dx.doi.org/10.7916/D8N0153Q>.

## References

- 1 in 55 U.S. adults is on probation or parole. The Pew Charitable Trusts. (n.d.). Retrieved September 23, 2021, from <https://www.pewtrusts.org/en/research-and-analysis/articles/2018/10/31/1-in-55-us-adults-is-on-probation-or-parole>.
- Aholou T.M., Murray A., Sutton M.Y. (2016) The Social, Structural, and Clinical Context of HIV Prevention and Care for Black/African American and Hispanic Women/Latinas in the United States. In: Wright E., Carnes N. (eds) Understanding the HIV/AIDS Epidemic in the United States. Social Disparities in Health and Health Care. Springer, Cham. [https://doi.org/10.1007/978-3-319-34004-3\\_6](https://doi.org/10.1007/978-3-319-34004-3_6)
- Azhar, S., Berringer, K.R., & Epperson, M. (2014). A Systematic Review of HIV Prevention Interventions Targeting Women with Criminal Justice Involvement. *Journal of the Society for Social Work and Research*, 5, 253 - 289.
- Benton TD. Depression and HIV/AIDS. *Curr Psychiatry Rep*. 2008 Jun;10(3):280-5. doi: 10.1007/s11920-008-0045-y. PMID: 18652798.
- Bhardwaj, A., & Kohrt, B. A. (2020). Syndemics of HIV with mental illness and other noncommunicable diseases: a research agenda to address the gap between syndemic theory and current research practice. *Current opinion in HIV and AIDS*, 15(4), 226–231. <https://doi.org/10.1097/COH.0000000000000627>
- Booth RE, Mikulich-Gilbertson SK, Brewster JT, Salomonsen-Sautel S, Semerik O (2004) Predictors of self-reported HIV infection among drug injectors in Ukraine. *Journal of Acquired Immune Deficiency Syndromes (1999)* 35: 82; Needle R, Fisher DG, Weatherby N, Chit-wood D, Brown B, *et al.* (1995) Reliability of self-reported HIV risk behaviors of drug us-ers. *Psychology of Addictive Behaviors* 9: 242.
- Compendium of Evidence-Based Interventions and Best Practices for HIV Prevention. Content source: Division of HIV/AIDS Prevention, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Centers for Disease Control and Prevention. Retrieved from <http://medbox.iab.me/modules/en-cdc/www.cdc.gov/hiv/research/interventionresearch/compendium/index.html>
- Defechereux, P. A., Mehrotra, M., Liu, A. Y., McMahan, V. M., Glidden, D. V., Mayer, K. H., Vargas, L., Amico, K. R., Chodacki, P., Fernandez, T., Avelino-Silva, V. I., Burns, D., Grant, R. M., & iPrEx Study Team (2016). Depression and Oral FTC/TDF Pre-exposure Prophylaxis (PrEP) Among Men and Transgender Women Who Have Sex With Men (MSM/TGW). *AIDS and behavior*, 20(7), 1478–1488. <https://doi.org/10.1007/s10461-015-1082-2>

- Derogatis, L. R., & Melisaratos, N. (1983). The Brief Symptom Inventory: An introductory report. *Psychological Medicine*, 13(3), 595–605. <https://doi.org/10.1017/S0033291700048017>
- El-Bassel, N., Gilbert, L., Goddard-Eckrich, D., Chang, M., Wu, E., Hunt, T., Epperson, M., Shaw, S. A., Rowe, J., Almonte, M., & Witte, S. (2014). Efficacy of a group-based multi-media HIV prevention intervention for drug-involved women under community supervision: project WORTH. *PloS one*, 9(11), e111528. <https://doi.org/10.1371/journal.pone.0111528>
- El-Bassel N, Jemmott JB, Landis JR, Pequegnat W, Wingood GM, et al. (2010) National Institute of Mental Health multisite Eban HIV/STD prevention intervention for African American HIV serodiscordant couples: A cluster randomized trial. *Archives of Internal Medicine*. 170: 1594.
- Friedrich M. J. (2017). Depression Is the Leading Cause of Disability Around the World. *JAMA*, 317(15), 1517. <https://doi.org/10.1001/jama.2017.3826>
- Gilbert, L., Goddard-Eckrich, D., Chang, M., Hunt, T., Wu, E., Johnson, K., Richards, S., Good-win, S., Tibbetts, R., Metsch, L. R., & El-Bassel, N. (2021). Effectiveness of a Culturally Tailored HIV and Sexually Transmitted Infection Prevention Intervention for Black Women in Community Supervision Programs: A Randomized Clinical Trial. *JAMA network open*, 4(4), e215226. <https://doi.org/10.1001/jamanetworkopen.2021.5226>
- Golder, S., Hall, M. T., Logan, T. K., Higgins, G. E., Dishon, A., Renn, T., & Winham, K. M. (2014). Substance use among victimized women on probation and parole. *Substance use & misuse*, 49(4), 435–447. <https://doi.org/10.3109/10826084.2013.844164>
- Gonzalez, J. S., Batchelder, A. W., Psaros, C., & Safren, S. A. (2011). Depression and HIV/ AIDS treatment nonadherence: a review and meta-analysis. *Journal of acquired immune deficiency syndromes (1999)*, 58(2), 181–187.
- Holden, A. E., Shain, R. N., Miller, W. B., Piper, J. M., Perdue, S. T., Thurman, A. R., & Korte, J. E. (2008). The influence of depression on sexual risk reduction and STD infection in a controlled, randomized intervention trial. *Sexually transmitted diseases*, 35(10), 898–904. <https://doi.org/10.1097/OLQ.0b013e31817d7a33>
- Johnson, K., Gilbert, L., Hunt, T. *et al.* The effectiveness of a group-based computerized HIV/STI prevention intervention for black women who use drugs in the criminal legal system: study protocol for E-WORTH (Empowering African-American Women on the Road to Health), a Hybrid Type 1 randomized controlled trial. *Trials* 19, 486 (2018). <https://doi.org/10.1186/s13063-018-2792-3>

- Johnson, B., & Turner, L. A. (2003). Data collection strategies in mixed methods research. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of Mixed Methods in Social and Behavioral Research*. Thousand Oaks, CA: Sage Publications, Inc.
- Lovejoy TI, & Heckman TG (2014) Depression Moderates Treatment Efficacy of an HIV Secondary-Prevention Intervention for HIV-Positive Late Middle-Age and Older Adults, *Behavioral Medicine*, 40:3, 124-133, DOI: 10.1080/08964289.2014.893982
- Malcome, M. L. D., Fedock, G., Garthe, R. C., Golder, S., Higgins, G., & Logan, T. K. (2019). Weathering Probation and Parole: The Protective Role of Social Support on Black Women's Recent Stressful Events and Depressive Symptoms. *Journal of Black Psychology*, 45(8), 661–688. <https://doi.org/10.1177/0095798419889755>
- Mendez, N. A., Mayo, D., & Safren, S. A. (2021). Interventions Addressing Depression and HIV-Related Outcomes in People with HIV. *Current HIV/AIDS reports*, 18(4), 377–390. <https://doi.org/10.1007/s11904-021-00559-w>
- Messina, N., Grella, C., Burdon, W., & Prendergast, M. (2007). Childhood Adverse Events and Current Traumatic Distress: A Comparison of Men and Women Drug-Dependent Prisoners. *Criminal Justice and Behavior*, 34(11), 1385–1401. <https://doi.org/10.1177/0093854807305150>
- Michalopoulos, L.M., Jiwatram-Negrón, T., Choo, M.K.K. et al. The association between psycho-social and structural-level stressors and HIV injection drug risk behavior among Malaysian fishermen: A cross-sectional study. *BMC Public Health* 16, 464 (2016). <https://doi.org/10.1186/s12889-016-3125-7>
- Mugavero, M. , Lin, H. , Willig, J. , Westfall, A. , Ulett, K. , Routman, J. , Abrams, S. , Raper, J., Saag, M. & Allison, J. (2009). *Clinical Infectious Diseases*, 48(2), 248-256. doi: 10.1086/595705.
- Napper LE, Fisher DG, Reynolds GL, Johnson ME (2010) HIV risk behavior self-report reliability at different recall periods. *AIDS and Behavior* 14: 152–161
- Nellis, A., & Mendel, R. (2020, December 9). *Incarcerated women and girls*. The Sentencing Project. Retrieved September 23, 2021, from <https://www.sentencingproject.org/publications/incarcerated-women-and-girls/>.
- Nydegger, L. A., & Claborn, K. R. (2020). Exploring patterns of substance use among highly vulnerable Black women at-risk for HIV through a syndemics framework: A qualitative study. *PloS one*, 15(7), e0236247. <https://doi.org/10.1371/journal.pone.0236247>

Office of Infectious Disease and HIV/AIDS Policy, H. H. S. D. last updated: J. 02. (2021, June 2). *Overview*. HIV.gov. Retrieved September 23, 2021, from <https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/overview>.

*Probation and parole systems marked by high stakes, missed opportunities*. The Pew Charitable Trusts. (n.d.). Retrieved September 23, 2021, from <https://www.pewtrusts.org/en/research-and-analysis/issue-briefs/2018/09/probation-and-parole-systems-marked-by-high-stakes-missed-opportunities>.

Remien, R. H., Stirratt, M. J., Nguyen, N., Robbins, R. N., Pala, A. N., & Mellins, C. A. (2019). Mental health and HIV/AIDS: the need for an integrated response. *AIDS (London, England)*, 33(9), 1411–1420. <https://doi.org/10.1097/QAD.0000000000002227>

Sherr, L., Clucas, C., Harding, R., Sibley, E., & Catalan, J. (2011). HIV and depression--a systematic review of interventions. *Psychology, health & medicine*, 16(5), 493–527. <https://doi.org/10.1080/13548506.2011.579990>

Short, M. E., Goetzel, R. Z., Pei, X., Tabrizi, M. J., Ozminkowski, R. J., Gibson, T. B., . . . Wil-son, M. G. (2009). How accurate are self-reports? Analysis of self-reported health care utilization and absence when compared with administrative data. *Journal of Occupational and Environmental Medicine*, 51(7), 786–796. doi:10.1097/JOM.0b013e3181a86671

Taniguchi, T., Shacham, E., Onen, N. F., Grubb, J. R., & Overton, E. T. (2014). Depression severity is associated with increased risk behaviors and decreased CD4 cell counts. *AIDS care*, 26(8), 1004–1012. <https://doi.org/10.1080/09540121.2014.880399>

Thomas, K., Wilson, J.L., Bedell, P. et al. “They didn’t give up on me”: a women’s transitions clinic from the perspective of re-entering women. *Addict Sci Clin Pract* 14, 12 (2019). <https://doi.org/10.1186/s13722-019-0142-8>; Jaimie P. Meyer, Sandra A. Springer, and Frederick L. Altice. *Journal of Women’s Health*. Jul 2011.991-1006.<http://doi.org/10.1089/jwh.2010.2328>

Tsai, A.C., Mimiaga, M.J., Dilley, J.W. et al. Does Effective Depression Treatment Alone Reduce Secondary HIV Transmission Risk? Equivocal Findings from a Randomized Controlled Trial. *AIDS Behav* 17, 2765–2772 (2013). <https://doi.org/10.1007/s10461-013-0600-3>

U.S. Department of Health and Human Services. (n.d.). NOT-MH-20-013: *Notice of special Interest (NOSI): Mental Health comorbidities in HIV prevention and treatment*. National Institutes of Health. Retrieved September 23, 2021, from <https://grants.nih.gov/grants/guide/notice-files/NOT-MH-20-013.html>.

- U.S. Department of Health and Human Services. (n.d.). *NIH guide: COMORBID mental disorders and HIV/STD prevention*. National Institutes of Health. Retrieved September 23, 2021, from <https://grants.nih.gov/grants/guide/rfa-files/RFA-MH-99-008.html>.
- U.S. Department of Health and Human Services. (n.d.). *Rfa-mh-21-117: Mood disorders in people living with HIV: Mechanisms and pathways (r21 clinical trial optional)*. National Institutes of Health. Retrieved September 23, 2021, from <https://grants.nih.gov/grants/guide/rfa-files/RFA-MH-21-117.html>.
- U.S. Department of Health and Human Services. (n.d.). *NIH guide: HIV/AIDS and other infections among drug users in the criminal justice system*. National Institutes of Health. Retrieved September 23, 2021, from <https://grants.nih.gov/grants/guide/rfa-files/RFA-DA-04-015.html>.
- U.S. Department of Health and Human Services. (n.d.). *Rfa-da-20-028: Implementing the HIV ser-vi-ce cascade for justice-involved populations (u01 clinical trial required)*. National Institutes of Health. Retrieved September 23, 2021, from <https://grants.nih.gov/grants/guide/rfa-files/rfa-da-20-028.html>.
- U.S. Department of Health and Human Services. (n.d.). *NOT-MH-20-013: Notice of special Inter-est (NOSI): Mental Health comorbidities in HIV prevention and treatment*. National Institutes of Health. Retrieved September 23, 2021, from <https://grants.nih.gov/grants/guide/notice-files/NOT-MH-20-013.html>.
- van Luenen, S., Kraaij, V., Spinhoven, P., Dusseldorp, E., & Garnefski, N. (2020). Moderators of the effect of guided online self-help for people with HIV and depressive symptoms. *AIDS care*, 32(8), 942–948. <https://doi.org/10.1080/09540121.2019.1679703>
- Williams, D. R., Gonzalez, H. M., Neighbors, H., Nesse, R., Abelson, J. M., Sweetman, J., Jackson, J. S. (2007). Prevalence and distribution of major depressive disorder in African Americans, Caribbean Blacks, and non-Hispanic Whites: Results from the National Survey of American life. *Archives of General Psychiatry*, 64, 305–315. doi:10.1001/archpsyc.64.3.305
- Women of color in the United States* (QUICK TAKE). Catalyst. (2021, June 15). Retrieved September 23, 2021, from <https://www.catalyst.org/research/women-of-color-in-the-united-states/>.
- Ye, J., Shim, R., & Rust, G. (2012). Health care avoidance among people with serious psychological distress: analyses of 2007 Health Information National Trends Survey. *Journal of health care for the poor and underserved*, 23(4), 1620–1629. <https://doi.org/10.1353/hpu.2012.0189>

## Health Communication, HIV/AIDS, and Black Women

**Gwendolyn West, D.Min., M.A.**

Merck Public Health Post-Doctorate Fellow

National Center for Bioethics in Research and Health Care

Tuskegee University

Phone: 786-287-8582

Email: [gspence45@aol.com](mailto:gspence45@aol.com); [gwest@tuskegee.edu](mailto:gwest@tuskegee.edu)

### Abstract

Communications is a vital component of everyday life. Without it, many people may find it hard to survive in today's society. There is a multiplicity of ways to communicate, be it verbal or non-verbal. However, if the constructs of communication are misconstrued, it is worthless. Especially, when there is an urgency to save lives using communications. Health communications is one aspect that is critical for population health. If used properly, it can reduce the risk of epidemics and pandemics. Globally, HIV/AIDS became a pandemic in the early 1980s. The World Health Organization (WHO) reported by 2020, there were more than 55.9 million confirmed cases of HIV/AIDS and 36.3 million died from the dread disease worldwide. Out of these grave statistics, Black women are affected more than any other group by the HIV/AIDS pandemic. This article aims to shed light on this growing issue and set in motion an understanding how adequate health communications can eradicate Black women from the growing demise of HIV/AIDS.

