

## Black Women's Contribution to the HIV/AIDS Fight

Raphael M. Mutepa<sup>1</sup>, Samson Chama<sup>2\*</sup>

<sup>1</sup>Professor, Department of Social Work, West Virginia State University Institute, United States

<sup>2</sup>Professor, Department of Social Work, Alabama A & M University, United States

\*Correspondence should be addressed to Samson Chama; Samson.chama@aamu.edu

**Received date:** December 3, 2019, **Accepted date:** January 6, 2020

**Copyright:** © 2020 Mutepa RM, et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

### Abstract

AIDS was first described in 1981 homosexuals in Los Angeles and other cities. By 1982, AIDS was an infection conveyed through body fluids and was affecting men and women erratically. Its second definition ushered in several subgroups and morphed into an epidemic of non-White, women, and heterosexuals. This article strives to inspire women to acquaint themselves with their forerunners' achievements in this regard and to engage them in the fight against HIV/AIDS. Through the narrative inquiry method, we gathered, analyzed, and portrayed the women's stories as captured from their cultural contexts. We ultimately learned that Black women's contributions to the AIDS fight are concurrently overflowing, overlapping, and yet specifically targeted.

**Keywords:** African American women, HIV/AIDS, Black church, DEBIs, Determination.

### African American Women's Contribution to the Fight against the Spread of HIV/AIDS

After thousands of years of gender conflicts, the world now stands at the beginning of the feminine era, when women will rise to their proper standing, and the entire world will experience the harmony between men and women [1-4]. In the field of the Human Immunodeficiency Virus (HIV) and the Acquired Immunodeficiency Syndrome (AIDS), this harmony is already being experienced as men and women who became infected with HIV are now involved in the fight against the spread of the epidemic in our communities. Because of the various and concurrent positions that women hold in the socio-economic, political, cultural, and spiritual realms of society, they became and will continue to be a major determinant in the fight against the spread of the HIV/AIDS epidemic.

The fight against HIV/AIDS has been a protracted battle against a plethora of barriers that are still exhibited at various social, cultural, economic, and political fronts. Even though these barriers seemed insurmountable, men and women at the frontline of this cause stood firm in their resolute optimism to fight on. They were not startled by the hostile situation that was then so evident. Instead, they remained diligent in their dedication to a social justice agenda that would take the HIV/AIDS struggle to

a new level. These courageous men and women formed the earliest networks of HIV care, founding the first AIDS service agencies and leading advocacy efforts on behalf of people living with HIV/AIDS (PLWHA). In the United States of America (U.S.), the African American women became an integral part of the fight and are still operational in several areas of the fight against the spread of the virus. The purpose of this article is to show how Black women took part and are still taking part in the eradication of the epidemic in our areas. The terms African American and Black American are used interchangeably in this exposé.

### Literature Review

In the U.S., AIDS was first described in 1981 in five sexually active homosexual young men in Los Angeles and clusters of patients in other cities. HIV, a lentivirus that causes HIV infection and ultimately AIDS, was said to be the root of this new illness [5-7]. By late 1982, it was verified that AIDS was an infectious disease conveyed through body fluids, namely blood, semen, rectal, and vaginal fluids, and breast milk [8]. It was also projected that all infected persons would eventually become seriously ill with HIV-related disease and Azidothymidine (AZT) was then the only drug licensed as an effective antiviral drug [6,9]. Without treatment, average survival time after the infection was estimated to be 9 to 11 years,

depending on HIV subtypes [10]. It is worth noting that the disease had cycled through many names: Human T Cell Lymphotropic Virus (HTLV) type I, II, III [11]; Gay-related immune deficiency (GRID) [12] before the scientific community settled on AIDS in 1982 [9].

As the world was busy blaming White gay men for the disease, women, and children were being infected as it was then believed that AIDS was confined to White gay men, prostitutes, intravenous drug users, and hemophiliacs. Even though the morbidity and mortality statistics of the day did not reflect women's and children's patients, the number of afflicted women, children, hemophiliacs, and others were growing exponentially. The Centers for Disease Control and Prevention [CDC] (2016) [13] reports that women between the ages of 18 and 44 years is the fastest-growing group of people infected with HIV/AIDS today and that Black women have a 1 in 32 chance of acquiring HIV in their lifetime, compared to White women, who have only a 1 in 588 chance of HIV infection.<sup>12</sup> In 1993/1994, when the world gained more insight into the spectrum of HIV-related illness, the re-definition of the disease incorporated conditions only found in women infected with HIV or suffering from AIDS [14].

The second definition of AIDS ushered in several subgroups and the epidemic gradually morphed into an epidemic of non-White people, women, and heterosexuals. Today, women account for 1 in 5 of new HIV infections in the U.S. Women of color, mostly Black women, are notably hard hit and represent most women living with the disease and women newly infected. AIDS is now the leading cause of death among Black women ages 25-34 and the epidemic is entirely feminized [13]. The isolation of the HIV virus [15], its presence in body fluids [16] the ensuing transmission through sex (Phillips, Zacharopoulos, Tan, & Pearce-Pratt, 1994), and the incidence of morbidity and mortality among African American women [17], made them realize that AIDS was also their illness and that they had to join in the fight and ultimately the eradication of this new affliction. This article strives to inspire women of all walks of life to acquaint themselves with what their forerunners had achieved in this regard and to incite and motivate them to do more in the fight against HIV/AIDS.

## Methods

The narrative inquiry (or narrative analysis) method was our method of choice. Narrative inquiry is a way of understanding and inquiring into an experience through "a collaboration between researcher and participants, over time, in a place or series of places, and social interaction with milieus" [18]. Based on this definition and following the steps suggested by [19] the writing of this article began with a conversation with Anita, one of the professors

who serve on the state HIV Community Planning Group (CPG) when she returned from a workshop where they discussed the funding of HIV/AIDS activities in the State. When asked about the CPG achievements so far, Anita retorted that the CPG had funded several community-based organizations and that women, especially African American women, had been at the forefront of the fight against the spread of HIV/AIDS in our communities. She offered to speak to the faculty about African American women's contribution to the fight against HIV. Her presentation consisted of a summarization of the many books she had read about HIV/AIDS and an explanation of how black women had worked and are still working to change their situations on the ground. Soon many more women (Julie, Clara, Ms. Mwenya...) joined the conversations and the presentations grew in quality and contents.

