

FOREWORD: THE PARADIGM SHIFT—THE IMPACT OF HIV/AIDS ON BLACK WOMEN AND FAMILIES: SPEAKING TRUTH TO POWER

Gail E. Wyatt, PhD¹;
Cynthia Davis, MPH, DHL²

Ethn Dis. 2020;30(2):241-246;
doi:10.18865/ed.30.2.241

Keywords: HIV/AIDS; Black Women; Black Families

¹ Department of Psychiatry & Biobehavioral Sciences, University of California, Los Angeles, CA

² College of Medicine & College of Science and Health, Charles R. Drew University of Medicine and Science, Los Angeles, CA

Address correspondence to: Gail E. Wyatt, PhD; UCLA Department of Psychiatry & Biobehavioral Sciences; GWyatt@mednet.ucla.edu

INTRODUCTION

When the United States Constitution was written, it described man's (and ultimately woman's) unalienable rights to equal treatment, but that right has yet to be achieved when it comes to health care. Since the arrival of African slaves in the 16th Century, the status of health care in American health care systems for African Americans has also included no care, inadequate, antiquated and substandard treatments, and hostile health professionals. Their exploitive and discriminatory practices have resulted in inequalities in health and a mistrust in the medical care system that deters efforts among some to seek care to this day.^{1,2} There is no question that America is still struggling to openly address the AIDS epidemic in the United States as the "greatest public health catastrophe of the twentieth century."³

It was C. Everett Koop, MD who, in his two terms as Surgeon General, had the arduous task of providing a congressionally mandated brochure to the American public defining HIV and AIDS, identifying who was most at-risk and recommending steps to avoid

transmission in 1988.⁴ This mailing to every household was an effort to demystify some of the hysteria around how AIDS was spread, to reframe AIDS as a chronic disease and to recommend testing and long-term management with drugs and behavioral approaches to reduce transmission risks. It was in this brochure that the Surgeon General stated that longer years of marriage could be a protective factor for women, depending on the behaviors of both partners.^{5,6}

Unfortunately, women in long-term marriages breathed a sigh of relief because they assumed that their husbands and partners were transparent and monogamous.

However, far too many women were in the position of Mrs. Smith, a middle-aged African American wife of a well-respected pastor of a mega-church with a star-studded congregation. On his death bed, her husband whispered in her ear, "I have not been faithful. Get yourself tested: I have AIDS." The shock and disbelief that her marriage had been a lie was only made worse when she did get tested and found that she, too, had AIDS. It was not the number of years of her marriage that provided protection, but it was the

assumption of monogamy and the behaviors of her partner unknown to her that increased her risks.

This story represents the confusion surrounding how individuals, especially women, can become infected. Even the cautionary messages about risky sexual behaviors, multiple sexual partners, the non-use of condoms, and IV drug use

The need for women's voices to urgently promote women-centered approaches to AIDS prevention is borne out of the current statistics identifying African American women at most risk for HIV/AIDS. Is the single solution approach for men and women working?

that could promote disease transmission were rendered incomplete. Mrs. Smith had engaged in unprotected sexual practices as she had for generations with her husband because of their mutual desire for children and to demonstrate their love and commitment to each other in a presumably monogamous

relationship. Those assumptions did not fall into the at-risk public health messages from Dr. Koop nor were they conveyed by any other AIDS researchers and they still are not today. It has become increasingly clear to HIV prevention advocates for women and girls that they need to increase their knowledge of high-risk transmission routes. They need to learn how to negotiate with partners about the mutual importance and commitment to their relationships, having children, and what it takes to preserve families. Finally, women need to plan for the risks of being dependent upon partners for financial security. Without assurances, followed by observing behaviors that might suggest that the partner is cheating and having continued conversations about the status of the relationship, the method of protection from unwanted outcomes of pregnancy and disease transmission should totally prevent pregnancy, HIV and STI transmission. Today, the skills needed to engage in conversations with sexual partners about past and current risks to HIV/AIDS, how to overcome barriers to becoming sexually and financially responsible for oneself and what to do when the commitment to the relationship is not mutual has been sidelined for the single message of 'HIV treatment as prevention' for everyone. Where does that leave women today?

The need for women's voices to urgently promote women-centered approaches to AIDS prevention is borne out of the current statistics identifying African American women at most risk for HIV/AIDS. Is

the single solution approach for men and women working? No, and that is why this special section in *Ethnicity & Disease* came about.