*Keywords:* Health Communication, populations health, Black women, Pandemic, HIV/AIDS, stigma, gendered racism, optimal health

### Introduction

Statistics show that Black women represent six out of ten new cases of HIV/AIDS in the United States (U.S.) (Laurencin, C.T., Murdock, C.J., Laurencin, L., & Christensen, D.M., 2018). There has been a misnomer, that some people among the Black population deems these findings misconstrued, lead to stigmas, and lack trustworthiness towards current health communications. Individuals with multiple occurring devalued social identities often experience stigmas. Race/ ethnicity, and sex/gender for most Black women have an associated stigma that can contribute to mental and emotional disparities. For the most part, many Black women are oppressed and experience stereotypes because of the stigma associated with heightened rates of HIV/AIDS findings among this sector of the population. Some Black women have been the blame for being the culprit of the spread of the disease. Even though, in the late 1960s, the disease was diagnosed predominately among male-to-male and among white men. The Center of Disease Control (CDC), reports that today, Blacks have the most severe burden of HIV/AIDS than any other racial/ethnic group in the U.S. (CDC, 2018). It is of utmost importance to discern why and how black women have become so drastically affected by HIV/AIDS in this sector of the population.

### Gender Racism

In an American Journal on Public Health (AJPH) report, Aggleton and Parker argued that gender and race are strongly linked to health outcomes including disparities along the HIV/AIDS continuum among Black women (Aggleton & Parker 2018). Additionally, they said, “much of the prevention and intervention work for Black women has failed to focus on the multifaceted nature of health and well-being for women of color” (Aggleton & Parker 2018). The existing HIV work, the issues of race, gender, and socioeconomic status, are largely treated as discrete categories rather than interconnected issues. As a result, race and gender are often isolated and treated as an independent contributor to health outcomes, which causes gendered racism and detriment for Black women seeking care (Aggleton & Parker 2018). Gender racism functions as a way to distinguish races as inferior or superior to one another and is a form of oppression that occurs due to race and gender (Perry, Brea L., Harp Kathi, & Oscar Carrie B., 2013). Stigmas relating to gendered racism pushes some Black women to keep their statuses hidden, places them in an increased risk of HIV/AIDS infection, and forces them to stay at home rather than engage in HIV/AIDS continuum. Providing Black women an opportunity to receive validation about their experiences of gender racism is critical. People who feel in control of their lives are more likely to engage in health affirming activities, seek help, and practice lifestyles that communicate optimal health.

### Inadequate Communication Health

Some scholars see inadequate health communication as another factor of decreased presence of HIV/AIDS among Black woman’s populace in the U.S. and calls for a more accurate consensus of how effective, if any, is health communications among this sector of the populations.

To understand health communications, one must first have an overview of communication science. Then, understand the role that health communications play within vulnerable and susceptible populations of Black women. Health communications is the study and practice of communicating promotional health information such as public health campaigns, and health education between doctors, health practitioners, and patients (Berger C.K., 1987). The purpose is to influence personal health choices by improving health literacy. Just as the field of medicine, epidemiology, public health, and bioethics, are vast fields of research and practices, no one can claim to have knowledge of all that health communications entails. It is a vast and growing discipline. However, communications in itself is a mechanism to how teachers teach and learners learn. It is where marketers promote services and products, and consumers decide what to buy and consume. It is also, where communities build consensus and enforce policies, rules, and norms. On the other hand, health communications is how health providers and professionals provides care and seek patients to use their services, and develop a process by which the populates are asked to live healthy or unhealthy lives and lifestyles. Health communications is a subset of the communication science discipline. Many Communications Scientist deem health communications as a confusing discipline and is curious about how it affects health outcomes (Berger C.K., 1987). In the latter part of the



20th century, health communications grew from diverse roots of many disciplines such as sociology, political science, anthropology, political science, electrical engineering, cybernetics, and neuroscience. No wonder it is a confusing discipline for them. Communications scientists defer to communications as a fundamental human process without which most individuals, groups, organizational and societal activities could not happen, including how people think and respond to health issues such as HIV/AIDS. (Berger C.K., 1987).

Moreover, communication science seeks to understand diverse mechanisms and processes by which information can mobilize strategically in domains such as public health (Berger, C.K., 1987). Some communication scientist recognize that communications occurs on multifaceted levels, such as interpersonal, intrapersonal, network and organizations, and macro-societal. Interpersonal is the realm of social relationships. Intrapersonal is the realm of emotional, cognition, and decision-making. Network and organization is the realm of norms and social structure. Macro-societal is the realm of large social systems and culture (Schramm, W. 1963). Unfortunately, many people outside the field consider communications to be the messages and materials that communicators produce such as, pamphlets in the doctor's offices, pharmaceutical commercials on television and radio, billboards, bus benches, and home visits from health care workers. These types of understandings under-mind the range of possibilities that health communications can produce in HIV/AIDS prevention for Black women. Especially when health communication can channel negative connotations as well, towards certain populations, particularly Black women, by continuing the use of stereotypes that encourage stigmas. Communication health must rely on strategies to promote positive messages, which in return will influence positive outcomes and attitudes toward HIV/AIDS testing among Black women. By shifting the perception about HIV risk, increasing confidence in preventing infection, increasing the salient social norms about testing, diminishing stereotype about Black women, and encouraging friends to "get" tested. Health communications can help create and sustain a positive supportive environment within which HIV/AIDS risk behaviors occurs. In which, can promote positive behavior changes.

Health communications can be a combination of verbal, non-verbal, visual, oral, and written, with or without the aid of technology. It is an important tool in the prevention and treatment of HIV/AIDS. Although, health communications have no effects on the virus that is responsible for HIV/AIDS, it can have an enormous effect on knowledge, attitudes, social norms, risk perception and behavioral decision among Black women. It can expose how the virus is transmitted, where and when testing and care should be sought, how care is delivered, and what the cost are in association with treatment.

Historically, there have been much silence over funding for the HIV/AIDS epidemic. Health officials became aware of the deadly disease the summer of 1981 and for an additional four years, they remained silent and unresponsive to this health emergency. It was not until late 1985 that the President Ronald Reagan announced HIV/AIDS publicly. By then, the virus was full blown and more than 4700 people succumbed to the disease (Francis, 2012). Since that time, it has been an ongoing crisis. Laura Cheevers, an associate administrator for the HIV/AIDS Bureau, Health Resources and Service Administration, United State Health and Human

Resources, noted in a demonstration project, the focus on improving HIV care and treatment for Black Women, accounted for the largest share and highest rate of new HIV infections among women in 2018 (Cheever 2018). A national health communications plan in the U.S. will be idea for the expulsion of the spread of HIV/AIDS in vulnerable and susceptible populations, especially among Black women.

### Resources for HIV/AIDS

Every year the Federal government commits significant resources to fight against HIV/AIDS. By law, they must provide information on how the funds are allocated. For the fiscal year of 2020/2021, the U.S. government's investment in domestic response to HIV has risen to more than \$28 billion (HIV.gov., 2020). Forty percent of the funds were divided among 195 agencies and the remaining sixty percent was allocated to the Ryan White fund. The Ryan White Program is the largest source of federal funding for HIV/AIDS care in the U.S., after Medicare and Medicaid (KFF, 2020). The program was initiated because Ryan White, a thirteen years old white male, was affected by HIV/AIDS after a blood transfusion in 1984, and given six months to live (HIV.gov, 2020). However, he lived five additional years than predicted. At that time, there was no health communications surrounding the disease and no precautions in place by hospital. However, according to Ryan's mother, CDC just showed up one day and put together all precautions such as gloves, masks, gowns, and so forth. All of a sudden, everything changed for Ryan. (HIV/AIDS Bureau, 2017). Ryan was deathly ill for more than one and a half years. Mrs. White thought, every cough, sneeze, or fever would be his last one. As Ryan began to get healthier, he desired to go back to school in hopes of not having to repeat seventh grade. That decision ended up in a huge court battle. People in Ryan's community were not kind and were extremely discriminatory, that banished Ryan from school, leaving he and his family no other choice, but to uproot, and move to another town. After relocating, Ryan's situation became increasing better because of the new school's class president, a girl named Jill. When she heard of Ryan's condition, she reached out to doctors, medical professionals, and health communicators, to talk to the students about the disease, and assisted with distributing information about the disease with other parents. Luckily, Ryan was able to go back to school. He was able to live a normal life until two months before his high school graduation. After that time, he succumbed to the virus. In 1990, as a testament to Ryan's honor, Congress passed a legislation bearing his name, causing his legacy to be that people living with HIV/AIDS are getting their medicines and treatments (HIV/AIDS Bureau, 2017). Even though, the Ryan White program targets those who are living with HIV/AIDS, there is an ongoing need to hone in on the population that is most vulnerable among the HIV/AIDS population, and that is the population of Black women in the U.S.

### A Florida Family

If adequate communications health was at the forefront during the initial outbreak of HIV/AIDS, a Florida mother of five would have known to be more cautious of this deadly disease and protected herself. Eventually, she and her entire family succumbed to the disease. During the beginning of the outbreak, some medical professional and many healthcare

practitioners deemed HIV/AIDS as a gay man's disease. The Florida mother, newly married, and unbeknown to her, the new husband was bi-sexual. Years later, after fathering five children, he became very ill and died. He was diagnosed as having complications from pneumonia. The mother was never told that he nor she was infected with the HIV/AIDS virus. After a few years, the woman marries again and bore a beautiful baby girl. Soon after, one of the children became ill and died. Again, the child was diagnosed with complications of pneumonia. A few months later, two more of the children became ill with the same symptoms. The Family and Children Services were informed about the health issues this family were experiencing, and the hospital began to research why all the children were falling ill and dying. After numerous of tests were ran at Jackson Memorial Hospital, the doctors diagnosed all the children, mother, and stepfather as being affected with HIV/AIDS. Subsequently, the entire family died from the dread disease. Because earlier on, the disease had been a gay man's disease, no one ever bothered to run additional test to find out the root cause of this family's ailment until it was too far gone. The Florida mother's case is one that represents many vulnerabilities and susceptibilities that Black women face because of inadequate communication health issues.

### Mandate for Special Attention

Since HIV/AIDS is intensely prevalent among the populations of Black women, the need for special attention and a mandate to address this group is critical. Since it is well documented, and if the findings are valid that six out of every ten new infections are Black women, there should be more extreme measures in place to combat the growing issue of HIV/AIDS that Black women face in the U.S. For so long, many Black women continues to be the most affected when it comes to disparities of any kind in the United States. Despite major advances in knowledge about HIV/AIDS, none can be received successfully if the underlining source of the information is not communicated vastly among the population of Black women who are most vulnerable and susceptible to the disease. According to Jacob Heller, doctor of the Sociology, Old Westbury New, Jersey, "The social context of the early HIV/AIDS epidemic in the United States provided grounds for rumors about the transmission" (Heller, 2015). He went on to say, "Today, however, rumors about HIV/AIDS persist only with the African American public" (Heller 2015). Rightfully so, because historical racial oppression, unethical practices, and distrust between Blacks and health professionals, have left an indelible stain. Building trust and empowerment in health communications is important to improve the crisis of HIV among Black women in the U.S. Health communications must be communicated trustworthily, without stereotypes. Black women can no longer be the blame for issues and epidemics that the U.S. suffer from and called names referring to her as the problem. Health communications about the diseases is crucial. Whoever controls the communication system controls the power. Information is useless unless someone communicates it (Shannon and Nicholas, 2009).

### Conclusion

Until information about HIV/AIDS is communicated targeting Black woman in ways that they can receive it, the dilemma will continue. Health communication is not utilized enough in this sector of population to decrease the number of HIV/AIDS cases. A greater emphasis on new programs to be established to target the disproportionate and increasing numbers among the Black women's AIDS sufferers in the U.S. or the epidemic will continue to grow (Laurencin, C.T., Murdock, C.J., Laurencin, L., & Christensen, D.M., 2018). Since it is communicated that Black women are the highest group who are affected by HIV/AIDS, specific fundings for this group should be allocated solely in their direction also. Just as it was necessary to target Ryan White's group to get others to understand his plight with HIV/AIDS, it is equally important to target Black women sufferers as well. In order for this sector of the population to get a clear consensus how to discern why this population is more effected than others. The more informed Black women are, the more likely they will know what to do and where to go to seek care. If the statistics are valid, Black women should receive support by increasing resources to build community capacity to address these challenges as they arise. Empowerment is a key component to health communications. It deploys skills, knowledge and resources that will facilitate efforts of knowing how and why HIV/AIDS manifests itself vastly among Black women in the U.S. Adequate health communications is vital to eradicate HIV/AIDS among Black women who are increasing in numbers daily.

## Citations

- Berger, C.K., Chaffee S. H., eds. (1987), *Handbook of Communication Science*. Los Angeles, CA: Sage.
- CDC, (2018), [www.gov/HIV/group/racial/african-americans/index.html](http://www.gov/HIV/group/racial/african-americans/index.html).
- Christy L. Erving, L. A. S. (n.d.). Psychologically resilient, but physically vulnerable? exploring the psychosocial determinants of african american women's mental and physical health – Christy L. Erving, Lacey A. Satcher, Yvonne Chen, 2021. SAGE Journals. Retrieved November 21, 2021, from <https://journals.sagepub.com/doi/10.1177/2332649219900284>.
- Claxton, G. (2020). Health benefits in 2020: Premiums in employer-sponsored plans grow 4 percent; & employers consider responses to pandemic: *Health Affairs Journal*. Health Affairs. Retrieved November 21, 2021, from <https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2020.01569>.
- Content Source: Office of Infectious Disease and HIV/AIDS Policy, H. H. S. D. last updated: J. 15. (2021, April 8). HIV national strategic plan (2021-2025). HIV.gov. Retrieved November 21, 2021, from <https://www.hiv.gov/federal-response/hiv-national-strategic-plan/hiv-plan-2021-2025>.
- Francis. (n.d.). (2021), Commentary: Deadly aids policy failure by the ... - jstor home. Retrieved November 21, 2021, from <https://www.jstor.org/stable/23253449>.
- Heller J. (2015). Rumors and Realities: Making Sense of HIV/AIDS Conspiracy Narratives and Contemporary Legends. *American journal of public health*, 105(1), e43–e50. <https://doi.org/10.2105/AJPH.2014.302284>.
- Hab.hrsa.gov/about-ryan-white-hiv-aids-program/who-was-ryan-white. (n.d.). Retrieved November 21, 2021, from [http://sociallaw.weebly.com/uploads/1/3/9/3/13930203/the\\_ryan\\_white\\_care\\_act\\_ppp.pdf](http://sociallaw.weebly.com/uploads/1/3/9/3/13930203/the_ryan_white_care_act_ppp.pdf)
- Hutchinson P, & Wheeler J., 2006, The cost-effectiveness of health communication programs: what do we know? *J Health Commun*. 2006;11 Suppl 2:7-45.
- Laurencin, C., Murdock, C.J., Laurencin, L., & Christensen, D.M., 2018, HIV/AIDS and the African American Community 2018: a Decade Call to Action, *Journal of Racial and Ethnic Health Disparities: An Official Journal of the Cobb-NMA Health Institute*. Vol. 5. Number 3. P.449-458.
- Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social science & medicine* (1982), 57(1), 13–24. [https://doi.org/10.1016/s0277-9536\(02\)00304-0](https://doi.org/10.1016/s0277-9536(02)00304-0)

## Articles

---

Shannon, Thomas A., & Kockler, Nicholas, 2009, *An Introduction to Bioethics*, Pauline Press, Boston, MA.

West, CM. (2008), Mammy, Jezebel, Sapphire, and their home-girls: Developing an “oppositional gaze” toward the images of Black women. In: Chrisler J, Golden C, Rozee P, editors. *Lectures on the psychology of women*. New York, NY: McGraw Hill; pp. 286–299.

World Health Organization. (n.d.). Home. World Health Organization. Retrieved November 21, 2021, from <https://www.who.int/>.