This is how we gathered, analyzed, and represented women's stories as captured from their cultural standpoints. From their presentations, we deduced all the themes, insights, and understandings argued in the article. This article is a reconstruction of women's experiences in relationship both to the other and to a social milieu [20]. Through the meticulous use of the Narrative Inquiry, we also learned that Black women's contributions to the fight against HIV/AIDS are concurrently overflowing, overlapping, and yet specifically targeted.

## Results

To corroborate black women's resolve to fight and even eradicate the spread of HIV in our midst, this article presents and discusses its findings in following areas of influence: Black women as patients, Black women as therapists, Black women as informal caregivers, Black women ministers and HIV/AIDS, Black women as physicians in infectious diseases in hospitals, and Black women as community popular opinion leaders. None of these features is enough by itself, but in conjunction with others, they describe the Black women's contribution to the fight.

### Black women as patients

When the AIDS epidemic was eventually accepted as a universal phenomenon, it had relentlessly and indiscriminately spread to men and women of all races/ethnicities, abilities, ages, sexual orientations, religions, and social classes worldwide. Black women realized that they were disproportionately affected by the disease and that they needed to act fast to remedy the situation. Hence, their first contribution to the fight against HIV/AIDS was to avail themselves as patients and as exhibits to enhance the garnering of scientific knowledge as extraordinarily little was known about the disease. As patients, Black women helped in the search for a cure to assuage their physical and psychological pains

including stigma, mental stress, and a host of psychiatric challenges. It is now common knowledge that the HIV/AIDS disease is associated with stigma, mental stress, and psychiatric morbidity ([21] and that the existence of HIV-related stigma compromises public health efforts toward prevention, treatment, and provision of the support needed for effective management of the disease [22]. Thirty-five years after the onset of the epidemic, the HIV-related stigma still exists [23] and evidence suggests that it is rampant among African Americans compared to White people [24]

Besides the stigma and physical afflictions, Black women transcended the medical distrust that runs from the Tuskegee Syphilis Project to the current issues of health disparities in the U.S. [25,26]. Blacks' fears of exploitation by the medical establishment date back to the antebellum period when slaves were used as subjects for dissection and medical trialing [27]. But, when the epidemic needed cases from which to derive knowledge, the infected Black women offered themselves to advance science and to save the millions that were still untouched. Posthumously, Henrietta Lacks, an African American woman whose cancer cells are one of the most important cell lines in medical research, offered her cells to develop a potential vaccine against HIV/AIDS [28-30]. Her immortalized cell line which reproduces itself indefinitely under specific conditions continues to be a source of invaluable medical data to the present day. While it was rumored that the Black women's coming-out was for their benefit, it should also be admitted that their resilience profited the world more than it did to themselves. People living with HIV

(PWHA) from the developing nations underscore this point [31].

### Black women as therapists

From the redefinition of AIDS, Black women explicitly learned that the social structure of HIV risk and transmission was also a gendered experience added to their vulnerability to HIV. The female anatomy, oppressive gender norms, violence against women, limited health literacy, and limited negotiation skills all negatively impact girls and women and increase their risk for HIV infection. The link between HIV risk and transmission and race [32] and class oppression [33] is self-evident. Hence, to protect women against HIV infection and/or reinfection, women ought to be given a variety of options from which to choose a prevention solution that best suited their needs and risk profile. HIV research grounded in women's empowerment theory that recognizes a woman's ability and willingness to protect herself from HIV stems from her sense of empowerment acquired through daily exchanges and experiences in her social contexts [34].

Hence, Black women launched non-governmental organizations or joined hands with existent agencies to create behavioral interventions to inspire women to practice safer sex by improving expertise and beliefs and by building skills to practice safer behaviors [35,36]. They joined the CDC to develop, implement, and assess the Diffusion of Effective Behavioral Interventions (DEBIs), evidence-based, group and community-level HIV/STD prevention interventions, for health departments and

		Description
1	Sister-to-Sister	It increases women's knowledge and mends condom negotiation and refusal skills through a brief one-on-one intervention and role-playing activities [38].
2	SIHLE (Sistas Informing, Healing, Living, and Empowering)	It emphasizes ethnic and gender pride for Black girls and upholds abstinence, using condoms consistently, having fewer sex partners, and developing healthy relationships [39].
3	The Future is Ours	It helps women to understand and personalize their individual risk for HIV and recognizes the role of intimate partner violence in vulnerability to HIV acquisition [40].
4	Real AIDS Prevention Project,	It is a community mobilization program in high-risk areas aimed at increasing condom use with peer street outreach, small group activities, and local media campaigns [41].
5	Stepping Stones	It is a broad program that offers discussions on sexual health issues including pregnancy, safer sex, and gender-based violence [42].
6	Intervention with Microfinance for AIDS and Gender Equity (IMAGE)	It offers micro-financing solutions along with an HIV and gender training curriculum to women to help reduce gender-based violence and HIV risk behaviors.
7	Sonagachi Project	It was developed to empower sex workers to use health services to reduce HIV incidence and develop their own programs focused on better working conditions and human rights protections [43].

**Table 1:** Debis-conceived and designed in conjunction with women.

community-based organizations nationwide [37].

Conceived and designed in conjunction with women, DEBIs include among others the following programs (Table 1).

Behavioral scientists, including Black women among them, have made sizable strides in developing HIV evidence-based prevention interventions to promote behavior change among African American women, even though, maintenance of these health behaviors remains a challenge [44].

These DEBIs have been executed and evaluated in social settings such as schools, clinical venues, prisons, and substance abuse treatment facilities and have been proven effective through research that showed positive behavioral (e.g., condom use; cut in number of partners) and/or health results (e.g., cut in the number of new STD infections). Black women's contributions did not stop here, but, as cell tentacles, they moved to other areas where they were needed.