CONVENING TO ADDRESS HIV/AIDS ISSUES FACING AFRICAN AMERICAN WOMEN

In fall 2016, after attending and participating in the Annual Congressional Legislative Black Caucus meeting in Washington, DC, five African American women convened a meeting to discuss critical HIV/AIDS-related issues combating the African American community and African American women and families, in particular. The group consisted of experts in the field of HIV/AIDS service provision, clinical care and treatment, academic research, primary prevention and public policy. We were concerned and alarmed that after decades of working in our respective fields to stem the tide of the HIV/AIDS epidemic, that African American communities and African American women and families, in particular, were still being disproportionately impacted by HIV/AIDS. How could this be? Billions of dollars from the public and private sector have been made available to increase access to care and services and to increase and enhance HIV/AIDS primary prevention initiatives throughout the country over four decades. We concluded that the US government had failed our communities, and something had to be done.

In order to engage in a call to

action to funders, policy makers, advocates, elected officials, and the broader African American community, more innovative and creative initiatives were needed to stop HIV/AIDS in its tracks. We were fully aware that African American women, after decades of community-based interventions and research, were still being infected at a rate 20 times greater than White Women.⁷ Many of these disparities were directly attributed to numerous social determinants of health that have affected African American communities, including institutional racism, homophobia, discrimination, sexism, misogyny, social and economic inequities, and the list goes on.^{8,9}

In lieu of these realities, we felt it was time for us to take the decision makers of HIV/AIDS policies and funding to task by forming a collaborative of like-minded individuals to generate solutions to this crisis. The primary recommendation of the group was to convene a national conference on HIV/AIDS' impact on African American women and families. We wanted to highlight major HIV/AIDS-related health disparities; but to go a step further, we wanted to provide the historical context as to why these health disparities had evolved over time and have been sustained for generations. Recommendations from the first conference were as follows: 1) the urgent need to support more "women-centered and focused" research funded nationally targeting African American researchers; 2) a need for changes in governmental public policies to ensure that comprehensive sexual and repro-

ductive health initiatives are being spearheaded and funded in African American communities across the nation (this is especially true in the Deep South, where HIV/AIDS and STI rates have been at a heightened level for decades); 3) a mechanism established whereby a network of African American junior researchers can be mentored and financially supported is needed in order to create a new generation of investigators who are knowledgeable and aware of the past history of discrimination, racism and overt benign neglect on the part of the public sector which has led to insufficient funding for research studies supported by the NIH and CDC led by African American women; research led by and for African American women should be a priority.

However, the barriers to health, testing and treatment have not been considered within an ethnic specific or gendered context and prioritized, as such. Given the significant history of unequal health service delivery and the medical mistrust based on illegal and unethical medical experimentation with African Americans,^{10,11} not all communities have responded to initial generic calls for HIV prevention. Not all communities have been approached by investigators with NIH funding with prevention strategies within the context of how African Americans had been treated in the past with regard to health care or epidemics. We cannot overlook 400 years of oppression that serve as barriers to medical adherence that is needed for the successful uptake of current medications or medical

mistrust that heighten suspicions about intent and results in drop outs.^{12,13} Everyone does not perceive of their risks for infection in the same way, particularly those who consider themselves to be in monogamous relationships. For many African Americans, everyday life is often risky with potentially life-threatening outcomes. HIV-related risk taking is not a priority, but survival is.¹⁴ And finally, everyone does not cope with risks in the same way. Women have reproductive along with sexual and gynecological health to consider, and yet services for HIV/AIDS are often separated from other women-centered services. As a result, women often must travel to more than one location to receive affordable sexual and reproductive health services. However, far too often they must figure out how reproductive concerns can be achieved along with HIV and STI prevention. More than a few HIV doctors will prescribe PEP for an unanticipated sexual encounter with partners whose histories are unknown. They often, however, do not recommend or prescribe "the morning after" pill for an unintended sexual encounter that might also have resulted in unprotected sex that could lead to pregnancy.

RESEARCH WITHIN THIS ISSUE

This special section of *Ethnicity & Disease* attempts to fill the gap of the scarcity of research that addresses some of the barriers that African American women and transgender

women face in reducing their risks. The articles in this section include a multi-disciplinary group of women and men who were either of African American, or African descent or who were mentored, supervised and informed by experienced African American investigators. We recognize that while there are too

Our message to those who will read this section of the journal and learn more about the numerous issues concerning HIV/AIDS' impact in the African American community and African American women, in particular, is to join us in this struggle to "Shift the Paradigm" around funding, research, public policy and advocacy.

few women conducting AIDS research, too few have been adequately mentored to also recognize the importance of the context of relationships, the scarcity of health-related services that address health disparities and how discrimination

can affect changes to healthy behaviors. These articles are a sampling of the issues that need to be incorporated into HIV/AIDS prevention.