## **Influence of Spirituality, HIV Stigma and Education on HIV Knowledge in Rural African American Congregants in the Deep South: Additional Findings from Project FAITHH**

**Corresponding Author: Shameka L. Cody, PhD, AGNP-C**

Assistant Professor, Capstone College of Nursing  
The University of Alabama  
650 University Blvd E.  
Tuscaloosa, AL  
Tel: (205) 348-3374 Fax: (205) 348-5559  
Email: slcody@ua.edu

**Raheem J. Paxton, PhD**

Associate Professor, College of Community Health Services  
The University of Alabama School of Medicine  
Northeast Medical Center  
211 Peter Bryce Boulevard  
Tuscaloosa, AL 35487  
Tel: (205) 348-6857  
Email: rpaxton@ua.edu

**Hannah Woodard**

Medical student, University of Alabama at Birmingham  
School of Medicine  
1720 2nd Ave. S.  
Birmingham, AL 35294  
Tel: (205) 975-8884  
Email: hnwoodard@uab.edu

**Pamela Payne-Foster, MD, MPH**

Professor, College of Community Health Services  
The University of Alabama School of Medicine  
Northeast Medical Center  
211 Peter Bryce Boulevard  
Tuscaloosa, AL 35487  
Tel: (205) 348-5148  
Email: pfoster@ua.edu

### **Authors' Note**

This manuscript includes additional findings from Project FAITHH. This work has been supported by the National Center for HIV, STD and TB Prevention at the U.S. Centers for Disease Control and Prevention under Grant No. 1201 PS00332-O1. The study was approved

by The University of Alabama's Institution Review Board (12-OR-063-R7, 2013-2019). There are no conflicts of interest. The authors have nothing to disclose. This study was approved by The University of Alabama's Institution Review Board. The data are available upon request.

### Abstract

HIV incidence has shifted racially and geographically in the United States and now represents higher proportions of African Americans living in the Rural South. Lower levels of HIV knowledge may be the culprit behind the increasing HIV rates observed in the Rural South. The purpose of this study was to investigate the individual and joint correlates of HIV knowledge in a sample of rural African Americans. Baseline data from a faith-based anti-stigma intervention (Project FAITHH, N= 210) was used to assess associations between sociodemographic characteristics, spirituality, stigma, and HIV knowledge scores. Associations were examined with recursive partitioning. Statistical significance was determined at  $P < 0.05$  with a two-sided test. Recursive partitioning revealed five distinct groups based on the data. HIV knowledge scores were highest among participants who attended some college ( $P < 0.001$ ) with lower levels of individual stigma ( $P < 0.001$ ). HIV knowledge scores were lowest among less educated individuals ( $P < 0.001$ ) who had lower levels of perceived community stigma ( $P = 0.002$ ). Future interventions designed to improve HIV knowledge in rural African Americans should consider tailoring content to those who have the greatest deficits in HIV knowledge, which may be based on perceived community stigma and education levels.

*Keywords:* HIV knowledge, spirituality, stigma, rural, African Americans, religion

### Introduction

African Americans made up approximately 42% of new human immunodeficiency virus (HIV) diagnoses in 2018 (CDC, 2020). The Southern region of the United States represents the largest proportion of African Americans (AA) living with HIV (54%), which is significantly higher than that of the Northeast (39%). Given that the prevalence of AAs living with HIV is higher in the South, there is a need to examine the perceptions and beliefs of HIV among African Americans living in this geographical region (Reif S, et.al., 2017).

A few studies have identified sociodemographic factors influencing level of HIV knowledge among AAs in the South. In a study of 1,864 AAs, lower levels of HIV knowledge were associated with being older (i.e., aged 50 or older), having no more than a high school education, and not knowing anyone who had been infected with HIV (Klein H, Sterk CE, & Elifson KW, 2016). In another study of younger AAs, higher HIV knowledge was associated with being age 26-30, being female, having a Bachelor's degree and higher, and using selected media as an HIV/AIDS information source (Okumu E. et al., 2017). Data from focus groups conducted in four southern states among AAs revealed age differences in HIV perception with older individuals describing HIV as a "death sentence", younger individuals having less fear of HIV, and some individuals associating transmission of HIV with stereotypes such as being gay (Reif S, Wilson E, & McAllaster C, 2018). A lack of positive response to HIV



from the faith-based community emerged as another stigma-related influence among the AA community in the South. Some participants reported negative sermons related to HIV in the church and sexual orientation which impact their beliefs about HIV and self-perceptions should they become diagnosed (Reif S, Wilson E, & McAllaster C, 2018). Fear of rejection and discrimination within some AA communities contribute to lack of disclosure for people living with HIV, which in turn may foster HIV-related myths and avoidance of discussions related to HIV and sexuality in the community and home (Reif S, Wilson E, & McAllaster C, 2018).

In the AA community, spirituality is embedded in the fabric of society (Coffman K. et. al., 2014). According to a recent PEW research study (Hackett C. et. al., 2014), AAs (79%) were more likely than individuals of other racial and ethnic origins (56%) to report that religion was very important in their lives; this was even true for those AAs who were not affiliated with any particular faith. Overall, these data suggest that African Americans, regardless of their affiliations, are conscious about religion and that religion shapes their thoughts and behaviors.

The topic of HIV, its risk factors, and perceptions, conflict with the tenants of spirituality which focus on love, kindness and inclusivity. In the rural South, those who consider themselves to be religious also report high levels of HIV stigma (Wooster J. et. al., 2011; Muturi N. & An S., 2010; Foster P. et. al., 2011). These studies are consistent with national and international studies indicating that variables such as religion/spirituality and stigma are closely related (Clum G. et. al., 2009; Shrestha R. et. al., 2017).

During the onset of the HIV infections during the 1980s, many in the AA church viewed the disease as God using nature to punish those that participated in illicit drug use or deviant sexual behavior (Jeffries, Sutton, & Eke, 2017). As time has progressed, AA churches progressed from being the center of HIV/AIDS-related condemnation and stigma to a source and support system to promote wellness among its members (Holt-Lunstad J. et. al., 2011; Francis SA. & Liverpool J., 2008), even those living with HIV.

There have been a variety of strategies and interventions developed to address HIV stigma in the community at large both domestically and internationally (Brown, Macintyre, & Trujillo, 2003; Ehiri, JE. et. al., 2005; Kuhn, Steinburg, & Mathews, 1994) with fewer in faith-based settings. The majority of HIV/AIDS specific peer reviewed interventions are designed to reduce stigma at the community level by increasing the tolerance of persons living with HIV/AIDS (PLHA) among the general population (Brown L. et. al., 2003). The predominant strategy underlying these interventions is education through the provision of factual information about HIV/AIDS (Ehiri, JE. et. al., 2005; Kuhn L. et. al., 1994). A few studies aimed at increasing the willingness of healthcare providers to treat PLHA and at developing coping skills among PLHA were also identified in the literature; however, much of what is known is theory and not tested, validated or peer reviewed (Prost A. et. al., 2007). More recently, researchers have begun to expand the scope of HIV interventions by utilizing faith-based interventions designed to reduce stigma in U.S. minority church settings (Berkley-Patton J. et. al., 2010; Derosé KP. et. al., 2016; Payne-Foster P. et. al., 2017). For example, faith-based interventions have sprung up in the Midwest (i.e., "Taking it to the Pews") (Berkley-Patton J.

et. al., 2010), and out west (i.e., Los Angeles) (Derose KP. et. al., 2016). Despite promise, these interventions often failed to target the population with the highest prevalence of HIV-infection-AAAs in the Rural Deep South (Coleman JD. et. al., 2016) Project FAITHH filled the void by demonstrating that a faith-based and anti-stigma HIV intervention can significantly decrease HIV stigma and increase HIV knowledge in this population (Payne-Foster P. et. al., 2017).

To date, intervention and correlation studies have identified correlates of HIV-risk related behaviors and stigma; these studies have largely been successful. However, to our knowledge, limited information exists on the determinants or correlates of HIV knowledge. Prior studies examining the psychosocial factors related to HIV have been limited to traditional regression-based approaches that are limited by sample size and not capable of taking into account complex and higher-order interactions or nonlinear associations that may exist among multiple correlates (Gass K. et. al., 2014). Non-parametric approaches such as recursive partitioning are capable of unraveling the complex associations that exist between multiple indicators (Leach H. et. al., 2016). Recursive partitioning has several advantages over traditional statistical approaches. For example, recursive partitioning (a) is capable of classifying individuals that are mutually exclusive from each other, (b) detects interactions without a priori decisions, and (c) is not limited by sample size or power to detect associations as is regression (Strobl, Hothorn, & Zeileis, 2009; Kiernan M. et. al., 1998). Recursive partitioning could be useful in understanding the determinants of HIV knowledge because it extracts one or more decision rules that describe relationships between independent and dependent variables (Winters R, 2015). Each rule assigns observations to a subgroup based on a specified value or category for a particular variable. Once the series of decision rules are identified, they can be applied to other data.

The overall purpose of Project FAITHH (Faith-based Intervention to Heal HIV) was to decrease HIV stigma in a sample of rural AA congregants which has been previously reported (Payne-Foster P. et. al., 2017). This paper reports on a secondary analysis of Project FAITHH in effort to examine complex relationships that may exist among sociodemographic, spiritual, and stigma related correlates of HIV knowledge scores. In this study, we used recursive partitioning to examine potential interactions between variables of interest. The proposed data-driven approach will allow us to investigate whether spirituality, stigma, and sociodemographic characteristics interact to predict higher or lower HIV knowledge scores. This work is of significance because it attempts to characterize subgroups of rural African American congregants based on several key factors that influence their HIV-related behaviors.

## Methods

### *Participants*

Churches were recruited using a variety of methods: referral from the four ministerial liaisons who were a part of the research team, referral from other members of the research team, referral from denominational leaders, or during visits with churches in our targeted area. The principal investigator met with each interested pastor to explain the study. Some pastors were not comfortable addressing HIV in their churches and declined participation. A list of 12 churches and two alternates was compiled. Alternate churches became participants when

a church on the primary list could not participate or was not responsive after three follow-up phone calls. Each pastor selected a church representative to coordinate study recruitment and intervention implementation logistics.

Congregants were recruited via a church representative, brochure, verbal announcements at church, and/or word-of-mouth. The PI verbally screened interested individuals using four eligibility criteria: (1) are you affiliated with the participating church (i.e., as a formal member, relative of a member or affiliated member) (2) are you at least 19 years of age, (3) do you self-identify as African-American, and (4) are you able to give informed consent? Congregants provided informed consent before participating. All protocols were approved by the PI's Institutional Review Board and funding agency's project determination process.

### *Data collection*

Pre-post surveys were administered onsite via audio computer assisted self-interview method. Paper and pencil survey administration was available for participants who could not use the computers. Assistance was provided for participants who lacked reading skills. The intervention consisted of eight modules and was given at the convenience of the church schedule.

### *Measures*

We assessed HIV-related knowledge as the primary outcome of our study. Additional variables such as perceived individual and community stigma, several domains of spirituality, and sociodemographic characteristics were all treated as independent variables.

#### *HIV knowledge*

Basic HIV knowledge was assessed using a 32-item, multiple-choice survey that was developed by the Joint United Nations Program on HIV/AIDS (Payne-Foster P. et. al., 2017). Two author-created items which assessed knowledge of HIV-related disparities locally in Alabama were also included (Payne-Foster P. et. al., 2017). Sample items included: "HIV is present in blood, sexual fluids, and sweat," and, "In what region of the U.S. is the rate of new infections of HIV increasing the greatest?" Participants received one point for each correct response. Potential scores ranged from 0 to 32, with higher scores indicating more knowledge. See Appendix 1 for HIV knowledge survey.

#### *HIV-related stigma*

Stigmatizing attitudes towards people living with HIV/AIDS was measured using the HIV-Related Stigma parallel scales (Visser MJ. et. al., 2008). The 12-item instrument was rated on a 5-point Likert-Type response scale ranging from strongly disagree (1) to strongly agree (5). However, two additional response options (do not know and refused) were added to the instrument. A sample statement included, "I would not like someone with HIV to be living next door." The instrument contains two domains. Participants reported personal attitudes (individual-level stigma) and their perception of others in their congregation or community (community-level stigma). The potential range was 0 to 12, where higher scores indicated

higher levels of stigmatizing attitudes (Visser MJ. et. al., 2008). See Appendix 2 for HIV-related stigma survey.

### *Spirituality*

Spirituality was measured with the Multidimensional Measurement of Religiousness/Spirituality (The Fetzer Institute, 2019). The subscales were composed of Religious and Spiritual History (3-items), Forgiveness (3-items), Private Religious Practices (5-items), Religious and Spiritual Coping (8-items), Religious Support (4-items), Organizational Religiousness (2-items), Overall Self-Ranking (2-items), and Meaning subscales (2-items). Items were measured using various Likert-type response scales. The response options of 'don't know' and 'refused' were also included. Forgiveness was rated on a scale that ranged from 1 (Always) to 4 (Never). Private Religious Practices was rated on a scale that ranged from 1 (more than once a day) to 8 (never). Religious and Spiritual Coping was rated on a scale that ranged from 1 (a great deal) to 4 (not at all). Religious Support were rated on a scale that ranged from 1 (a great deal) to 4 (none), while the other two items were rated on a scale that ranged from 1 (very often) to 4 (never). Organizational Religiousness was rated on a scale that ranged from 1 (more than once a week) to 6 (never). Overall self-ranking was rated on a scale that ranged from 1 (very religious) to 4 (not religious at all). Meaning was rated on a scale that ranged from 1 (strongly agree) to 4 (strongly disagree). The reliability of validity of this instrument was established elsewhere (The Fetzer Institute, 2019). See Appendix 3 for Spirituality survey.

### *Sociodemographic characteristics*

Participants self-reported their age, Religiosity, educational level, and whether they had a leadership role in the church. In addition, other variables such occupation, prior HIV testing, and HIV status were assessed.

## Statistical Analysis

Descriptive statistics were computed to characterize the study population as well as the psychosocial variables examined in the study. Means and standard deviations were computed for many of the items. In addition, we estimated the range of scores for our dependent variable (HIV Knowledge) and the spirituality subscales. Spearman correlation coefficients were calculated to examine associations among the continuous theoretical and psychosocial factors. All descriptive and bivariate statistics were conducted in SAS version 9.4 (Winters, 2015).

To examine the associations of HIV knowledge with sociodemographic, spirituality, and stigma variables, we followed several steps. Initially, we computed Conditional Inference Trees (CITs) (28), a type of recursive partitioning analysis, to estimate the relationship between mean levels of HIV knowledge and all variables of interest. CIT analysis works by identifying the variable with the strongest relationship to the dependent variable and finding a significant binary split that denotes statistical independence. The parent node (i.e., the initial split) of the tree is split into daughter nodes by asking a series of hierarchical Boolean (yes/no) questions

(e.g., if education  $\geq$  high school graduate). The procedure is repeated until the global null hypothesis cannot be rejected (e.g., Bonferroni adjusted P-value  $\geq 0.05$ ), and the maximal differentiation between subgroups is retained (Strobl, Malley, & Tutz, 2009). At each stage of tree development, every variable is a potential candidate to be split, even if it has already appeared in the model.

CITs are superior to other recursive partitioning programs because it avoids overfitting and selection bias toward covariates with many possible splits (Strobl, Malley, & Tutz, 2009). This procedure is optimal because it relies on statistical testing; therefore, no pruning or cross-validation is required (Strobl, Hothorn, & Zeileis, 2009). CITs were computed with the Partykit package in R (Strobl, Malley, & Tutz, 2009). Once subgroups were identified, Chi-square test of independence and nonparametric Kruskal-Wallis test were used to examine differences between nodes. All statistical tests were two-sided, and significance was determined at  $P \leq 0.05$ .