### **Black women as community popular opinion leaders**

Another area where the women contributed to the fight against HIV was in their role as community popular opinion leaders. Popular Opinion Leader is a DEBI that was originally developed by Kelly and his colleagues to help in the fight against the spread of HIV [45]. A derivative of this program is the Community Popular Opinion Leader (C-POL). Tapping into community strengths, altruism, and people's desire to do something to help fight against HIV, the C-POL intervention uses social networks and opinion leaders of social networks to fuel prevention messages and behavior change at a population level [46,47]. Using the diffusion of innovation theory, it stresses community empowerment, seeks to increase safer-sex and other HIV-related norms among members of a well-defined target population as its theoretical base [46]. Several adaptations of the C-POL intervention have been utilized with African American Men having Sex with Men (MSM) [48], young Latino migrant MSM [49], male sex workers, and women [50]. As a result, a C-POL promotes risk reduction supportive opinions and practices to their friends and associates within their shared social networks [17,51].

Equipped with all the needed information, female C-POLs first provided entrée and legitimation to external change agents, then acted as conveyor-belt from their communities back to agencies executing programs, and finally acted as role models for behavior change within the community [52]. Utilizing the methodology described above, Black women, as C-POLs, yielded the following results: a) Decrease in unprotected intercourse and increase in condom use in MSM and minority women [53],

b) Decrease in number of sex partners (MSM), c) Increase in communication with partners in minority women [54], d) Decrease in paid, unprotected anal intercourse (male sex workers), and e) HIV/STD risk reduction [55]. Needless to add that these women acted and still act as perfect managers. In other areas of development, the evidence reveals that female leaders typically show more compassion and empathy, and a more open and inclusive negotiation style. Having spent half of his career in family planning and social development my manager can attest that placing women in leadership positions on development programming assures that resources are allocated fairly and effectively (J. Munkanta, personal communication, December 26, 2017).

Dr. Morris (2016) study on the impact of women in public service indicates that women have had a clear impact on policy, programs, and operations in natural resources, human resources, and international relations, and that current global problems require leaders that have diverse skill sets and innovation that can only come from diverse ideas and players. Having women in leadership roles is breaking down cultural and structural barriers, thereby improving leadership around the world and showing everyone what women can achieve. Besides all the information these women needed, they were also determined to protect the uninfected in the community, to stop the process of reinfection in those already infected, and to work towards the protection of future generations of Black people [56].

### **Black women as informal caregivers**

Now that the prevention side was partially assured, the women faced the duty of caring for the infected and the afflicted. Worldwide, caregiving is becoming increasingly exacerbated than before. Caregivers are faced not only with the aging and their geriatric conditions, but also with all the people living with chronic illnesses, such as AIDS, cancers, and others of the like. In their study about expectation about future long-term services, Henning-Smith and Shippee (2015) [57] found that most Americans undervalue their future need for long-term services and supports (LTSS) and do not fully plan for their old age whereas Johnson, Toohey, and Wiener (2007) [58] projected that the number of Americans needing LTSS may reach 40 million by 2040. On the side of the AIDS epidemic, it is estimated that there were 39, 782 new cases of HIV infection in 2016, of which 41% were African American men and women (CDC, 2017). If the onset of powerful antiretroviral therapy has transformed HIV from a fatal infection to a manageable chronic disease for those with access to therapy, then, the number of those needing care will continue to explode, and more so among Blacks (CDC, 2016; 59).

Faced with this explosion of people needing care,

Black women revealed their other side as caregivers for themselves, the family, and society. Caregiving is usually performed informally or professionally. A caregiver is defined as someone who provides care and support for spouses, children, parents, and friends who need support because of age, disabling medical conditions, chronic injury, and long-term disability. An informal caregiver provides free emotional, financial, nursing, and social supports, homemaking, and other services on a daily or intermittent basis for a needy person whereas a professional caregiver is hired to provide the same. Caregivers, formal or informal, pass on their patience, guidance, humor, and resources to people who are often living with fear or pain [60]. For their contribution to the fight, Black women functioned and still function in both capacities.

As informal caregivers, Black women volunteered their time, without pay, to help with the care needs of a loved one. They assisted the person with tasks such as preparing and eating food, taking medicine, bathing, and dressing. Activities such as these are not only stressing, but also have the potential of affecting caregivers in the provision of their services [61]. Because of the advanced antiretroviral treatments, AIDS patients now live longer and the demands on the caregivers are worsening day after day. Both formal and informal caregivers go through the same plight.

It is worth noting that, while Black women provided care to the infected, some became infected in the process and their healthcare needs were not being met because of poverty and lack of access to the medical establishment. Symptoms of poor physical health were visibly present among AIDS caregivers and pointedly linked to care-related demands and stressors. Caring for these women created challenges related to the context of their lives, the ambiance created by the presence of HIV, and their psychological status. These women faced several risk factors as well as lack of empowerment and social support (Meyer, Springer, & Altice, 2012), lack of access to women-specific HIV care [62, & Gilbert, 2009), and their caregivers' challenges. Confronted with their own sickness and that of their loved ones, these caregivers often placed their health care needs behind the needs of spouses, children, and grandchildren [63] and felt that they could not show any signs of weakness or needing help [64,65].

It is also significant to note that countless Black women ordinarily assume several roles including those of family health manager, breadwinner, advocate, and faith/spirituality devotee. Hence, it is not shocking that, with the explosion of single-parent households, women have gradually assumed the role of the family "breadwinner" and informal caregiver in that they execute unpaid tasks to

satisfy the health needs of family members, and the social role of advocate by sharing their stories and encouraging other women to practice "safe" behaviors and improved self-management deeds. Living with AIDS is difficult, and managing the many daily tasks required to live well with AIDS is more challenging for most women, even though this is accomplished daily by millions of women around the world [66].