In the first article, Victoria A. Cargill, MD, MSE and a keynote presenter at the first conference, addresses the need to understand how to conduct research and to offer gender- and sex-related services and treatment to transgender populations. With the assistance and insights of Vann Michael Milhouse, MA, Dr. Cargill also discusses the need for more research in many areas related to sex and gender in this commentary.

Many African American women have resisted HIV prevention efforts because of their perceived relationship status, as mentioned in the experience of Mrs. Smith. The next few articles consider the relationship context as a barrier or facilitator to behavior change. Kristina B. Hood, PhD, Calvin J. Call, MS, Bianca D. Owens, MS, Alison J. Patev, MS, and Faye Z. Belgrave, PhD, also a speaker at the first Paradigm Shift conference, describe some of the conspiracy beliefs and partner status disclosure of rural Black women in Mississippi. This article represents the challenges of working with young, rural populations whose past health care and treatment have been compromised by disparities in health care and treatment of marginalized populations. The history of these beliefs must be addressed and confronted before services are offered.

Past histories of discrimination have been linked to disparities in health care utilization.¹⁵ Jenna Alar-

con, MPH, CHES, Tamra B. Loeb, PhD, Nicholas Moss, MD, MPH, Condessa M. Curley, MPH, FAAFP (one of the Sankofa Collaborative's founding members), Muyu Zhang, MS, Wilbert, Jordan, MD, Gloria Lockett, Cynthia Carey-Grant (a founding member), and Gail E. Wyatt, PhD (a founding Sankofa Collaborative member and conference co-chair) examined the impact of personal characteristics and experiences of racial discrimination on the likelihood of being tested for STIs.¹⁶ Testing for sexually transmitted infections (STIs) among couples where one partner is HIV positive and the other partner is HIV negative represents another barrier and a high-risk group for HIV and STI infection.¹⁷

Women in relationships often struggle to seek health care, especially if their partners are not in support of their efforts.¹⁵ Jacqueline Mthembu, PhD, Alison B. Hamilton, PhD, MPH, Norweeta G. Milburn, PhD (a Paradigm Shift conference presenter), Deborah Sinclair, MA, Siyabulela Mkabile, MA, Mmathabo Mashego, MA, Thabile Manengela, MA and Gail E. Wyatt, PhD, examined qualitative data to describe how sero-discordant couples responded to a culturally congruent HIV intervention for couples. In this article, it was evident that the influence and participation of a partner can increase participation in risk-reducing skill-building. Drs. Milburn, Hamilton and Wyatt mentored the co-authors in their emerging careers as predoctoral students. While this manuscript involved African American cou-

ples, discussions also included how the intervention could be adapted for the South African context.

HIV prevention is only effective if young adolescents can benefit from and learn about risk reduction strategies as they mature. Tamara Taggart, PhD, MPH, Norweeta G. Milburn (a Paradigm Shift presenter), Kate Nyhan MLS, and Tiarney D. Richwood, PhD are early career faculty and were mentored by Dr. Milburn to consider the environmental context, characteristics, social networks and community level factors as determinants of HIV risk behaviors in their review of studies on Black adolescent girls.

In another article in this issue, Megan T. Ebor, PhD and Aurora P. Jackson, PhD report on a faith-based intervention for African American women aged ≥ 55 years to reduce symptoms of depression. This article illustrates the value of collaborating with well-established, community-based institutions (eg, the church) to offer HIV prevention/protection on an ongoing basis. Dr. Williams mentored Dr. Ebor in this effort.

Our message to those who will read this section of the journal and learn more about the numerous issues and behavior change strategies concerning HIV/AIDS' impact in the African American community and African American women, in particular, is to join us in this struggle to "Shift the Paradigm" around funding, research, public policy and advocacy. In the next five years, we need to witness a significant reduction in HIV/AIDS rates in African American communities in the United States and see an emergence of

"grass roots" sustained activism by a new generation of HIV/AIDS advocates, stakeholders, and researchers.

Surgeon General Koop believed that "the government is not going to solve the AIDS problem. The AIDS problem in the Black community can only be solved by people who live in that community."¹⁸ The government can, however, support research and training opportunities to prioritize women-centered prevention efforts led by African American or culturally competent women. HIV/AIDS primary prevention and advocacy initiatives that are culturally based and appropriate will break barriers when it comes to HIV/AIDS-related stigma, sexism and homophobia. We can eventually end the HIV/AIDS epidemic in our communities and within our lifetime.

The struggle continues.