## Results

Descriptive statistics of participants. Descriptive statistics for study participants are reported in Table 1. A total of 210 participants provided usable data for the present study. The sample consisted mostly of women (85%), those who had a prior HIV test (58%), who reported attending school past their high school graduation (61%), were at least 51 years old at study enrollment (52%), and were of a Baptist (49%) denomination. In addition, less than half (43%) of the sample reported being married.

*Table 1. Descriptive Characteristics N = 210*

	Total
Female	178 (85%)
Age Group	
$\leq 50$ years	100 (48%)
51+years	110 (52%)
Education	
$\leq$ High School	82 (39%)
Some College or more	128 (61%)
Married	91 (43%)
Religion	
Baptist	90 (43%)
AME or CME	61 (29%)
Pentecostal/Holiness/Disciples of Christ	35 (17%)
Nondenominational	24 (11%)
Leadership role	106 (51%)

*Note.* AME = African Methodist Episcopal; CME = Christian Methodist Episcopal

Descriptive statistics for key study variables. Participants were categorized into three groups and HIV knowledge was assessed. Group 1 received the Project FAITHH intervention which consisted of HIV anti-stigma and faith-based messages. Group 2 received standard HIV education without HIV anti-stigma and faith-based messages. Group 3 only received HIV pamphlets left at the church. HIV knowledge scores ranged from 2 to 31. Perceived individual and community stigma scores ranged from 0 to 13 and 0 to 17, respectively. Private practice of religion scores ranged from 5 to 29. HIV Knowledge scores were significantly and negatively correlated with individual stigma ( $r = -0.39$ ,  $P < 0.01$ ), but positively correlated with community stigma ( $r = 0.33$ ,  $P < 0.01$ ). No other variables were significantly correlated with HIV knowledge ( $P > 0.05$ ). Descriptive statistics of subscales and correlations with HIV knowledge are reported in Table 2.

Table 2. Spirituality Subscales and Correlations with HIV Knowledge

	Mean	SD	
HIV Knowledge	19.93	5.43	
Individual Stigma	3.29	2.68	-0.39**
Community Stigma	10.11	4.71	0.33**
Forgiveness	4.00	1.34	-0.04
Private Religious Practices	11.22	5.40	0.08
Religious Support	6.78	2.23	-0.05
Organizational Religiousness	4.72	1.90	-0.00
Overall Self-Ranking	3.01	1.13	0.07
Meaning	2.80	1.04	-0.05
Religious and Spiritual Coping	13.00	2.30	-0.10

Note. SD=Standard deviation; \*\* $P < 0.01$

Conditional Inference Tree. The CIT analysis categorized participants into three distinct groups, with varying levels of HIV knowledge scores ( $P < 0.001$ , See Figure 1). In Tables 3 and 4, we report sociodemographic, stigma, and spirituality subscale differences by the five distinct nodes. The two variables that were retained as the most important correlates of HIV knowledge in the Conditional inference Tree analysis were education and individual stigma. HIV knowledge scores were highest in node 4. Node 4 consisted mostly of individual who attended at least some college ( $P < 0.001$ , See Table 3) and had lower levels of individual stigma ( $P < 0.001$ , See Table 4). HIV knowledge scores were lowest among less educated individuals ( $P < 0.001$ ). Other node differences that were not revealed in the Conditional Inference Tree, but was observed in the bivariate analyses were marital status ( $P=0.022$ ), organized religion ( $P = 0.032$ ), and community stigma ( $P = 0.002$ ). Figure 1 contains a depiction of our Conditional Inference Tree (CIT).

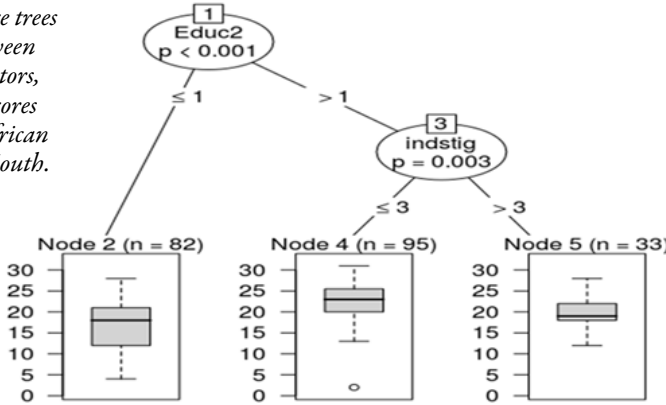
Table 3. Sociodemographic Differences in Subgroup Categories

	Node2	Node4	Node5	P-value
Age Group				0.229
≤ 50 years	33 (40%)	50 (53%)	17 (52%)	
51+years	49 (60%)	45 (47%)	16 (48%)	
Education				<0.001
≤ High School	82 (100%)	0 (0%)	0 (0%)	
Some College or more	0 (0%)	95 (100%)	33 (100%)	
Married	28 (34%)	51 (54%)	12 (36%)	0.022
Religion				0.628
Baptist	36 (44%)	38 (40%)	16 (48%)	
AME or CME	20 (24%)	33 (34%)	8 (24%)	
Pentecostal/Holiness/Disciples of Christ	17 (21%)	12 (13%)	6 (18%)	
Nondenominational	9 (11%)	12 (13%)	3 (9%)	
Leadership role	41 (51%)	52 (55%)	13 (39%)	0.316

Table 4. Differences in Subgroup Categories by Religious Constructs

Religious Subscales	Node2 M (5, 95)	Node4 M (5, 95)	Node5 M (5, 95)	P-value
Meaning	2 (2, 5)	2 (2, 5)	2 (2, 5)	0.496
Overall Self-Ranking	3 (2, 6)	3 (2, 5)	3 (2, 5)	0.912
Organizational Religiousness	4 (2, 9)	4 (2, 7)	6 (3, 9)	0.032
Religious Support	6 (4, 10)	6 (4, 11)	6 (4, 12)	0.656
Religious and Spiritual Coping	13 (11, 18)	12 (10, 17)	13 (9, 18)	0.081
Private Religious Practices	10 (5, 24)	10 (5, 22)	11 (5, 24)	0.537
Forgiveness	3 (3, 8)	3 (3, 6)	4 (3, 6)	0.200
Community-level Stigma	9 (2, 16)	12 (2, 16)	12 (5, 17)	0.002
Individual-Level Stigma	3 (0, 10)	2 (0, 3)	5 (4, 10)	<0.001
HIV Knowledge	18 (7, 25)	23 (16, 28)	19 (14, 26)	<0.001

Figure 1. Conditional inference trees exploring the relationship between sociodemographic, religious factors, stigma, and HIV knowledge scores in a sample of church-going African Americans in the rural Deep South. Educ2 = education; indstig = individual stigma



### Conclusion

This study explored whether sociodemographic variables, individual and community stigma, and components of religiosity were associated with HIV knowledge scores. To our knowledge, this is one of the first studies to use recursive partitioning to understand the correlates of HIV knowledge in a sample of rural church members in the Deep South. Our analysis indicated that key determinants of HIV knowledge scores consisted of complex interactions among individual and community stigma, education, but not private practice of religion or spirituality. This is important, particularly in light of the fact that this area of the country has become a “new” epicenter for the HIV epidemic. Because of the importance of this subpopulation as a potential barrier in improving HIV knowledge and reducing stigma, these data are potentially important in providing insight for developing more effective interventions, which might affect the HIV epidemic in the future.

In this study, education was associated with HIV knowledge scores. Data from the 2003 National Assessment of Adult Literacy showed that lower health literacy rates corresponded to lower education level (Kutner M. et. al., 2006). This same study showed that states in the Deep South had lower literacy rates in regard to basic prose skills compared to other regions such as states in the northeast (Kay ES. et. al., 2018). Despite lower levels of education and literacy in the rural Deep South, there is an opportunity to capitalize on this teachable moment. Rural churches have rarely been the foci for faith-based and minority-based interventions. Interventions such as Project FAITHH have the potential to not only increase knowledge about HIV and its risk factors, but also help to change perceptions and stigma in the community. Our data in Project FAITHH showed that interventions can be designed to decrease HIV stigma and increase HIV knowledge, however, better characterization of factors or modulators which affect both are needed to fine tune interventions. Therefore, tailoring HIV educational interventions to various subgroups have the potential to overcome barriers such as health literacy (Kutner M. et. al., 2006) which is crucial to advancing the field and should be considered for next steps.

Characterizing the exact role that stigma plays in the HIV epidemic is also important. The medical literature has only recently begun to characterize community stigma (Brown, Macintyre, & Trujillo, 2003; Ehiri, JE. et. al., 2005; Kuhn, Steinberg, & Mathews, 1994), which appears to fuel and create barriers for primary prevention and testing. However, HIV related stigma may also play a role in secondary and tertiary prevention, which prevents those living with HIV from accessing care and ultimately lower viral loads and bring the epidemic to zero (Kutner M. et. al., 2006; Integrating HIV Innovative Practice, 2013). Given the role that stigma plays in HIV-related behaviors and practices, we were not surprised to observe associations between stigma and HIV knowledge, but we still do not know which comes first: a lack of HIV knowledge which is fueled by stigma or vice versa. We can only speculate that the relationship between stigma and HIV-related behaviors could be mediated by HIV knowledge and that other contextual and sociodemographic factors that may moderate these pathways. Therefore, additional research to better characterize HIV stigma and its interplay with other factors, such as HIV knowledge, particularly in various geographic areas of the U.S. is needed.



Lastly, this study was conducted in a faith-based setting. The role of religion and spirituality on HIV knowledge continues to be understudied. This study indicated that although a minor finding, its role in HIV knowledge needs to continue to be studied and better understood. In examining the role of factors such as religion and religious/spiritual beliefs and practices, churches may need to play a direct role in HIV education. Faith leaders and pastors continue to grapple with ways to integrate HIV prevention and biblical principles in the congregation (Pichon et al., 2020). An ethnographic study revealed that pastors expressed feelings of acceptance of people regardless of their life choices, but still struggled with the belief that homosexuality is a sin (Quinn, Dickson-Gomez, & Young, 2016). Scripture-guided messages about sexuality can unintentionally perpetuate stigma and lead to further isolation of lesbian, gay, bisexual, transgender, and queer (LGBTQ+) members in the church (Pingel & Bauermister, 2018; Quinn et al., 2016). Rather than facing these challenges, many black churches in the Deep South avoid sensitive topics such as HIV and sexuality (Pichon et al., 2020). The role of faith leaders in HIV prevention and for coordination of care among people living with HIV is critical in the Deep South. It is particularly important for faith leaders to learn how to encourage discussion of sensitive topics, and to provide HIV education in a larger context of health and well-being in a nonjudgmental way.

There were several limitations of this study. First, this was a small study and mostly female. The fact that the study was mainly female is not surprising, since more females than males attend church more regularly in the Deep South. Additionally, nationally, according to the Religious Landscape survey by the Pew Research Center, 59% of historically Black Protestant churches are female (America's Changing Religious Landscape: Overview, 2019). Therefore, although we were able to show statistical differences, a larger sample may yield more subgroups, variables of interest, and potential power to detect. We also note that several churches declined to participate, which may have contributed to selection bias. In particular, churches that declined may have higher levels of HIV-related stigma and lower HIV knowledge scores. Additionally, this study was conducted in African American congregational members in rural Alabama. The sample of African American church members residing in the rural Deep South may not be generalizable to other African Americans living in other areas of the United States. Moreover, these data are cross-sectional and do not imply causal inference. Despite these limitations, the study results are suggestive of the interplay between education, HIV stigma and religion and may indicate the need for more research in this area in order to better tailor our HIV prevention messages. In addition, we used robust statistical methods to explore the correlates of HIV knowledge. The CIT analysis are based on hypothesis testing, therefore pruning and cross-validation were not needed with these procedures (Strobl, Hothorn, & Zeileis, 2009). Lastly, we hope that results of study at some point in time could be translated to other parts of the Deep South where the HIV epidemic is increasing to ensure that HIV-stigma is decreased in vulnerable communities.

In summary, we believe that the models here help to shed light on possible synergistic relationships that exist among variables HIV knowledge and stigma, and although this sample of rural AA church members was small, we believe the study provides an example of how the

church and its leadership and setting could be a powerful resource for promoting wellness and reducing stigma, particularly as the epidemic continues in the rural Deep South. Additional studies are needed to determine the correlates of other key variables that drive HIV-related knowledge and behaviors. Such studies could use similar analyses and examine the correlates of stigma especially as it relates to the unique population of congregational members who reside in this part of the U.S.

## References

- America's Changing Religious Landscape: Overview. (2019). *Sociology of Religion*, 1–7. doi:10.4324/9781315177458-1
- Berkley-Patton, J., Bowe-Thompson, C., Bradley-Ewing, A., Hawes, S., Moore, et. al. (2010). Taking it to the pews: A CBPR-guided HIV awareness and screening project with Black churches. *AIDS Education and Prevention*, 22(3), 218–237. doi:10.1521/aeap.2010.22.3.218
- Brown, L., Macintyre, K., & Trujillo, L. (2003). Interventions to reduce HIV/AIDS stigma: What have we learned? *AIDS Education and Prevention*, 15(1), 49–69. doi:10.1521/aeap.15.1.49.23844
- Centers for Disease Control and Prevention (2020). HIV Surveillance Report, 2018 (Updated); vol.31. <https://www.cdc.gov/hiv/library/reports/hiv-surveillance/vol-31/index.html>. Accessed September 5, 2021
- Clum, G., Chung, S. E., & Ellen, J. M. & The Adolescent Medicine Trials Network. (2009). Mediators of HIV-related stigma and risk behavior in HIV infected young women. *AIDS Care*, 21(11), 1455–1462. doi:10.1080/09540120902883069
- Coffman, K., Aten, J. D., Denney, R. M., & Futch, T. (2014). African American Spirituality. *Encyclopedia of Psychology and Religion*, 20–21. doi:10.1007/978-1-4614-6086-2\_14. New York, NY: Springer
- Coleman, J. D., Tate, A. D., Gaddist, B., & White, J. (2016). Social determinants of HIV-related stigma in faith-based organizations. *American Journal of Public Health*, 106(3), 492–496. doi:10.2105/ajph.2015.302985
- Derose, K. P., Griffin, B. A., Kanouse, D. E., Bogart, L. M., Williams, M. V., Haas, A. C., Stucky, B. D. (2016). Effects of a pilot church-based intervention to reduce HIV stigma and promote HIV testing among African Americans and Latinos. *AIDS and Behavior*, 20(8), 1692–1705. doi:10.1007/s10461-015-1280-y
- Ehiri, J.E., Anyanwu, E.C., Donath, E., Kanu, I., & Jolly, P.E. (2005). AIDS related stigma in SubSaharan Africa: Its contexts and potential intervention strategies. *AIDS & Public Policy Journal*, 20:25–39.
- Foster, P. P., Cooper, K., Parton, J. M., & Meeks, J. O. (2011). Assessment of HIV/AIDS prevention of rural African American Baptist leaders: Implications for effective partnerships for capacity building in American communities. *Journal of the National Medical Association*, 103(4), 323–331. doi:10.1016/s0027-9684(15)30313-8