### **Black women in clinical trials**

From being patients and informal caregivers, African American women also turned to clinical trials as another area where they could contribute profitably. Clinical trials are an area where Blacks and other minority groups were historically and excluded until the National Institutes of Health required the inclusion of women and minorities in studies for any funding [67]. To defend their exclusion of minority groups, several scientists cited "the difficulty of recruitment and retention, a general belief that racial populations are essentially monolithic, without significant differences, and the desire and need to focus on optimizing internal validity" [68], and to justify their rejection of trials, Blacks alluded to past medical experimentation, their mistrust in the medical establishment, and their resistance to participate in research activities for their lack of interest in clinical trials [69,31] They also revealed a lack of awareness about trials, low socioeconomic status, poor communication skills, a lack of disease education [70] and a fear of being used as guinea pigs [71] as barriers to their participation in clinical trials. These women understood that adequate minority enrollment in clinical trials was vital if differential effects among diverse groups were to be assessed and for the results to be generalized [72]. As a result, they gladly enrolled in clinical and medical trials.

Drawing on their experience during slavery when they were selectively and partially attended to by the medical establishment [73] and from the time of segregation when they were mostly attended to by their physicians and in their own communities [27], African American women roused their "sistas" and their own communities to seek medical care and to participate in clinical trials as the future of their children and communities in general depended on this act of faith [72]. They also understood quite well that, to run successful research and treatment of AIDS, African Americans and researchers ought to work together with a spirit of openness and collaboration and to understand that cultural competency, health literacy, establishing trust and building relationships were all salient factors that ought to be taken into consideration when recruiting and working with minority populations [74]. Hence, these women played and are still playing the role of mediator and advocate between their communities and the medical establishment.

### **Black women ministers and HIV/AIDS**

At the onset of the AIDS epidemic, the Black Church, historically a place of social, political, cultural, and religious, activities was still at war against homosexuality and noticed that its pastors, choir directors, and male congregants were dying from rare forms of cancers and pneumonia which later became known as AIDS-related illnesses. Some ministers were adding humbling comments in their sermons to express disdain toward black gay men, some others were openly upholding gay parishioners [75], while the remainder remained utterly silent. The black gay men living with AIDS felt alienated from Black religious gatherings. They experienced various homophobic and AIDS-phobic messages that raised their feelings of castigation, diminished their religious identity, and threatened the loss of salient cultural and historical resources unique to Black congregations [76]. A palpable silence around homosexuality pervaded and still exists in several Black churches, even though there are today Black congregations that are socially and theologically liberal.

Even though Black gay men often struggled with feelings of disapproval from God and churches [77], spirituality always helped them maintain their formal connections to religious establishments [75] though they have now started to reinterpret church teachings in light of their sexualities [78]. Disenfranchised from their own mother body, the church, and shunned by the White gay community, African American gays and lesbians were striving to find a place of their own within Black churches, and in some cases, they were even abandoning the main church to create their place. The Black church was on the brink of disruption and its clergy caught between the decision to continue preaching against homosexuality or accepting and allowing it to come to the spiritual aid of those dying from the disease [79].

Black women promptly jumped into the fray to bring about the serenity that ought to portray the fight against the spread of HIV/AIDS. Cathy J. Cohen, Mary Pattillo-McCoy, Patricia Hill Collins, Kelly Brown Douglas, and Mindy Fullilove, all African American women, and religious scholars, joined hands to promote and guarantee a good understanding of the fight between the Black church, homosexuality, and men. Cathy Cohen who wrote *The Boundaries of Blackness*, the first full-scale exploration of the social, political, and cultural impact of AIDS on the African American community, bravely brings to light how the epidemic fractured, rather than united, the Black community. She traces how the disease separated Blacks along different fault lines and analyzes the resulting struggles and debates [81]. Kelly Brown Douglas, a priest in the Episcopal Church whose books include *The Black Christ, Sexuality and the Black Church*, and *Black Bodies and the Black Church: A Blues Slant*, echoed how vital it was and still is for Black churches and

the public to understand and transcend their resistance to openly addressing complex, painful issues of sexuality and embrace healthier definitions of Black manhood [82]. There are many related stories to tell in support of women.

Today, thanks to Black women's contributions, more African Americans churches are well-positioned to provide HIV education, screening, and support services, using church-appropriate, easy-to-deliver HIV tools that can be applied developmentally. In their examination of church capacity to develop and disseminate a religiously appropriate HIV tool kit with Black churches, Berkley-Patton and his colleagues (2013) reported that 96% of participants wanted to learn more about HIV and how to discuss it with their parishioners to bring about change in their specific communities. Most study representatives had skills in various research and community outreach ministries and had facilitated HIV/AIDS education prevention and adolescent sex education activities [83].

### **Black women's spirituality**

Besides their outward expression of spirituality and religion, Black women are inherently spiritual and committed to their religion through its different denominations [84]. Research holds that Blacks are more likely than Whites to pray privately, practice religious rituals, attend religious services, and believe that the Bible is the word of God [87]. Hence, the Bible, Prayer, and the church community are the resources religious Black women use to meet daily needs [83]. Religion is seen as influencing how individuals appraise situations, participate in activities, and develop goals for themselves. Religious individuals have reported using a wide variety of religious coping methods, such as seeking support from a clergy or church members, seeking spiritual support, using spirituality and religion to support those in need either physically and spiritually [89]. Historically, both religion and spirituality for Black women are centered in slavery with its attempt to destroy African culture, its sexual abuse of Black women, and its separation of families [90]. Enslaved women transcended and altered their experiences through a spirituality that offered hope in personal and community liaisons and embraced a religious experience that affirmed the presence of God in their struggle [91]. God is seen as a deliverer from unjust suffering and the comforter in times of trouble [92]. According to Greer and his colleagues, women viewed spirituality as an intimate relationship with transcendent forces such as God and humans that inspired faith, trust, adherence, and they relied on these forces for all things about life. They noted that religion was an external act that prepared individuals for the internal experience of spirituality [93].

Religion and spirituality are important aspects of African

American life and have been described as the stronghold for many African Americans. Women's spirituality pointedly influences what they think and believe and is associated with positive health outcomes from an improved perception of health status to the ability to withstand the diagnosis of HIV. Spirituality has also been implicated in helping African Americans overcome barriers to HIV diagnosis and adhering to prescribed medications [94]. Numerous studies, conducted with different populations, indicate that religious individuals (spirituality and religion) evidence a range of physical and mental health benefits [95]. Faith and spirituality are sources of optimism and motivation, and our participants used them during their services to the infected and afflicted and in the community. It is our humble belief that African American women used spirituality to heal themselves during their struggles around HIV and to heal those that were either infected or affected in the community.