ACKNOWLEDGEMENT

The authors, founding members of the Sankofa Collaborative and co-chairs of the Paradigm Shift Conferences in 2017 and 2020, wish to thank the following universities, colleagues and staff for support in these research endeavors: the Semel Institute of the Department of Psychiatry and Biobehavioral Sciences at UCLA and the College of Medicine and College of Science and Health, Charles R. Drew University of Medicine and Science; manuscript preparation assistance from Amber Smith, MA, Tamra Loeb, PhD and Alex Kim. Funding for this research was provided in part by the UCLA -South Africa Center for Chronic Mental Disorders (Tirisano) (1D43TW009685) and Implementing EBAN II: An Evidence-Based Intervention for Sero-Discordant Couples (1R01MH093230).

REFERENCES

1. Riley P. *Closing the Equity Gap in Health Care for Black Americans*. Commonwealth Fund. 2016. Last accessed Jan. 27, 2020 from <https://www.commonwealthfund.org/>

- blog/2016/closing-equity-gap-health-care-black-americans.
2. Stallings E. *This Is How the American Healthcare System Is Failing Black Women*. Oprah Magazine. June 18, 2019. Last accessed Jan. 27, 2020 from <https://www.oprahmag.com/life/health/a23100351/racial-bias-in-healthcare-black-women/>
3. Koop CE. Surgeon General's report on acquired immune deficiency syndrome. *JAMA*. 1986;256(20):2783-2789. <https://doi.org/10.1001/jama.1986.03380200021005> PMID:3773188
4. Valdiserri R, Department of Health and Human Services. In Memoriam: C. Everett Koop. Feb. 27, 2013. Last accessed Jan. 24, 2020 from <https://www.hiv.gov/blog/in-memoriam-c-everett-koop/>.
5. Centers for Disease Control (CDC). Understanding AIDS: an information brochure being mailed to all U.S. households. *MMWR Morb Mortal Wkly Rep*. 1988;37(17):261-269. PMID:2834628
6. Koop, CE. *AIDS and American Values*. Oral Presentation at: The World Affairs Council; September, 1987; Los Angeles, CA.
7. National Institutes of Health, Office of Research on Women's Health. *HIV Infection and AIDS*. Last accessed Jan. 24, 2020 from https://orwh.od.nih.gov/sites/orwh/files/docs/WOC_Booklet_HIV_AIDS-2C-508.pdf
8. Braveman P, Gottlieb L. The social determinants of health: it's time to consider the causes of the causes. *Public Health Reports*. 2014;129(1_suppl2):19-31. <https://doi.org/10.1177/00333549141291s206>
9. McGibbon E, McPherson C. Applying intersectionality & complexity theory to address the social determinants of women's health. *Womens Health Urban Life*. 2011;10(1):59-86.
10. Brandt AM. Racism and research: the case of the Tuskegee Syphilis Study. *Hastings Cent Rep*. 1978;8(6):21-29. <https://doi.org/10.2307/3561468> PMID:721302
11. Friedman SR, Cooper HLF, Osborne AH. Structural and social contexts of HIV risk Among African Americans. *Am J Public Health*. 2009;99(6):1002-1008. <https://doi.org/10.2105/AJPH.2008.140327> PMID:19372519
12. Cuffee YL, Hargraves JL, Rosal M, et al. Reported racial discrimination, trust in physicians, and medication adherence among inner-city African Americans with hypertension. *Am J Public Health*. 2013;103(11):e55-e62. <https://doi.org/10.2105/AJPH.2013.301554> PMID:24028222
13. McQuaid EL, Landier W. Cultural issues in medication adherence: disparities and directions. *J Gen Intern Med*. 2018;33(2):200-206. <https://doi.org/10.1007/s11606-017->

Foreword: The Paradigm Shift: Impact of HIV/AIDS on Black Women and Families - Wyatt and Davis

- 4199-3 PMID:29204971
14. Mastroianii, B. Why many HIV-positive women choose basic survival over treatment. *Healthline*. Last accessed Jan. 24, 2020 from <https://www.healthline.com/health-news/for-many-hiv-positive-women-survival-not-viral-suppression-is-top-priority>
 15. Alcalá HE, Cook DM. Racial discrimination in health care and utilization of health care: a cross-sectional study of California adults. *J Gen Intern Med*. 2018;33(10):1760-1767. <https://doi.org/10.1007/s11606-018-4614-4> PMID:30091123
 16. Alcaron JE, Loeb TE, Wyatt GE, Curley CE, Hamilton AE. Barriers to testing for sexually transmitted infections among HIV-serodiscordant heterosexual couples: the influence of discrimination. *Ethn Dis*. 2020;30(2):261-268.
 17. Medley A, Garcia-Moreno C, McGill S, Maman S. Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: implications for prevention of mother-to-child transmission programmes. *Bull World Health Organ*. 2004;82(4):299-307. PMID:15259260
 18. Fisher M. Surgeon general minces no words on AIDS. *Poughkeepsie Journal*. February 28, 1988:12A.