- Francis, S. A., & Liverpool, J. (2008). A review of faith-based HIV prevention programs. *Journal of Religion and Health*, 48(1), 6–15. doi:10.1007/s10943-008-9171-4
- Gass, K., Klein, M., Chang, H. H., Flanders, W. D., & Strickland, M. J. (2014). Classification and regression trees for epidemiologic research: An air pollution example. *Environmental Health*, 13(1). doi:10.1186/1476-069x-13-17
- Hackett, C., Grim, B., Stonawski, M., Skirbekk, V., Kuriakose, N., & Potančoková, M. (2014). Methodology of the Pew Research Global Religious Landscape Study. Yearbook of International Religious Demography, 167–175. doi:10.1163/9789004275065\_011
- Holt-Lunstad, J., Steffen, P. R., Sandberg, J., & Jensen, B. (2011). Understanding the connection between spiritual well-being and physical health: An examination of ambulatory blood pressure, inflammation, blood lipids and fasting glucose. *Journal of Behavioral Medicine*, 34(6), 477–488. doi:10.1007/s10865-011-9343-7
- Integrating HIV Innovative Practice. (2013). The Challenges of Care: Continuum, Determinants and Stigma. Integrating HIV Innovative Practice. In Innovative Approaches to Engaging Hard-to-Reach Populations Living with HIV/AIDS into Care: Tools from the Integrating HIV Innovative Practices Program. Retrieved from <https://targetHIV.org/ihp/Chapter-2-challenges-care-continuum-determinants-and-stigma>.
- Jeffries, W. L., Sutton, M. Y., & Eke, A. N. (2017). On the Battlefield: The Black church, public health, and the fight against HIV among African American gay and bisexual men. *Journal of Urban Health*, 94, 384–398.
- Kay, E. S., Rice, W. S., Crockett, K. B., Atkins, G. C., Batey, D. S., & Turan, B. (2018). Experienced HIV-related stigma in health care and community settings. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 77(3), 257–263. doi:10.1097/qai.0000000000001590
- Kiernan, M., King, A. C., Kraemer, H. C., Stefanick, M. L., & Killen, J. D. (1998). Characteristics of successful and unsuccessful dieters: An application of signal detection methodology. *Annals of Behavioral Medicine*, 20(1), 1–6. doi:10.1007/bf02893802
- Klein, H., Sterk, C. E., & Elifson, K. W. (2016). Knowledge about HIV in a community sample of urban African Americans in the South. *Journal of AIDS & Clinical Research*, 7(10):622. doi:10.4172/2155-6113.1000622
- Kuhn, L., Steinberg, M., & Mathews, C. (1994). Participation of the school community in AIDS education: An evaluation of a high school programme in South Africa. *AIDS Care*, 6(2), 161–171. doi:10.1080/09540129408258627

- Kutner, M., Greenberg, E., Jin, Y., & Paulsen, C. (2006). The Health Literacy of America's Adults: Results From the 2003 National Assessment of Adult Literacy (NCES 2006-483). U.S.
- Leach, H. J., O'Connor, D. P., Simpson, R. J., Rifai, H. S., Mama, S. K., & Lee, R. E. (2016). An exploratory decision tree analysis to predict cardiovascular disease risk in African American women. *Health Psychology, 35*(4), 397-402. doi:10.1037/hea0000267
- Muturi, N., & An, S. (2010). HIV/AIDS stigma and religiosity among African American women. *Journal of Health Communication, 15*(4), 388-401. doi:10.1080/10810731003753125
- Okumu, E., Jolly, D. H., Alston, L., Eley, N. T., Laws, M., & MacQueen, K. M. (2017). Relationship between Human Immunodeficiency Virus (HIV) knowledge, HIV-related stigma, and HIV testing among young Black adults in a southeastern city. *Frontiers in Public Health, 5*, 166. doi:10.3389/fpubh.2017.00166
- Payne-Foster, P., Bradley, E. L. P., Aduloju-Ajijola, N., Yang, X., Gaul, Z., et. al. (2017). Testing our FAITHH: HIV stigma and knowledge after a faith-based HIV stigma reduction intervention in the Rural South. *AIDS Care, 30*(2), 232-239. doi:10.1080/09540121.2017.1371664
- Pichon, L. C., Powell, T. W., Stubbs, A. W., Becton-Odum, N., Ogg, S., Arnold, T., et al. (2020). An exploration of US Southern faith leaders' perspectives of HIV prevention, sexuality, and sexual health teachings. *International Journal of Environmental Research and Public Health, 17*(16):5734. doi: 10.3390/ijerph17165734.
- Pingel, E. S., & Bauermeister, J. A. (2018). 'Church hurt can be the worst hurt': community stakeholder perceptions of the role of Black churches in HIV prevention among young Black gay and bisexual men. *Culture, Health & Sexuality. 20*(2):218-231. doi: 10.1080/13691058.2017.1338756
- Prost, A., Elford, J., Imrie, J., Petticrew, M., & Hart, G. J. (2007). Social, and random forests. *Psychological Methods, 14*(4), 323-348. doi:10.1037/a0016973
- Quinn K., Dickson-Gomez J., & Young, S. (2016). The influence of pastors' ideologies of homosexuality on HIV prevention in the Black church. *Journal of Religion and Health. 55*:1700-1716. doi: 10.1007/s10943-016-0243-6.
- Reif, S., Safley, D., McAllaster, C., Wilson, E., & Whetten, K. (2017). State of HIV in the US Deep South. *Journal of Community Health, 42*(5), 844-853. doi:10.1007/s10900-017-0325-8

- Reif, S., Wilson, E., & McAllaster, C. (2018). Perceptions and impact of HIV stigma among high risk populations in the US Deep South. *Journal of HIV and AIDS*, 4(2). doi: <http://dx.doi.org/10.16966/2380-5536.154>
- Shrestha, R., Copenhaver, M., Bazazi, A. R., Huedo-Medina, T. B., Krishnan, A., & Altice, F. L. (2017). A moderated mediation model of HIV-related stigma, depression, and social support on health-related quality of life among incarcerated Malaysian men with HIV and opioid dependence. *AIDS and Behavior*, 21(4): 1059–1069. doi:10.1007/s10461-017-1693-x
- Strobl, C., Hothorn, T., & Zeileis, A. (2009). Party on! *The R Journal*, 1(2), 14. doi:10.32614/rj-2009-013
- Strobl, C., Malley, J., & Tutz, G. (2009). An introduction to recursive partitioning: Rationale, application, and characteristics of classification and regression trees, bagging and random forests. *Psychological Methods* 14(4):323-48. doi:10.1037/a0016973
- The Fetzer Institute. (2019). Multidimensional Measurement of Religiousness, Spirituality for Use in Health Research. Retrieved from [https://fetzer.org/sites/default/files/resources/attachment/%5Bcurrentdate%3Atiny%5D/Multidimensional\\_Measurement\\_of\\_Religiousness\\_Spirituality.pdf](https://fetzer.org/sites/default/files/resources/attachment/%5Bcurrentdate%3Atiny%5D/Multidimensional_Measurement_of_Religiousness_Spirituality.pdf)
- Visser, M. J., Kershaw, T., Makin, J. D., & Forsyth, B. W. C. (2008). Development of parallel scales to measure HIV-related stigma. *AIDS and Behavior*, 12(5), 759–771. doi:10.1007/s10461-008-9363-7
- Winters, R. (2015). Developing interactive decision trees using inpatient claims (with SASn Enterprise Miner). *Practical Predictive Analytics and Decisioning Systems for Medicine*, 757–794. doi:10.1016/b978-0-12-411643-6.00034-x
- Wooster, J., Eshel, A., Moore, A., Mishra, M., Toledo, C., ... Wright-De Agüero, L. (2011). Opening up their doors: Perspectives on the involvement of the African American faith community in HIV prevention in four communities. *Health Promotion Practice*, 12(5), 769–778. doi:10.1177/1524839910362313

## **People, Pulpits and Non-Profits: Outlining A Model for Collaboration Near the Origins of the HIV Epidemic**

**Victoria Revelle, MPH**

Consultant

Tel: (919) 724-7327

Email: victoriarevelle@gmail.com

**Ruth Gilliam Phillips, MS, DPM**

Executive Director

Community Health Coalition, Inc.

P.O. Box 15176

Durham, NC 27704

Tel: (919) 480-8685

Email: ruth@communityhealthcoalition.com

### **Authors' Note**

The program/initiative mentioned in this article may have been funded through grants awarded to the Community Health Coalition, Incorporated (CHC). I want to express my sincere gratitude to all who participated in ensuring the success of this program/initiative. I am also grateful to Dr. Hart-Brothers (co-founder of the CHC) as this program/initiative occurred before my time with the CHC and during her tenure as Executive Director of the CHC.

### **Abstract**

A collaborative HIV health promotion program was implemented in Durham, North Carolina to aid in mitigating the deleterious impact of HIV in the African American community. This equity-centered program produced engagement and action at the community, organizational and individual socio-ecological levels. A variety of organizations successfully collaborated in this effort. This cooperative act details the collective power of community members, Black faith-based organizations, a local health department and two community-based non-profit organizations to actualize solutions regarding the HIV epidemic. Health equity and social justice were promoted as a result of this successful initiative.

*Keywords:* HIV, Black Community, Public Health, Health Disparities, Health Equity and Collaboration

## Introduction

### *Background*

Human Immunodeficiency Virus (commonly known as HIV) is a virus that attacks the body's immune system annihilating white blood cells (World Health Organization, 2020). This process aids in diminishing the body's protection against many conditions including infections and some cancers (World Health Organization, 2020). This international public health issue continues to be a significant concern. Since its inception, it is estimated that more than 33 million people have died from HIV worldwide (World Health Organization, 2020). As of March 2021, approximately 38 million people were living with HIV throughout the world (Kaiser Family Foundation, 2021). Acquired Immunodeficiency Syndrome (AIDS) is a later stage of HIV, manifesting when the body's immune system is severely impaired as a result of this virus (HIV.gov, 2020).

In the United States, it is estimated that 1.2 million people are living with HIV, yet 14 % of those are unaware of their status and need to be tested (HIV.gov, 2020). Nationally, the largest rates of novel HIV diagnosis continuously transpire in the southern portion of the United States (HIV.gov, 2020). At the conclusion of 2019, there were a reported 34,460 people living with HIV in North Carolina (North Carolina Department of Health and Human Services, Division of Public Health, Communicable Disease Branch, HIV/STD/Hepatitis Surveillance Unit, 2020) and there were 69 reported newly diagnosed HIV infections in Durham County (North Carolina Department of Health and Human Services, Division of Public Health, Communicable Disease Branch, Epidemiology Section, HIV/STD Surveillance Unit, 2020).

Along with the non-profit sector, the legal and political sectors can be crucial in the progression of ending the HIV epidemic. More than three decades ago, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 was signed into law (HIV.gov, 2020). This resulted in the development of the largest federal program designated to center solely on delivering treatment services and care to people with HIV (HIV.gov, 2020). Truly, policies and laws play a key role in designating funding and in ensuring the provision of healthcare services.

### *Objective*

The CHC is a non-profit which strives to eradicate racial health disparities and to achieve health equity in Durham County and the surrounding areas. The CHC has over 30 years of public health service and experience. As an original site of the United States government's Healthy People initiative, the Coalition continuously advocates for health and well-being. In 1991, near the commencement of the HIV epidemic in the United States, approximately 748,000 people were reported to be infected with HIV (Centers for Disease Control and Prevention, 2020). Additionally, HIV infection was the leading cause of death for black males ages 25-44 and the third leading cause of death for black women ages 25-44 (Centers for Disease Control and Prevention, 1994). As such, the CHC was determined to positively impact Durham's African American community (relative to this epidemic).



## Methodology

### Decision Tree

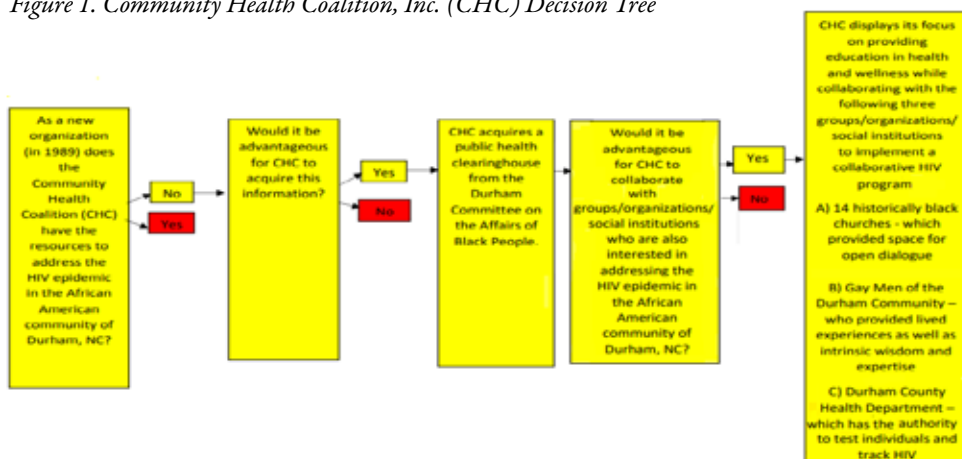
In developing an evolutionary approach to this disease, a literature review was performed, current data regarding HIV was examined and engagement was implemented with HIV positive stakeholders. In understanding the serious nature of this virus, the need to have an abundance of HIV-related resources at a moment's notice was recognized. Thus, the CHC inherited an HIV clearinghouse from the Durham Committee on the Affairs of Black People (DCABP) which is missioned "to support, empower and promote the welfare of the citizenry in civic, cultural, economic, education, health, housing, political, religious, youth and human affairs" (DCABP, 2021).

In an effort to develop solutions to positively impact Durham's African American community, a health promotion program for community involvement, engagement and action was implemented. This program methodically addressed the HIV epidemic through the collaboration of a variety of organizations holding authority relative to the social determinants of health.

### Roles and Responsibilities

Four groups/organizations/social institutions collaborated in the implementation of this program. The CHC possess educational and practical authority along with previous experience in educating the Durham community on health and wellness. The CHC is also experienced in supporting a Safe Needle Exchange initiatives (in an effort to improve the quality of life for those living with HIV). Thus, the CHC collaborated with (self-identified) gay men

Figure 1. Community Health Coalition, Inc. (CHC) Decision Tree



of the Durham Community (who provided lived experiences as well as intrinsic wisdom and expertise), 14 historically black churches (which provided space for open dialogue) and the Durham County Health Department (which possesses authority to test individuals and track HIV). A diagram of this collaboration is shown in the CHC Decision Tree (in Figure 1). Many health disparities spring from inequities in the opportunities and resources which are a necessity to experience optimal health (Robert Wood Johnson Foundation, 2021). In acknowledging health disparities regarding HIV, this initiative promoted both, health equity – “the attainment of the highest level of health for all people” (Healthy People, 2030) and social justice – “the view that everyone deserves equal rights and opportunities - this includes the right to good health” (American Public Health Association, 2021).

## Results

### *Socio-Ecological Model*

This program bolstered community involvement, engagement and action while prioritizing the individual, community and organizational levels of the socio-ecological model. Bronfenbrenner’s theory (which guides the socio-ecological model) demonstrates that individuals are surrounded by various systems which contain strong influences (Kilanowski, 2017). The paradigm of health is broadly constructed in the socio-ecological model and is indeed grounded in significant factors that affect health (Kilanowski, 2017). Truly, health is impacted by the interplay of aspects surrounding the individual, the community and the environment (Kilanowski, 2017).

On many levels, this program mirrors a Centers for Disease Control and Prevention’s rendition of the socio-ecological model (as shown in Figure 2). Health status and behavior are outcomes that can be viewed as being determined by many factors (including the knowledge, skills and attitudes of an individual). In this program, each of the 14 churches provided an opportunity (after the preached word on one Sunday per month) for congregants to receive health education (regarding HIV) from the CHC and the Durham County Health Department as well as wisdom, intrinsic expertise and lived experiences from gay men in the community. These actions were implemented in a collective effort to inform the knowledge, skills and attitudes of congregants.

The organizational level of this socio-ecological model acknowledges that organizations and social institutions can play a large part in impacting health status and behavioral outcomes. Organizations and social institutions are quite influential in the progression of behaviors and may impose behavior-determining guidelines and protocols (The Borgen Project, 2017). Rules and policies that lead, direct and enforce behavior are taken into account at the organizational level (Council of State and Territorial Epidemiologist, 2015). Indeed, this program prioritized the organizational level by ensuring that the Durham County Health Department, the CHC, the gay men of the Durham community and the 14 historically

black churches played a major and distinctive role in implementing this initiative. Each of these groups/organizations/social institutions may possess their own sets of rules and policies which may lead, direct and enforce behavior.