### **Black women as a gift to humanity**

Another African American woman contribution is located at the intersection of the Africentric worldview, Spirituality, and Feminism (Womanism). The interplay between these three factors continues to inspire African American women in their fight against HIV/AIDS. The Africentric worldview is broadly defined as "the worldview of people of African descent" and consists of the values, beliefs, and behavior of people of African heritage (Belgrave & Allison, 2006, p. 28). These values, beliefs, and behaviors operate as a blueprint for people of African descent to live by, as a means for them to make sense of the world (Butler, 1992) and to adapt to life's contexts.

Belgrave and Allison (2006) [96] identified the following features as the basis of the Africentric worldview: spirituality; collectivism; time orientation; orality; sensitivity to affect and emotional cues; verve and rhythm; and balance and harmony with nature. These facets are said to have sustained enslaved Africans who held onto them as a means of survival in America and to have been passed down through the generations [97] research does not determine whether an Africentric worldview is innately determined [98] as well as whether it is exclusive to persons of African descent [99], it is agreed that it can be found to some extent among most people of African descent [96]. Whether acquired through nature or nurture, the Afrocentric worldview is deeply anchored in African Americans and inspires them to value unity, cooperative effort, mutual responsibility, empathy, and reconciliation [100]. Otherwise, how can we justify their readiness to bring about reconciliation and harmony in the church and to serve as informal caregivers to so many AIDS patients?

The second face of the intersection is the spirituality that

surrounds the African American women. The blend of the Africentric worldview on one side and spirituality/religion on the other makes the Black woman the priest who is constantly in contact with her inner self and perpetually in the presence of God interceding for her people and the sick. As such, when the African American women took up the caregiving of AIDS patients, their dedication was such that, in the absence of medication that could prolong their lives, their patients easily accepted to move in the presence of God. Both spirituality and religion focus on the sacred, beliefs about the sacred, the effects of these beliefs on behavior, and practices used to attain a sense of the sacred.

The last facet of this intersection could be seen in her unique devotion to humanity as a woman and as the guardian of traditions. That devotion could have been labeled in many ways, but the African American women chose and cherished the term "Womanism," a viewpoint concerned with the "right" relationships between Black men and women and an emphasis on family and community. Womanism, a Black feminist standpoint, provides a background through which to explore and savor African American women's spirituality. Karen Baker-Fletcher, a renowned African American Professor of Systematic Theology, celebrates Womanism with Black women's redefinition of their womanhood in contrast to the belittling perpetuated during slavery and segregation. This emphasis on the notion that God identifies with and liberates the oppressed is a central theme of the womanist religious perspective. In Black churches, women relive the power of the Spirit as a healing resource supplying meaning during trials and tribulations (Baker-Fletcher, 1998). Women become therapists to each other, and the church assumes the role of "an asylum of therapeutic assistance," as well as a place of shelter [100].

### **Limitations**

Our study has several limitations. First, we selected Narrative Inquiry, a method that is broadly subjective in many ways. We chose and used a series of journal articles as the units of analysis to research and understand how African American women contributed and are still contributing to the fight against the spread of HIV/AIDS in our communities. Secondly, many topics could have been used in our findings, but we subjectively insisted on the few ones we thought could tell our story. While we agree that our study was not after 'generalizability,' we can assert its 'transferability' to similar situations in the world.

### **Conclusion**

The purpose of this article was to show how the African American women took part and are still participating

in the fight and eradication of the HIV/AIDS epidemic from our areas. Because many African American women were silently infected when the world thought that the epidemic was restricted to White gay people, with the redefinition of HIV/AIDS, Black women understood that the epidemic was also theirs and that they needed to become engaged in all its different facets. As patients, they offered themselves as guinea pigs to advance the acquisition of knowledge concerning the HIV/AIDS epidemic and transcended the medical distrust that runs from the Tuskegee Syphilis Project to the current issues of health disparities in the U.S. to access medical services wherever they could. They joined existing organizations to develop gender tailored and theoretically derived interventions to protect those who were still uninfected. As ministers in the black Churches and as academicians, the African American women calmed the tempest that was ravaging the Church, extended a welcoming hand to those planning to leave the church because of their sexuality, and as informal caregivers, they brought healing to the infected and affected. Finally, we could not have made it so far without the contribution of the Black women, our unsung heroes.

## References

1. Heilman S, Friedman M. *The Rebbe: the life and afterlife of Menachem Mendel Schneerson*. Princeton University Press; 2010 May 10.
2. Sheldon K. *African women: Early history to the 21st century*. Indiana University Press; 2017 Apr 24.
3. Vahdat F. *Islamic Ethos and the Specter of Modernity*. Anthem Press; 2015 Jun 15.
4. Zheng J. *New feminism in china: Young middle-class Chinese women in Shanghai*. Springer; 2016 Mar 25.
5. Centers for Disease Control, Pneumonia P. Los Angeles- Morbidity Mortality Weekly Report. June. 1981;5:30.
6. Gottlieb MS, Schroff R, Schanker HM, Weisman JD, Fan PT, Wolf RA, Saxon A. Pneumocystis carinii pneumonia and mucosal candidiasis in previously healthy homosexual men: evidence of a new acquired cellular immunodeficiency. *New England Journal of Medicine*. 1981 Dec 10;305(24):1425-31.
7. Weiss RA. How does HIV cause AIDS?. *Science*. 1993 May 28;260(5112):1273-9.
8. Lifson AR. Do alternate modes for transmission of human immunodeficiency virus exist?: A review. *Jama*. 1988 Mar 4;259(9):1353-6.
9. Jackson MM, Lynch P. The epidemiology of HIV infection, AIDS, and health care worker risk issues. *Family & community health*. 1989 Aug 1;12(2):34-42.
10. UNAIDS W. 2007 AIDS epidemic update. PDF. Retrieved. 2008 May;20080312.
11. Poiesz BJ, Ruscetti FW, Gazdar AF, Bunn PA, Minna JD, Gallo RC. Detection and isolation of type C retrovirus particles from fresh and cultured lymphocytes of a patient with cutaneous T-cell lymphoma. *Proceedings of the National Academy of Sciences*. 1980 Dec 1;77(12):7415-9.
12. Centers for Disease Control (CDC). A cluster of Kaposi's sarcoma and Pneumocystis carinii pneumonia among homosexual male residents of Los Angeles and Orange Counties, California. *MMWR. Morbidity and mortality weekly report*. 1982 Jun 18;31(23):305.
13. CDC. HIV Surveillance Report. 2016; 27, 1-114.
14. CDC. Diagnoses of HIV Infection and AIDS in the United States and Dependent Areas. HIV Surveillance Report, 2008. Retrieved from <http://www.cdc.gov/hiv/topics/surveillance/resources/reports>.
15. Ehrnst A, Sönnnerborg A, Bergdahl S, Strannegård Ö. Efficient isolation of HIV from plasma during different stages of HIV infection. *Journal of Medical Virology*. 1988 Sep;26(1):23-32.
16. Lane JR. Isolation and expansion of HIV from cells and body fluids by coculture. In *HIV Protocols 1999* (pp. 3-10). Humana Press.
17. CDC (2018). High Impact Prevention. Popular Opinion Leader. Retrieved From <https://effectiveinterventions.cdc.gov/en/HighImpactPrevention/Interventions/POL/ResourcesTools.aspx>
18. Clandinin DJ, editor. *Handbook of narrative inquiry: Mapping a methodology*. Sage Publications; 2006 Dec 28.
19. Murray M. Levels of narrative analysis in health psychology. *Journal of health psychology*. 2000 May;5(3):337-47.
20. Clandinin DJ, editor. *Handbook of narrative inquiry: Mapping a methodology*. Sage Publications; 2006 Dec 28.
21. Prachakul W, Grant JS, Keltner NL. Relationships among functional social support, HIV-related stigma, social problem solving, and depressive symptoms in people living with HIV: a pilot study. *Journal of the Association of Nurses in AIDS Care*. 2007 Nov 1;18(6):67-76.
22. Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social science & medicine*. 2003 Jul 1;57(1):13-24.
23. Herek GM, Capitanio JP, Widaman KF. HIV-related stigma and knowledge in the United States: prevalence and trends, 1991-1999. *American journal of public health*. 2002 Mar;92(3):371-7.
24. Emlet CA. Experiences of stigma in older adults living with HIV/AIDS: A mixed-methods analysis. *AIDS patient care and STDs*. 2007 Oct 1;21(10):740-52. 25.
25. Brandon DT, Isaac LA, LaVeist TA. The legacy of Tuskegee and trust in medical care: is Tuskegee responsible for race differences in mistrust of medical

- care?. *Journal of the National Medical Association.* 2005 Jul;97(7):951.
26. Halbert CH, Armstrong K, Gandy OH, Shaker L. Racial differences in trust in health care providers. *Archives of Internal Medicine.* 2006 Apr 24;166(8):896-901.
27. Kennedy BR, Mathis CC, Woods AK. African Americans and their distrust of the health care system: healthcare for diverse populations. *Journal of cultural diversity.* 2007 Jun 1;14(2).
28. Skloot, R. *The Immortal Life of Henrietta Lacks.* New York: Broadway Paperbacks. 2011.
29. Smith V. Wonder woman: The life, death, and life after death of Henrietta Lacks, unwitting heroine of modern medical science. *Baltimore City Paper.* 2002 Apr;17.
30. Thomas J. Ripped from Which Headline? "Immortal." *Slate.* 2010. Retrieved from [http://www.slate.com/content/slate/blogs/browbeat/2010/05/19/ripped\\_from\\_which\\_headline\\_immortal.html](http://www.slate.com/content/slate/blogs/browbeat/2010/05/19/ripped_from_which_headline_immortal.html)
31. Sullivan PS, McNaghten AD, Begley E, Hutchinson A, Cargill VA. Enrollment of racial/ethnic minorities and women with HIV in clinical research studies of HIV medicines. *Journal of the National Medical Association.* 2007 Mar;99(3):242.
32. Wyatt GE, Gómez CA, Hamilton AB, Valencia-García D, Gant LM, Graham CE. The intersection of gender and ethnicity in HIV risk, interventions, and prevention: New frontiers for psychology. *American Psychologist.* 2013 May;68(4):247.
33. Amaro H, Raj A. On the margin: Power and women's HIV risk reduction strategies. *Sex roles.* 2000 Apr 1;42(7-8):723-49.
34. Sanders-Phillips K. Factors influencing HIV/AIDS in women of color. *Public Health Reports.* 2002;117(Suppl 1):S151.
35. Panda B. Top down or bottom up? A study of grassroots NGOs' approach. *Journal of Health Management.* 2007 May;9(2):257-73.
36. Reimann KD. A view from the top: International politics, norms and the worldwide growth of NGOs. *International Studies Quarterly.* 2006 Mar 1;50(1):45-67.
37. Collins C, Harshbarger C, Sawyer R, Hamdallah M. The diffusion of effective behavioral interventions project: development, implementation, and lessons learned. *AIDS Education & Prevention.* 2006 Aug;18(supp):5-20.
38. Jemmott LS, Jemmott III JB, O'Leary A. Effects on sexual risk behavior and STD rate of brief HIV/STD prevention interventions for African American women in primary care settings. *American journal of public health.* 2007 Jun;97(6):1034-40.
39. DiClemente RJ, Wingood GM, Harrington KF, Lang DL, Davies SL, Hook III EW, Oh MK, Crosby RA, Hertzberg VS, Gordon AB, Hardin JW. Efficacy of an HIV prevention intervention for African American adolescent girls: a randomized controlled trial. *Jama.* 2004 Jul 14;292(2):171-9.
40. Ehrhardt AA, Exner TM, Hoffman S, Silberman I, Leu CS, Miller S, Levin B. A gender-specific HIV/STD risk reduction intervention for women in a health care setting: short-and long-term results of a randomized clinical trial. *AIDS care.* 2002 Apr 1;14(2):147-61.
41. Tiedje LB. A Community-Level HIV Prevention Intervention for Inner-City Women: Results of the Women and Infants Demonstration Projects. *MCN: The American Journal of Maternal/Child Nursing.* 2000 Jul 1;25(4):223.
42. Jewkes R, Nduna M, Levin J, Jama N, Dunkle K, Puren A, Duvvury N. Impact of stepping stones on incidence of HIV and HSV-2 and sexual behaviour in rural South Africa: cluster randomised controlled trial. *Bmj.* 2008 Aug 7;337:a506.
43. Gangopadhyay DN, Chanda M, Sarkar K, Niyogi SK, Chakraborty S, Saha MK, Manna B, Jana S, Ray P, Bhattacharya SK, Detels R. Evaluation of sexually transmitted diseases/human immunodeficiency virus intervention programs for sex workers in Calcutta, India. *Sexually transmitted diseases.* 2005 Nov;32(11):680.
44. Feldman MB, Silapaswan A, Schaefer N, Schermele D. Is there life after DEBI? Examining health behavior maintenance in the diffusion of effective behavioral interventions initiative. *American Journal of Community Psychology.* 2014 Jun 1;53(3-4):286-313.
45. Kelly JA. Popular opinion leaders and HIV prevention peer education: resolving discrepant findings, and implications for the development of effective community programmes. *AIDS care.* 2004 Feb 1;16(2):139-50.
46. Kelly JA, St Lawrence JS, Stevenson LY, Hauth AC, Kalichman SC, Diaz YE, Brasfield TL, Koob JJ, Morgan MG. Community AIDS/HIV risk reduction: the effects of endorsements by popular people in three cities. *American Journal of Public Health.* 1992 Nov;82(11):1483-9.
47. NIMH Collaborative HIV/STD Prevention Trial Group. The community popular opinion leader HIV prevention programme: conceptual basis and intervention procedures.
48. Jones KT, Gray P, Whiteside YO, Wang T, Bost D, Dunbar E, Foust E, Johnson WD. Evaluation of an HIV prevention intervention adapted for Black men who have sex with men. *American Journal of Public Health.* 2008 Jun;98(6):1043-50.
49. Somerville GG, Diaz S, Davis S, Coleman KD, Taveras S. Adapting the popular opinion leader intervention for Latino young migrant men who have sex with men. *AIDS Education & Prevention.* 2006 Aug;18(supp):137-48.
50. Sikkema KJ, Kelly JA, Winett RA, Solomon LJ, Cargill VA, Roffman RA, McAuliffe TL, Heckman TG,