The community level of this socio-ecological model acknowledges that relationships between organizations can also play a large part in impacting health status and behavioral outcomes. This level comprises of the communities that people engage in (which may include but are not limited to the “location in the community, the built environment, neighborhood associations, community leaders, on/off-campus housing, businesses (e.g. bars, fast food restaurants, farmers markets), commuting, parking, transportation, walkability, parks” (American College Health Association, 2018). It may also include “the communities that individuals operate in (e.g. professional networks, associations, neighborhoods, community attitudes and the relationships among different institutions within communities”) (Newes-Adeyi et al., 2000). This program prioritized the organizational level by ensuring a cooperative collaboration between the Durham County Health Department, the CHC, the gay men of the Durham community and the 14 historically black churches.

*Figure 2. Socio-Ecological Model: Framework for Prevention Centers for Disease Control and Prevention, 2015*



### Conclusion

#### *Discussion*

Indeed, a collaborative HIV health promotion program was successfully implemented. This produced community involvement, engagement and action while methodically uniting a variety of groups/organizations/social institutions holding authority (relative to the social determinants of health). Through this initiative, a didactic public health experience occurred: the CHC was able to fulfill its hope of positively impacting Durham's African American community, gay men of the Durham community were able to share stories of lived experiences and provide intrinsic wisdom and expertise to congregants, and congregants were able to be educated on HIV (in an environment provided by the 14 churches). This equity-centered program embraced the individual, organizational and community levels of the socio-ecological model and demonstrated the power to promote health equity and social justice.

Even after the implementation of this successful initiative, the CHC has continued to serve the community. Additionally, in 2017 the Durham Board of County Commissioners declared December 14 as HIV CURE RESEARCH DAY. In 2018, the CHC provided HIV (Education) Health Tips to more than 17,000 people/groups. The CHC also transitioned its HIV outreach efforts to the Community Action Advocacy Restoration Empowerment (CAARE, Incorporated) while continuing to remain steadfast in providing resources, health education and health promotion.

#### *Recommendations*

Future recommendations include the replication of this program and the expansion of the CHC's public health services. Certainly, this initiative can be utilized as a blueprint for current and future pandemics. In May of 2021, African Americans in Durham comprised of the largest percentage (36.67%) of COVID-19 cases (Durham County Health Department, 2021). Yet, African Americans in Durham were not the largest percentage of people to be vaccinated against COVID-19 (Durham County Health Department, 2021). Surely, the successful HIV health promotion program model can be used as a guiding blueprint to aid in positively impacting COVID-19 disparities.

Moreover, expanding services is also vital to continue with advancing health equity throughout Durham's African American community. The CHC should consider expanding services to include an HIV health education portal on its website (as health education can be implemented virtually). This addition to the website could aid in honoring the CHC's past work and collaborators in the HIV arena, while sharing the latest developments and educational materials. As the old African adage states 'If you want to go fast, go alone. But if you want to go far, go together.' Indeed, as a successful non-profit, the CHC can continue to go further with collaborators and continuously impact Durham's African American community.

## References

- American College Health Association. (2018). *Ecological Model*. Healthy Campus. Promoting healthy campuses for over 30 years. Cornerstone. Community. Culture. [www.acha.org/healthycampus/healthycampus/ecological\\_model.aspx](http://www.acha.org/healthycampus/healthycampus/ecological_model.aspx)
- American Public Health Association (2021). *Social Justice and Health*. Social Justice. [www.apha.org/what-is-public-health/generation-public-health/our-work/social-justice](http://www.apha.org/what-is-public-health/generation-public-health/our-work/social-justice)
- Braveman, P., Arkin, E., Et. al. *What is Health Equity?* Robert Wood Johnson Foundation. [www.rwjf.org/en/library/research/2017/05/what-is-health-equity-.html](http://www.rwjf.org/en/library/research/2017/05/what-is-health-equity-.html)
- CAARE. (2020). *Health & Wellness*. Our Services. <https://www.caare-inc.org/services>
- CAARE. (2020). *Case Management*. Our Services. <https://www.caare-inc.org/services>
- Centers for Disease Control and Prevention. (1994, September 09). *AIDS Among Racial/Ethnic Minorities -- United States, 1993*. Morbidity and Mortality Weekly Report. <https://www.cdc.gov/mmwr/preview/mmwrhtml/00032522.htm>
- Centers for Disease Control and Prevention. (2015). *Hierarchical levels in the socioecological model*. The Social Ecological Model: A Framework for Prevention. <http://www.cdc.gov/violenceprevention/overview/social-ecologicalmodel.html> Retrieved 1, May, 2021 from <https://doi.org/10.1186/s12978-020-00992-x>
- Centers for Disease Control and Prevention. (2020, October 10). *HIV and AIDS Timeline*. National Prevention Information Network. <https://npin.cdc.gov/pages/hiv-and-aids-timeline>
- Council of State and Territorial Epidemiologist. (2015, June). *Chronic Disease Epidemiologist Orientation Manual*. A Resource for Applied Epidemiologists. [http://www.cste2.org/publications/cste\\_chronic\\_disease\\_epidemiologist\\_orientation\\_manual-a\\_resource\\_for\\_applied\\_epidemiologists.pdf](http://www.cste2.org/publications/cste_chronic_disease_epidemiologist_orientation_manual-a_resource_for_applied_epidemiologists.pdf)
- Durham Committee on the Affairs of Black People. (2021). *About DCABP, Inc*. Durham Committee on the Affairs of Black People. <https://www.dcabpinc.org/about-us>
- Durham County Board of County Commissioners. (2017). *Meeting Minutes*. Durham County Board of County Commissioners. <https://www.dconc.gov/home/showdocument?id=home24570>
- Durham County Health Department. (2021). *Case Data Overview*. Durham County Coronavirus Data Hub. <https://durhampublichealth-durhamnc.hub.arcgis.com>

- Durham County Health Department. (2021). *Case Data Overview (BY RACE AND ETHNICITY)*. Durham County Coronavirus Data Hub. <https://durhampublichealth-durhamnc.hub.arcgis.com>
- Durham County Health Department. (2021). *COVID-19 Vaccines*. Durham County Coronavirus Data Hub. <https://durhampublichealth-durhamnc.hub.arcgis.com/pages/vaccine-distribution>
- Engles, Tom. (2020, August 18). *HRSA Celebrates 30 Years of the Ryan White CARE Act*. HIV.gov. <https://www.hiv.gov/hiv-basics/overview/about-hiv-and-aids/what-are-hiv-and-aids>
- Healthy.gov. (2021, January 15). *Healthy People 2030 Questions & Answers*. Healthy People 2030. [health.gov/our-work/healthy-people/healthy-people-2030/questions-answers#q9](https://health.gov/our-work/healthy-people/healthy-people-2030/questions-answers#q9)
- HIV.gov. (2020, June 5). *What IS HIV? What Are HIV and AIDS?* <https://www.hiv.gov/hiv-basics/overview/about-hiv-and-aids/what-are-hiv-and-aids>
- Kaiser Family Foundation. (2021, March 2). *The Global HIV/AIDS Epidemic*. Global Health Policy. <https://www.kff.org/global-health-policy/fact-sheet/the-global-hiv-aids-epidemic/>
- Kilanowski, J. (2017, July 29). *Breadth of the Socio-Ecological Model*. Journal of Agromedicine, 22:4, 295-297, DOI: Retrieved 1, May 2021 from <https://doi.org/10.1080/1059924X.2017.1358971>
- Newes-Adeyi, G., Helitzer, D. L., Caulfield, L. E., & Bronner, Y. (2000). Theory and practice: applying the ecological model to formative research for a WIC training program in New York State. *Health education research*, 15(3), 283–291. Retrieved 1, May, 2021 from <https://doi.org/10.1093/her/15.3.283>
- North Carolina Department of Health and Human Services, Division of Public Health, Communicable Disease Branch, HIV/STD/Hepatitis Surveillance Unit. (2020, November 25). *HIV rates increased in North Carolina, 2019*. HIV in North Carolina, 2019. [https://testyourwell.nc.gov/cd/stds/figures/factsheet\\_hiv\\_2019.pdf](https://testyourwell.nc.gov/cd/stds/figures/factsheet_hiv_2019.pdf)
- North Carolina Department of Health and Human Services, Division of Public Health, Communicable Disease Branch, Epidemiology Section. HIV/STD Surveillance Unit. (2020, February 1). *North Carolina HIV/STD Quarterly Surveillance Report: Vol. 2020, No. 4* <https://epi.dph.ncdhhs.gov/cd/stds/figures/vol20no4.pdf>

The Borgen Project. (2017, July 10). *Community, Ecology, Socialization. Social-Ecological Model Offers New Approach to Public Health*. Posts. <https://borgenproject.org/tag/social-ecological-model/>

World Health Organization. (2020, November 30). *Key facts. HIV/AIDS*. <https://www.who.int/news-room/fact-sheets/detail/hiv-aids>





The background of the entire page is a complex, layered composition. It features several large, semi-transparent spheres of varying sizes. These spheres are covered in a dense pattern of small, circular, textured protrusions, resembling a microscopic view of a virus or a seed pod. Interspersed among these spheres are numerous small, stylized leaves or petals, some of which are attached to thin, curved stems. The overall color palette is muted, consisting of various shades of gray, beige, and a deep, dark brown that forms a diagonal band across the upper portion of the image. The lighting is soft and diffused, creating a sense of depth and texture throughout the composition.

## COMMENTARY



## HIV, Stigma and Me: One Woman's Story

**Lynn Jones Benson, PhD, M.Ed**

Assistant Professor

Department of Psychology and Sociology

College of Arts and Sciences

Tuskegee University

Phone: (334) 727- 8830

Email: lbenson@tuskegee.edu

### Abstract

The human immunodeficiency virus (HIV) attacks the body's immune system by destroying cells which fight disease and infection. If left untreated, it can lead to AIDS (acquired immunodeficiency syndrome) (1). African American women represent 13% of the total female population in the United States and account for 61% of new HIV diagnoses (2). There are various types of stigma associated with HIV (3). Enacted stigma refers to an individual's experiences of prejudice and discrimination because of their HIV status, whereas, internalized stigma refers to an individual's acceptance of negative attitudes or beliefs related to their HIV status (4). A positive status, can affect individuals on a daily basis as it relates to stigma. For example, guilt, shame, isolation, or perhaps low self-esteem. HIV does not discriminate. Individuals across all races, ethnicities, and socio- economic status have been diagnosed as HIV positive.

The HIV epidemic remains worldwide, disproportionately impacting African Americans. The focus of this paper is: 1). To bring attention to HIV in African American women in the United States 2). To bring attention to stigma associated with HIV in women 3) to highlight an African American female who has been living with HIV for close to 30 years.

Millions of people throughout the United States have been affected by the Human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) since the mid to late 1970s (5). According to the Centers for Disease Control and Prevention (CDC), advancements have been made in the prevention and treatment of HIV/AIDS; with proper medical care, HIV can be controlled, but not cured (6). Women account for 20% of people living with AIDS (PLWHA), yet 62% of these women identify as Black/African American (6). There are several contributing factors to elevated rates of HIV among Black women, including increased injection drug use, non-monogamous sexual relationships, exchanging sex for drugs or money, and history of incarceration; partner behavior; and social and contextual factors, including lower socioeconomic status, poverty, and higher rates of HIV/AIDS in general in the Black/African community (5).

African American or Black women living with HIV face numerous challenges on a daily basis. Some of which are inclusive of; stigma, racism, homelessness, financial struggles, discrimination of various sorts, mental illness, hunger, and the list goes on. In a study conducted

in 2016, data were collected through in-depth interviews with African American women living with HIV (WLH) in South Carolina (SC). The study aimed to identify resources at various socioecological levels that facilitate resilience and explore how the resources interacted with each other. The results were inclusive of participants describing six major resilience resources including: internal strength, religion and spirituality, hopefulness about life and future, self-awareness and self-care, social support from family and community, and HIV-related health facilities. Findings suggest that resilient African American WLH maintain hope in the face of adversity and seek and obtain social support (7). Though stigma was not a component within the study, it has a tremendous impact on WLH.

HIV related stigma is real and affects Black women in a number of ways. Stigma impacts the health and social well-being of people living with HIV/AIDS (PLWHA). Internalized or self-stigma takes into consideration the extent to which an individual internalizes negative beliefs about a personal characteristic or experience such as HIV/AIDS. Additionally, stigma from the general public, such as negative attitudes or beliefs about PLWHA and discriminatory behavior are experienced and potentially internalized (8). For example, an individual may view herself as having moral or character weaknesses or being a failure due to messages heard from family, friends, community members and the media. This can possibly lead to reduced self-esteem and increased hopelessness. Internalized stigma may further lead to impairment in social and occupational functioning and impact treatment engagement (8).

According to Earnshaw and Chaudor (2009), overtime, PLWHA may begin to anticipate future prejudicial and discriminatory experiences. This anticipated stigma can lead to worsened mental and physical health, social isolation, fear or reluctance to disclose their status to others, internalized stigma, and hesitancy to engage in HIV treatment.

The Social Cognitive Model is a theory which explains the development and persistence of HIV stigma. This model further suggests that an individual may initially become aware of negative beliefs about PLWHA early in life prior to contracting HIV. When an individual sees themselves as belonging to a stigmatized group, over time their personal cognitive coping style may lead them to accept negative beliefs about PLWHA as being either true or valid (5). For Black women, internalized and anticipated negative beliefs about HIV status can further be compounded by negative beliefs about being a racial and gender minority in the United States(5).

### **Cheryl's Story**

An African American woman who was not a participant in the aforementioned study allowed me to interview her. She is a native of North Carolina (NC) and HIV has lived with her for close to 30 years. Cheryl, in her early 50's, is the epitome of resilience.

Cheryl and Duane meet on a job in NC during the late 1980's. They quickly become friends then soon decide to date exclusively. The relationship progresses in a positive manner, so they decide to live together. A short time later Cheryl accepts a job offer from Clemson

University and the decision is made to move to South Carolina (SC). There is talk of marriage, but no definitive plans are made at this time. This is a young couple in love, happy, and enjoying life. As Cheryl is working at Clemson, Duane has begun working at a corrections facility not too far from where they live.

The road is relatively smooth with a few bumps and curves every now and then. Both Cheryl and Duane have settled into their respective jobs and enjoy what they are doing. They reside in a quiet community and have established friendly relationships with neighbors. However, that smooth road becomes extremely hilly and curvy in 1994.

Duane walks in the house one evening after work and informs Cheryl that he has tested positive for HIV. She was caught completely off guard. Utter shock. However, she immediately begins to comfort and console him. They sat quietly on the sofa and talked. During this conversation Cheryl learned that a prisoner spat on Duane while working. According to standard procedure, as an employee of the facility, Duane was required to be tested for HIV (blood test). Needless to say, this was a sleepless night for both of them. Duane managed to hold it together the next day when he returned to work. Cheryl went to work as well knowing that she also needed to be tested.

Cheryl (Duane accompanied her) went to the local health department to be tested approximately two weeks later. Rapid testing was not available at that time, so there was a one to two week waiting period for the results. Upon receiving the results, it was determined that Cheryl is HIV positive (+) For her, this is confirmation of the symptoms she was experiencing that something was amiss from a physical perspective. Confirmation, yet time for a long pause.