- Anderson EA, Wagstaff DA, Norman AD. Outcomes of a randomized community-level HIV prevention intervention for women living in 18 low-income housing developments. *American journal of public health.* 2000 Jan;90(1):57.
51. Rogers EM. *Diffusion of Innovations* 5th ed New York NY Free Press.
52. Valente TW, Pumpuang P. Identifying opinion leaders to promote behavior change. *Health Education & Behavior.* 2007 Dec;34(6):881-96.
53. Anastario MP, Dabreo J, Morris J, Hallum-Montes R, Arredondo G, Creel A, Cowan L, Chun H. Condom use following a pilot test of the Popular Opinion Leader intervention in the Barbados Defence Force. *Journal of community health.* 2013 Feb 1;38(1):46-53.
54. Ismail MM, Gerrish K, Naisby A, Salway S, Chowbey P. Engaging minorities in researching sensitive health topics by using a participatory approach. *Nurse researcher.* 2014 Nov 26;22(2).
55. Yancey AK, Siegel JM, McDaniel KL. Role models, ethnic identity, and health-risk behaviors in urban adolescents. *Archives of Pediatrics & Adolescent Medicine.* 2002 Jan 1;156(1):55-61.
56. Morris M. *Women's Leadership Matters: The impact of Women's Leadership in the Canadian Federal Public Service.* 2016 Jun 22.
57. Henning-Smith CE, Shippee TP. Expectations about future use of long-term services and supports vary by current living arrangement. *Health Affairs.* 2015 Jan 1;34(1):39-47.
58. Johnson RW. Meeting the long-term care needs of the baby boomers: How changing families will affect paid helpers and institutions.
59. United States Census Bureau. Annual estimates of the resident population by sex, race alone, or in combination, and Hispanic origin for the United States, states, and counties: April 1, 2010 to July 1, 2015.
60. Shaver PR, Mikulincer M, Gross JT, Stern JA, Cassidy JA. A lifespan perspective on attachment and care for others: Empathy, altruism, and prosocial behavior. Cassidy, J.; Shaver, PR (ed.), *Handbook of attachment: Theory, research, and clinical applications* (3rd ed.). 2016:878-916.
61. Baeten JM, Overbaugh J. Measuring the infectiousness of persons with HIV-1: opportunities for preventing sexual HIV-1 transmission. *Current HIV research.* 2003 Jan 1;1(1):69-89.
62. El-Bassel N, Caldeira NA, Ruglass LM, Gilbert L. Addressing the unique needs of African American women in HIV prevention. *American journal of public health.* 2009 Jun;99(6):996-1001.
63. Webel AR, Higgins PA. The relationship between social roles and self-management behavior in women living with HIV/AIDS. *Women's Health Issues.* 2012 Jan 1;22(1):e27-33.
64. Gilligan C. *In a different voice: Psychological theory and women's development.* Cambridge, MA: Harvard University Press.1983.
65. Woods-Giscombé CL. Superwoman schema: African American women's views on stress, strength, and health. *Qualitative health research.* 2010 May;20(5):668-83.
66. Vyavaharkar M, Moneyham L, Murdaugh C, Tavakoli A. Factors associated with quality of life among rural women with HIV disease. *AIDS and Behavior.* 2012 Feb 1;16(2):295-303.
67. Mendelsohn J, Moses HL, Nass SJ, editors. *A national cancer clinical trials system for the 21st century: reinvigorating the NCI Cooperative Group Program.* National Academies Press; 2010 Aug 8.
68. Taylor RE. Pharmacological and cultural considerations in alcohol treatment clinical trials: issues in clinical research related to race and ethnicity. *Alcoholism: Clinical and Experimental Research.* 2003 Aug.
69. Garber M, Hanusa BH, Switzer GE, Mellors J, Arnold RM. HIV-infected African Americans are willing to participate in HIV treatment trials. *Journal of general internal medicine.* 2007 Jan 1;22(1):17-42.
70. Coakley M, Fadiran EO, Parrish LJ, Griffith RA, Weiss E, Carter C. Dialogues on diversifying clinical trials: successful strategies for engaging women and minorities in clinical trials. *Journal of women's health.* 2012 Jul 1;21(7):713-6.
71. Katz RV. Race, medical research distrust, perceived harm, and willingness to participate in cardiovascular prevention trials. *Southern Medical Journal.* 2008 Jul;101(7):671.
72. Chalela P, Suarez L, Muñoz E, Gallion KJ, Pollock BH, Weitman SD, Karnad A, Ramirez AG. Promoting factors and barriers to participation in early phase clinical trials: Patients perspectives. *Journal of community medicine & health education.* 2014 Apr 24;4(281):1000281.
73. Sule E, Sutton RM, Jones D, Moore R, Igbo I, Jones LA. The past does matter: a nursing perspective on post traumatic slave syndrome (PTSS). *Journal of racial and ethnic health disparities.* 2017 Oct 1;4(5):779-83.
74. Institute of Medicine. *Roundtable on health literacy: Health literacy past, present and future: A workshop.* Washington, DC. 2014.
75. Ward EG. Homophobia, hypermasculinity and the US black church. *Culture, health & sexuality.* 2005 Sep 1;7(5):493-504.
76. Miller Jr RL. Look what God can do: African American gay men, AIDS and spirituality. *Journal of HIV/AIDS & Social Services.* 2006 Jan 5;4(3):25-46.
77. Quinn K, Dickson-Gomez J, Kelly JA. The role of the Black Church in the lives of young Black men who have sex with men. *Culture, health & sexuality.* 2016