Duane and Cheryl are living in Anderson and have recently found out that they are both positive. Life changing for sure. So many questions and too few answers. The fear of the unknown was legitimate. They are in survival mode from one day to the next. Daily thoughts at the time consisted of, "not letting family and friends know, the secrets, If I have a dental appointment do I have to let them know, since they will have to take precautions?" Living with the reality of "What if?" Awakening one morning yet not knowing whether or not today would be their last. The strength, the power of a virus that is invisible to the naked eye.

The stigma. Living in Anderson which was a small city at the time and not wanting people to know. The health department conducted the testing, provided results and subsequently dropped the ball there. Now what? A doctor or doctors are needed. Who? Where? Can this person or persons be trusted?

In a short period of time they chose a physician located 40 minutes from Anderson. You ask why so far away, the STIGMA! There was no desire to come into contact with anyone whom they knew. In the early to mid 90's, media portrayal of the virus was horrible. People were portrayed as lepers had been. There was so much shame associated with the virus; rejection and ostracism. The thought of being "found out" was stressful by itself.

There was little to no confidentiality. Imagine walking into a doctor's office with an appointment. As your name is called, you are asked which clinic you are going to. For example, if your response is "ID" (Infectious Disease), people within hearing distance begin making all kinds of assumptions. Incidents similar to this one occurred at various facilities. There may be a policy regarding Patient Right to Privacy (HIPPA), but what happens if a relative or someone you know works in this establishment? So much for confidentiality.

From a medical perspective their experiences were like a rollercoaster ride. Though they were under the care of a physician, this individual was not a specialist. The initial treatment plan for both was AZT (Zidovudine also known as Azidothymidine). AZT is an antiretroviral medication used to prevent and treat HIV/AIDS. There was no cocktail at the time. They were on this medication for close to two years. They were temporarily getting better but not significantly. Over a period of time, both were affected negatively while taking it. Cheryl experienced fevers, nausea, yeast infections and an extremely low blood count several times. She also experienced blood loss. Duane experienced many symptoms as well, with the most severe being difficulty with balance and a brain infection which came close to taking his life.

Both Duane and Cheryl were in and out of the hospital numerous times. The most serious being Duane's brain infection and Cheryl having pneumonia which is common in people with HIV or AIDs. Pneumocystis Pneumonia (PCP) is still the most common opportunistic infection which occurs more often or is worse in people with weak immune systems.

In spite of numerous hospital visits, they both continued to work. However, they also began discussing leaving SC and returning to NC, which was home for both of them. While still in SC, they made the decision to get married. Yes, they were in a committed relationship and had been for some time, but there was the underlying sense that according to Cheryl, "No one else would want them." Prior to moving, a lot of decisions needed to be made. Since they had missed a lot of work, a burning question was whether or not there was a need to disclose any information. Neither Duane nor Cheryl had informed their parents at this point. When and how were they to be informed?

Cheryl took the lead on breaking the news to her mother through a telephone conversation. Her mother was very encouraging and supportive. Prior to this conversation, she did not understand why there was a need to relocate to NC since they were settled into jobs and communities where they were. However, in talking with Cheryl, there was enlightenment as to the frequent doctors and hospital visits. This was the 'aha moment' for her mother. There is nothing like a mother's love. Cheryl's father on the other hand showed no emotion and never spoke with her about her positive status. This was not by any means a display of rejection but rather his normal response to most family matters. Cheryl has 12 siblings and her mother informed them in her own time and manner of Duane and Cheryl's status. Duane's parents and sibling were encouraging and supportive as Cheryl's mother had been.

Before leaving Clemson, Cheryl was hospitalized again. This time she was placed in isolation because it was believed that she might have Tuberculosis (TB). The word spread

like wildfire! Her colleagues at Clemson went into panic mode because they had been in her presence. TB is also an opportunistic infection which occurs more often in people and being more severe in those with a weakened immune system. Did Cheryl have TB? No!

Cheryl decided to leave Clemson on disability. The filing process was initiated in Human Resources. In the midst of all of the paperwork, her diagnosis was disclosed. Cheryl knew some of these people due to the type of work she was doing. Therefore, she also knew that they were talking behind her back. Where was the confidentiality in all of this? There was none, or very little.

Cheryl has always been an individual to speak the truth. With this experience she preferred that people speak directly to her as to what was going on, as opposed to talking behind closed doors. It took a significant amount of time before she felt the freedom to be open, unveil, be unashamed and share her truth.

The move was to Fayetteville to live with Duane's parents. Three or four of Cheryl's siblings drove down to assist with the move. There was no rejection, fear, isolation or negativity from either family.

Leaving SC was an excellent choice. While in Fayetteville, they are able to spend quality time with Duane's family in addition to a sense of normalcy. From the medical stand point, Duane and Cheryl began their care in the Duke University hospital system. No more general practitioners, but instead doctors specializing in infectious diseases. Unfortunately, the drive to Durham was even longer, being an hour as opposed to 40 minutes. Cheryl no longer feels like a guinea pig. While in Anderson it was, "Let's try this, or this". She was adamant about her healthcare and was her own advocate. Healthcare played a huge role in the decision to return to NC and the availability of receiving treatment from specialists. She never felt as though she was discriminated against or ostracized while being treated. However, the issue of confidentiality was also prevalent at Duke.

Cheryl eventually realized that being on disability was a crutch after about a year. Her ultimate trust and confidence had to be in God, that He would take care of her and supply all of her needs. Cheryl admittedly had no relationship with Christ prior to the diagnosis. This was her "Thorn in the flesh". She further states, "It definitely did not happen overnight."

Cheryl and Duane are in Fayetteville for close to two years. Throughout this time, they see God at work in their lives. They are feeling better and are experiencing a calmness that was nonexistent for some time. A home became available in Durham, so this move was made. A new location, new jobs and resettling in. Cheryl loved her job (working as an accountant) and slowly began becoming active in her community and taking a class or two as well. She became so wrapped up in work, that she without realizing it at the time began ignoring self-care. There were a few times on the job that a supervisor spoke to her about an assignment, and Cheryl's thinking was, "Why are you so concerned about this project when I am dealing with living with HIV on a daily basis?" She did not participate in any support groups. She was frustrated and



at times upset and began projecting these feelings onto others. During this time, Duane began utilizing drugs. Initially, Cheryl was naïve as to what was going on. Totally oblivious. However, this behavior was temporary. God began *nudging* Cheryl that it was time to surrender. She needed to talk, had to talk. The Bible verse, Psalms 81:10(NIV), *I am the Lord your God who brought you up out of Egypt. Open wide your mouth and I will fill it*, was placed on her heart. She meditated on this verse and begun to live it. She found her voice and began opening up to people. She shared her story with people one-on-one, during church services and events, and begun attending and participating in HIV related activities.

A lot has changed over the years. Cheryl's love for the Lord and His truth continues to blossom. Duane's drug use continued. Cheryl did not believe there was a correlation between the HIV and drug use. To the best of her knowledge, the usage began a few years after his diagnosis. She is, however, unsure as to whether or not he initially began using drugs as a coping mechanism. Duane and Cheryl eventually divorced as a result of his drug usage and infidelity. Duane died in 2014.

Cheryl remarried 10 years ago and she and her husband live in Mebane, NC. She informed him of her HIV early on in their relationship (prior to getting married). Cheryl's marrying someone who is HIV negative means that they use condoms every time they engage in intercourse. Beyond this, HIV is not an issue for them. She was wrong in believing that no one else (besides Duane) would want her. Someone else definitely wanted to be with her. She understandably experienced negative thoughts about herself following the diagnosis. For example, that she was tainted.

Her treatment plan currently consists of a one pill cocktail, Atripla, which is taken once daily. The cost of this medication is \$3200 per month. Cheryl receives her medication free of charge. She has also been on an STD medication for approximately 25 years. Due to immune system changes, an individual who is HIV positive, can receive a diagnosis. This has happened with Cheryl in the past. However, her viral loads are currently non-detectable and have been so for 15 years. Praise moment!! Her viral loads are tested annually.



## References

- Caiola, C., Docherty S, Relf M, Barrosa J. Using an intersectional approach to study the impact of social determinants of health for African American mothers living with HIV. *ANS Adv Nurs Sci.* 2014; 37(4): 287-98. CDC. HIV Surveillance in Women (through 2016). Atlanta: CDC: 2017
- Centers for Disease Control and Prevention. Diagnoses of HIV infection in the United States and dependent areas, 2014. *Centers for Disease Control and Prevention; 2016.* P. 123.
- Division of HIV/AIDS Prevention, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Centers for Disease Control and Prevention: 2017
- Earnshaw VA, Chaudoi SR. From conceptualizing to measuring HIV stigma: a review of HIV stigma mechanism measures. *AIDS Behav.* 2009; 13(6): 1160-77.
- Kemp, C.G., Lipira, L.L., Huh, D., Nevin, P.E., Turan, J., Simoni, J.M., Cohn, S.E., Bahk, M. Berzins, B., Andrasik, M., Mugavero, M., Rao, D. HIV stigma and viral load among African American women receiving treatment for HIV. *AIDS.* 2019 July 15; 33(9): 1511-1519.
- Travaglini, L., Himelhoch, S., and Li Juan Fang. HIV stigma and its relation to mental, physical and social health Among Black women living with HIV/AIDS. *AIDS and Behavior.* 2018; 22: 3783 – 3794. <http://doi.org/10.1007/s10461-018-2037-1>
- Turan B., Hatcher, A.M., Weiser, SD Johnson, M.O., Rice, W.S., Tiran, J.M. Framing mechanisms linking stigma, adherence to treatment, and Health outcomes. *American Journal of Public Health.* 2017; 107(6): 863-869.
- Qiao, S., Ingram, L., Deal, M.L., Xiaomong Li and S. Weissman. Resilience resources among African American women living with HIV in Southern United States. *AIDS* 2019; 33 (Suppl 1): S35-S44.



The background of the entire page is a complex, abstract composition. It features several large, semi-transparent spheres of varying sizes. These spheres are covered in a dense pattern of small, circular, textured protrusions, resembling a microscopic view of a virus or a seed pod. Interspersed among these spheres are numerous small, stylized leaves or petals, some of which are attached to thin, curved stems. The overall color palette is muted, consisting of various shades of gray, beige, and a deep, dark brown that forms a horizontal band across the upper portion of the image. The lighting is soft and diffused, creating a sense of depth and texture throughout the scene.

# AUTHOR REQUIREMENTS



# The Journal of Healthcare, Science and the Humanities

## I. General Information

The Journal of Healthcare, Science and the Humanities (JHSH) publishes a wide variety of articles intended to enrich and advance the knowledge of health and health care, science and the humanities, as well as the art and science of health care delivery and the health professions.

Program or project summaries/exemplars, formal case studies, or case scenarios are acceptable, but must be carefully constructed to avoid any subtle commercialization or politicization. Authors are free to submit academic manuscripts that present differing or alternative views to current issues and debates. The Editor will make final decisions regarding these issues after consultation with the members of the Journal Executive Leadership, including Intellectual Property Counsel if so required.

JHSH will not consider manuscripts that are being submitted or considered elsewhere simultaneously. If an author wishes to have a work rescinded from JHSH consideration for submission to another publication, the author must request in writing and be granted an official written notification regarding the same from the Editor or Senior Associate Editor.

Unless there is clear justification, and only with the written permission of the previous publisher, JHSH will not accept manuscripts published elsewhere, or that will be published prior to appearing in JHSH. Authors must inform the Editor of such matters at the time their manuscript is submitted; review by Intellectual Property Counsel may be required. Such matters must be acknowledged in the Author Note.

## II. Representative Manuscript Categories

JHSH encourages authors to choose from a wide range of subject matter categories. Authors may explore various categories and possibilities with the Senior Associate Editor, who will subsequently discuss with the Editor. The Editor has responsibility for final decisions in this area. The following are representative categories.

- a. Research papers, theoretical investigations.*
- b. Scholarly critiques and commentaries on various topics.*
- c. Formal case studies and program/project reports.*
- d. Reaction papers and editorials.*
- e. Book, film, media, law, education or other reviews.*
- f. Other academic or professional articles related to the JHSH interdisciplinary mission.*
- g. Creative work, including poetry and short fiction relevant to the JHSH mission.*

# Author Requirements

---

## III. Submission Review Processes

Submissions undergo a four-stage process of rigorous review, discernment, evaluation, and approval. The Editor may adapt these processes to meet specific circumstances.

### Stage 1:

Authors submit full manuscripts or manuscript concept proposals to both the Editor and Senior Associate Editor. The Editor, Senior Associate Editor, and Associate Editors will conduct a preliminary assessment for relevance to the JHSH mission. The Senior Associate Editor will provide guidance to the corresponding author about shaping the manuscript for JHSH readers. **All manuscripts, including all figures and graphics, must be formatted correctly and comply with JHSH Author Requirements before manuscripts will be allowed by the Editor to progress to Stage 2. Compliance with this requirement is mandatory. Exceptions will not be granted.**

### Stage 2:

After the Senior Associate Editor determines that all Stage 1 requirements are met and that all manuscript and graphics/figures formatting is in compliance, the Senior Associate Editor forwards the manuscript to the Chairs of the Academic Review Committee (ARC) for rigorous peer review. Also, at the time of Stage 2 submission, all authors must submit their completed Author Agreements and Copyright Release Forms. No article can be published unless this requirement is met by all authors. *All Journal peer reviewers have executed non-disclosure agreements and conflict of interest declarations to protect an author's rights and academic property.* Peer review routinely results in manuscript revision. The first author and the ARC Chairs work together to address matters stemming from peer review and to ensure that the manuscript is revised accordingly.

### Stage 3:

After successful peer review and revision, the ARC Chairs send the revised manuscript to the Chairs of the Manuscript Editorial Committee (MEC) for rigorous editorial and formatting review, revision, and critique of actual content and language. This also includes careful review of all figures, graphics, and other related elements for compliance with requirements. The MEC also reviews, critiques and recommends minor formatting needs. The author and the MEC Chairs process and finalize the manuscript. When this process is completed, the MEC Chairs send the final manuscript back to the Senior Associate Editor as certified ready for final review.

### Stage 4:

Upon receipt from the MEC Chairs, the Senior Associate Editor sends the final edition of the manuscript to the Journal Associate Editors for a final qualitative review. Any additional changes required are completed between the author and the Senior Associate Editor. Upon successful final qualitative review by the Associate Editors, the Senior Associate Editor sends the final edition to the Editor for final review and approval. If all items are in order, the Editor formally approves and accepts the manuscript for a future edition of JHSH. The Editor notifies the author of final acceptance.

*Note:* The Editor may make further determinations regarding requirements or revisions to manuscripts. In the event of circumstances, the Editor may disapprove a final edition.

### IV. Style Requirements

**APA Style Requirements:** JHSH has adopted the publication style manual of the American Psychological Association (APA). Copies are available in most public and university libraries or through most university psychology departments. Reference information: Publication Manual of the American Psychological Association (6th Ed., 2010), Washington, DC: American Psychological Association.

**APA Style Web Resources:** The URL links below provide additional information and assistance for APA style requirements.

<http://owl.english.purdue.edu/owl/resource/560/01/>

<http://www.apastyle.org/elecref.html>

<http://www.psychwww.com/resource/apacrib.htm>

### Formatting Specifics:

In addition to meeting APA style requirements, articles must be organized according to the format below. All papers must be divided into appropriate, titled sections and subsections based on subject matter.