- May 3;18(5):524-37.
78. Rhea R. Exploring spiritual formation in the Christian academy: The dialects of church, culture, and the larger integrative task. *Journal of Psychology and Theology.* 2011 Mar;39(1):3-15.
79. Rhea R. Exploring spiritual formation in the Christian academy: The dialects of church, culture, and the larger integrative task. *Journal of Psychology and Theology.* 2011 Mar;39(1):3-15.
80. Miller Jr RL. Legacy denied: African American gay men, AIDS, and the black church. *Social work.* 2007 Jan 1;52(1):51-61.
81. University of Chicago. Department of Political Science. Kathy Cohen. 2018. Retrieved from <https://political-science.uchicago.edu/directory/cathy-cohen>
82. Feminism & Religion. Author Archives. Kelly Brown Douglas. 2018. Retrieved from <https://feminismandreligion.com/author/kelbd>
83. Berkley-Patton J, Thompson CB, Martinez DA, Hawes SM, Moore E, Williams E, Wainright C. Examining church capacity to develop and disseminate a religiously appropriate HIV tool kit with African American churches. *Journal of Urban Health.* 2013 Jun 1;90(3):482-99.
84. Giger JN, Appel SJ, Davidhizar R, Davis C. Church and spirituality in the lives of the African American community. *Journal of Transcultural Nursing.* 2008 Oct;19(4):375-83.
85. Mattis JS. African American women's definitions of spirituality and religiosity. *Journal of black psychology.* 2000 Feb;26(1):101-22.
86. Templeton JL, Eccles JS. The relation between spiritual development and identity processes. *The handbook of spiritual development in childhood and adolescence.* 2006:252-65.
87. Putnam RD, Campbell DE. *American grace: How religion divides and unites us.* Simon and Schuster; 2012.
88. Bryant-Davis T, Wong EC. Faith to move mountains: Religious coping, spirituality, and interpersonal trauma recovery. *American Psychologist.* 2013 Nov;68(8):675.
89. Pargament KI, McCarthy S, Shah P, Ano G, Tarakeshwar N, Wachholtz A, Serrine N, Vasconcelles E, Murray-Swank N, Locher A, Duggan J. Religion and HIV: A review of the literature and clinical implications. *Southern Medical Journal.* 2004 Dec 1;97(12):1201-9.
90. Heath CD. A womanist approach to understanding and assessing the relationship between spirituality and mental health. *Mental Health, Religion & Culture.* 2006 Apr 1;9(02):155-70.
91. Collins PH. What's going on? Black feminist thought and the politics of postmodernism. In *Working the ruins* 2002 May 3 (pp. 47-79). Routledge.
92. Musgrave CF, Allen CE, Allen GJ. Spirituality and health for women of color. *American Journal of Public Health.* 2002 Apr;92(4):557-60.
93. Koenig HG. Religion, spirituality and aging.
94. Lewis LM, Ogedegbe G. Understanding the nature and role of spirituality in relation to medication adherence: A proposed conceptual model. *Holistic nursing practice.* 2008 Sep;22(5):261.
95. Townsend M, Kladder V, Ayele H, Mulligan T. Systematic review of clinical trials examining the effects of religion on health. *Southern medical journal.* 2002 Dec 1;95(12):1429-35.
96. Belgrave FZ, Allison KW. *African American psychology: From Africa to America.* Sage Publications; 2018 Apr 19.
97. Asante MK. Afrocentricity: The theory of social change. *African Amer Images;* 2003.
98. Kambon KK. The worldviews paradigm as the conceptual framework for African/Black psychology. *Black psychology.* 2004:73-92.
99. Grills C. African psychology. In R. Jones (Ed.). *African psychology.* Hampton, VA: Cobb and Henry. 2004.
100. Baldwin JA. Notes on an Africentric theory of Black personality. *The Western Journal of Black Studies.* 1981 Oct 1;5(3):172.
101. Funderburk JR, Fukuyama MA. Feminism, multiculturalism, and spirituality: Convergent and divergent forces in psychotherapy. *Women & Therapy.* 2002 Apr 30;24(3-4):1-8.