- a. *Introductory Material.* Each manuscript must begin with the title, name of author(s) with current title(s) and institutional affiliation(s). With the exception of creative essays pre-approved by the Editor, manuscript titles shall be consistent with the scholarly and professional nature of the Journal. Informality, a casual tone and colloquialisms must be avoided. When using degrees after an author's name, periods are omitted. (e.g., PhD, not Ph.D). Contact information for the corresponding author is to be included, either in the introductory material or as part of the Author Note. Authors are to provide complete, precise information for themselves and each co-author, to include street address, phone, fax and e-mail address (see example below):

**Mary Smith, MD, PhD, CPI**

Chair, Department of Surgery

University of Smithville

301 Smithville Road

Smithville, MD

Tel: (301) 456-1234

Fax: (301) 456-1235

Email: Mary.Smith@smithville.edu

- b. *Author Note.* Immediately following the title and author information, each manuscript must include a brief, un-indented paragraph containing important preliminary and/or disclaimer information. This paragraph, called an Author Note, will state the source of the subject material (e.g., preliminary presentation or doctoral dissertation). If the work was supported by a grant, contract, or similar instrument, proper credit must be given. In the Author Note it is required to place the information about IRB and IACUC review and approval with relevant protocol identification numbers and dates of approval or determination. The Author Note should include any required institutional disclaimers. The author/authors must declare any and all financial conflicts of interest (or lack thereof) in the Author Note. The Author Note shall include information regarding contributors.

## Author Requirements

---

See Section VII below concerning requirements for designating authorship as opposed to contributors. Acknowledgments are placed in the Author Note.

- c. *Abstract*. Immediately following the Author's Note and without any page break, all articles will have an abstract of approximately 200 words. The abstract is a single, unindented paragraph of plain text without bullets or subsections. The abstract must use key information from the text to provide a clear, concise and unbiased summary. Review Articles or Creative Writing submissions do not have an abstract.
- d. *Keywords*. Immediately following the abstract and without any page break, list at least three key words to facilitate electronic searches of the manuscript. The choice of key words will depend on the subject matter. Review Articles or Creative Writing submissions do not include key words.
- e. *Introduction*. Immediately following the Keywords and without any page break, the text must begin with a section entitled "Introduction." In the Introduction the author should preview what is about to be presented, and may chronicle the past history of the subject under discussion with appropriate use of references from the literature. Both the content and length of the introduction will vary according to subject matter. Review Articles and Creative Writing must include an introduction explaining the intent and providing important background to what follows.
- f. *Middle Sections*. Based upon subject matter and methodology, the middle portion of the manuscript is to be divided into appropriate sections and subsections, each of which must be appropriately titled. See Section V for the formatting of section and subsection headings.
- g. *Conclusion*. This section provides a concise summary of the materials previously presented, and points toward future or practical implications and/or implementation. Review Articles and Creative Writing should include a conclusion that points out the benefit of what has been presented to the reader and to the JHSH mission.
- h. *References*. For those manuscripts requiring them, references will be listed on a separate page following the text. Accuracy is the responsibility of the author; references will not be validated in editorial review. The APA publication manual provides detail on the correct format for references. Review Articles do not require references, unless deemed by the Editor as essential. However, if useful Review Articles, Commentaries, Academic Reflections and other non-research presentations strictly speaking may offer *Select Bibliographies* or listings of works as *For Further Reading*.

## V. Manuscript Preparation Requirements

Manuscripts must be submitted (including tables and figures) in single spaced copy. Standard American or UK English usage and spelling are the norm, the latter for authors from UK English-speaking communities. Except for clearly stylistic conventions that can be reasonably justified in an academic and professional publication of this nature, authors are to avoid overly informal compositional style and language. Similarly, to maintain the highest level of academic quality, the use of the first person singular or plural is normally not accepted in JHSH research-oriented works. However it can be used in commentaries, reviews, and creative works and in those categories where its usage mirrors the style of academic/scientific papers in



scholarly publications. Contractions are not to be used except for intentional style purposes or within quoted materials. For all tables and figures, see the Graphics Section below for detailed instructions. All manuscripts must use one-inch margins throughout. Authors are to submit all material in electronic format compatible with MS Word for MacOS and Windows. It is the author's responsibility to ensure software compatibility of both text and graphics. Manuscripts should not contain any specialized formats, automatic styles, or other features not easily translated between computing platforms or any content that cannot be shaped by desktop graphics technicians at the publishing house. For example, the use of references must not require editing or graphics personnel to obtain commercial notation software. Such editing must be able to be accomplished within MS Word. It is the responsibility of authors to require with this matter. Submission that do not comply will be returned until the matter is resolved.

### Bullets

Bullets are not permitted within the text. Numbered or lettered lists are acceptable.

### Electronic Submission

All manuscripts are to be submitted to the Editor and the Senior Associate Editor as an e-mail attachment. All manuscripts must be submitted in MS Word format for MacOS and/or Windows (.doc or .docx format). Do not send manuscripts using the pdf or webarchive format. Such will be returned. See Section VI regarding graphics. Authors may wish to review examples of previously published articles as guides. These can be made available upon request.

### Headings

Each manuscript must be subdivided into relevant sections as discussed above. Sections may be further subdivided to enhance the discussion or for other editorial reasons. Major sections should use Level 1 headings. Subsections should use headings for Levels 2 through 4. Directions for formatting Headings follow:

- Level 1: **Helvetica 14pt Centered Uppercase and Lowercase Heading [Bold]**
- Level 2: *Helvetica 11pt. Centered, Italicized, Upper and Lowercase Heading*
- Level 3: *Helvetica 14pt Flush Left, Italicized, Uppercase and Lowercase Heading*
- Level 4: *Helvetica 14pt Indented, italicized, lowercase paragraph heading and ending with a period.*

Authors who do not have Helvetica font may substitute Arial.

### Typeface

Except for headings as listed above, Times New Roman 12pt font is required for the body of the manuscript and references. Do not use bold or underlining for emphasis. Italics are allowed provided they fit APA style guidelines.

### Headers and Footers

Headers or footers (including footnotes) are not permitted in the manuscript.

Pagination is allowed at the bottom center or bottom right for review purposes only. Page numbers will be removed from the final versions of manuscripts.

# Author Requirements

---

## Length

Articles are typically approximately 15-25 pages single-spaced (approx. 9,000 – 15,000 words), not including references, tables, graphics, or other appendices.

For lengthier articles, authors may arrange with the Editor for the publication of companion manuscripts in back-to-back editions of the Journal.

Review and other similar works are limited to 10-15 pages single-spaced, including references.

## Punctuation

The Abstract and Author Note are single, unindented paragraphs. Indent all remaining paragraphs. Use a comma between elements and preceding the conjunction (and, or) in a series of three or more. Use a semicolon to separate elements in a series that contains commas. Use a colon between a grammatically complete introductory clause and a final clause. Do not use a colon to introduce an incomplete sentence. Avoid the overuse of double quotation marks for words. Introduce a key or new technical term in italics.

## References

The APA publication manual provides detail on the correct format, including the hanging indent for the second and subsequent lines of the reference. Double-space between references. A brief list of common citation types follows. Use Arabic numbers throughout the references unless a Roman numeral is part of a title.

### *Book (author):*

Hewlett, L.S. (1967). Title of work. Location: Publisher.

### *Book (editor):*

Roberts, N.M. (Ed.). (2001). Book title. Location: Publisher.

### *Chapter in an Edited Book:*

Hewlett, L.S. (1999). Title of chapter in book. In N.M. Roberts (Ed.), *Title of book*. (pp. xxx-xxx). Location: Publisher.

### *Journal Article (print):*

Hewlett, L.S., Evans, A. E., & Belfar, S. F. (in press). Title of article. *Title of Periodical*, volume xx(*number x*), (pp. xxx-xxx).

### *Journal Article, more than seven authors*

Allison, D. G., Bartolovich, E. H., Connolly, F. I., Davidson, G. J., Edwards, H. K., Franklin, I. L., . . . Zastrow, A. C. (2007). *Title of article*. Title of Periodical, volume xx(*number x*), (pp. xxx-xxx).

### *Journal Article (electronic):*

Justin, A.A. (2001). Title of on-line article. *Title of Periodical*. Retrieved day, month, year from [http://www...\[rest of source url address\]](http://www...[rest of source url address])

### *Newspaper Article (print):*

Schwartz, J. (1993, September 30). Obesity affects economic, social status. *The Washington Post*, pp. A1, A4.

### *Newspaper Article (electronic):*

Brody, J. E. (2007, December 11). Mental reserves keep brain agile. *The New York Times*. Retrieved from <http://www.nytimes.com>

## VI. Special Manuscript Preparations

JHSH regularly includes sections dedicated to special types of manuscripts. Such sections include:

Book , Film, or Other Reviews

Special Technical Reports, Scholarly Reflections, or Professional Summaries

Literary Works

Manuscripts for review and reports generally must follow all author requirements. However, such manuscripts require careful adaptation depending upon the nature of the manuscript, its intention, its place within the JHSH edition, and other factors. The adaptation of requirements for reviews and reports is subject to the direction and approval of the Editor. The Editor may delegate the same to the Senior Associate Editor.

Literary works submitted for publication must meet the highest standards for each specific literary genre. The requirements for literary works are subject to the direction and approval of the Editor. The Editor may delegate the same to the Senior Associate Editor.

## VII. Graphics Requirements

All graphics must be submitted within the individual manuscript at the end of the manuscript itself. With each figure or graphic, a short, explanatory caption must be provided. The caption is to be placed appropriately.

Where they are to be placed within the manuscript are to be indicated in a centered directions such as:

*Figure 1 inserted here.*

In addition to placing the graphic at the end of the manuscript, each is to be sent as a separate file in high resolution as a JPEG, TIFF, PNG etc. If the graphic is a Table created in MS Word, it is to be provided additionally as a separate graphic file that ensures that text and other elements are spaced and formatted correctly. During publication processes, first authors are to remain available for the publishing house to contact them for additional refinements for graphic elements. JHSH Editorial Leadership and the publishing house are not responsible for errors in graphics that should have been overseen and corrected by the actual authors.

## VIII. Authorship

The naming of authors must conform with the “Ethical Considerations in the Conduct and Reporting of Research: Authorship and Contributorship” of the International Committee of Medical Journal Editors ([http://www.icmje.org/ethical\\_1author.html](http://www.icmje.org/ethical_1author.html)). Authorship may only be ascribed to those individuals who personally, actually and substantively contributed to the actual writing of a manuscript, its design, conceptual development, or its academic or professional scholarship. Honorary authorship by virtue of one’s position within one’s institutional organizational structure (e.g., Department Chair) is not permitted at any time or for any reason. Authors are permitted to list other individuals as contributors in the Author Note when relevant and appropriate. However, information about contributors must be brief and relevant.

Authors submitting manuscripts must apprise the Editor immediately if controversies exist concerning authorship or other related issues. JHSH cannot take responsibility for mitigating author disputes or related controversies. If an author dispute is discovered and claimed after publication, JHSH and Intellectual Property Counsel have the right to direct retractions, errata, or other corrections in future JHSH editions in accordance with pertinent laws, regulations, federal requirements, or academic standards. These actions and others may be taken in the event of research misconduct.

## IX. Responsible Conduct of Research Standards

Authors must adhere to all standards regarding research integrity and the responsible conduct of research. JHSH strictly adheres to requirements regarding research misconduct, namely falsification, fabrication, and plagiarism. Any allegation of research misconduct is immediately referred to the Editor, who will immediately refer the matter to the JHSH Intellectual Property Counsel. JHSH will support all requirements and processes for such matters to their conclusion.

Articles involving human subjects or animal research must indicate appropriate IRB or IACUC protocol determinations, reviews and approvals with dates. Authors must cite the approved protocol numbers. Any information relative to these important areas must be placed within the Author Note. When there may be questions regarding whether data/materials are determined to involve either human subjects research or research exempt from human subjects regulations, the text must clearly indicate who has made such determinations and the date of determination. It is the right of the Editor and Senior Associate Editor to ensure that all such matters comply with requisite ethical standards, regulations, laws and requirements.

Similarly, authors must disclose relevant conflict of interest information where applicable (or the lack thereof). Any information relative to this area also must be placed within the Author Note.

All questions regarding these areas and other matters related to academic, research, or professional ethics are to be referred directly to the Editor or Senior Associate Editor.

## X. Intellectual Property Information

JHSH is a peer reviewed publication of international renown. As such, it upholds and complies with all requirements regarding the protection of intellectual property and copyrights as applicable. JHSH adheres rigorously to United States norms for publications and responsible authorship. JHSH furthermore honors the academic standards and expectations of other international peer reviewed publications.

When an author's manuscript is accepted for publication, authors must sign author agreements and comply with JHSH directives. One such area is to ensure that the JHSH respects the work of authors especially if it is derived from previous efforts. Therefore, all authors must disclose such factors and work with the Editor and Senior Associate Editor for the preservation of all intellectual property and copyright issues. JHSH will not publish any materials whose authors have not completed author agreement and copyright release requirements.

The following underscores information summarized previously. Questions concerning the information below and its applicability to specific cases are to be referred to the Editor and Senior Associate Editor.

Once an author submits a manuscript, the author is not permitted to have that work under simultaneous consideration by any other publisher or organization. Similarly, if an author submits a proposal for future manuscript development and the proposal is accepted, then the proposal and its subsequent manuscript cannot be submitted elsewhere. If by chance an error has been made in these regards, the author must obtain from the other publisher or publishers a clear release and submit this to the Editor and Senior Associate Editor for consideration. If an author wishes to have a previously submitted manuscript or already accepted proposal published by another organization, the author must submit a formal request to the Editor. Permission is needed before finalization.

In addition, unless there is clear justification and only with the written permission of the previous publisher, JHSH will not accept manuscripts that have been published elsewhere, or that will be published prior to appearing in JHSH. Authors must inform the Editor and Senior Associate Editor of such matters at the time a manuscript is submitted. Such matters must be acknowledged in the Author Note.

Similarly, if an author's manuscript is based upon one's thesis or dissertation, the author must inform the Editor and Senior Associate Editor regarding copyright ownership. If the copyright for the thesis or dissertation is owned by anyone other than the author, such as the degree granting institution of higher learning, the author must obtain and submit to the Editor and Senior Associate Editor a copyright release and permission to publish from the copyright owner. Until the matter of copyright is completely processed and resolved successfully, the author's manuscript cannot be published in the Journal.

**General Copyright Guidance:** Unless expressly agreed to by JHSH, the copyright (i.e., ownership) of the material belongs to JHSH itself and its publishers. Other arrangements may be made (e.g., exclusive or non-exclusive licenses) but must be proposed by the author at the time of submission. If a contributor prepared the submission in the scope of his or her employment, the employer must assign its rights, or the author must be able to prove that the employer has already ceded copyright back to the employee (e.g., through an institutional copyright policy). Government employees will be required to obtain publication clearance approvals in accordance with agency procedures for works prepared as a part of their official duties. Proof of government clearances will be required. Students submitting material from a dissertation or other academic work in development should check with their institution to confirm ownership. All authors must obtain permission for the use of any material owned by others, including tables, figures, graphs, charts, drawings, photographs and other illustrations, and digital media works.

## Author Requirements

---

**Regarding Reproduction and Copying for Private Use:** JHSH encourages copying and reproduction of information appearing in its editions so long as such copying and reproduction is strictly limited to non-commercial educational and personal use. Any other use must be under specific agreement. In every case, JHSH and the original author must be prominently acknowledged as the source of the material. Furthermore, if an article were to be used for widespread educational classes via on-line forums (e.g. MOOC), permission of the Editor and Senior Associate Editor is required to ensure that no commercial use will be tolerated after on-line use. Any use in on-line courses must also, as mentioned above, credit the original author and JHSH.

### **XI. Contact Information**

Manuscripts and/or concept proposals for articles are to be sent directly to [dhodge@tuskegee.edu](mailto:dhodge@tuskegee.edu).

If needed, call the Tuskegee University National Center for Bioethics in Research and Health Care at (334) 724-4554.



National Center for Bioethics  
in Research and Health Care



*Looking Back to Move Forward*

National Center for Bioethics in Research & Health Care  
Tuskegee University  
John A. Kenney Hall, 44-107  
1200 W. Montgomery Road  
Tuskegee, AL 36088