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AFRICAN AMERICAN WOMEN, HIV/AIDS, AND HUMAN RIGHTS IN THE U.S.

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Received March 2013; Accepted July 2013

Abstract

In the US alone, 84 percent of women’s HIV infections are due to heterosexual contact (CDC 2013). Fifty percent of all people globally who are living with HIV/AIDS are women (UNAIDS 2009), yet, HIV-positive women’s perspectives on prevention are mostly missing from the trajectory of scholarly literature on HIV/AIDS. I thought it imperative to go to the source (women living with HIV/AIDS) to get an insiders perspective on HIV prevention. Thirty HIV-positive Black women were recruited to participate in the study, which lasted seven months. These women live in a Florida inner-city and range in age from 21 to 60. Qualitative methods were employed in a narrative analysis (Reissman 1993) of ethnographic data. Based on these women’s narratives on 1) access to affordable housing, 2) access to comprehensive job training and welfare reform, and 3) the lack of comprehensive HIV/AIDS prevention interventions and education designed specifically for heterosexual men; I consider if a rights-based agenda is pivotal to the reduction of rates of HIV infection for African American women, one of the most highly infected populations in the US.

Keywords
HIV/AIDS, African American women, Southeast U. S., Prevention, Human Rights, Rights-based approach

Public health in the United States (US) primarily has used the biomedical model to determine factors for disease prevention, care, and treatment (Ratcliff 2002; Worcester and Whatley 2004). Biomedical models emphasize the need for “finding a pathology, locating disease in the individual, seeking biological causes, and focusing on a cure rather than prevention” (Ratcliff 2002: 1). The public health system has come under much scrutiny especially over the last thirty years as the US has worked to eradicate the HIV/AIDS epidemic. Once thought to be primarily a result of homosexual activity between men, we now know that HIV/AIDS is also transmitted through heterosexual relations. In the US alone, 84 percent of women’s infections are due to heterosexual contact (CDC 2013). Fifty percent of all people globally who are living with HIV/AIDS are women (UNAIDS 2009), yet, HIV-positive women’s perspectives on prevention are mostly missing from the trajectory of scholarly literature on HIV/AIDS. Ironically, in the narrative about sexually transmitted infections, African American women’s invisibility as knowledge bearers in HIV/AIDS prevention is overlooked because of
their preconceived status as either victims or deviants (Hammonds 1997). Despite the significant overall decline in women’s rates of HIV infection in 2008-2010, when compared to the rates of other women; African American women’s HIV infection rates are still significantly higher. Surging from the old rate of 15 times more HIV to a new high for Black women of 20 times more occurrences than other women (CDC 2012).

African American women’s rates of infection, while startling, may be connected to women’s contentious relationship with the public health framework (biomedical model). However, this model does not encompass the wealth of women’s health related experiences (Gollub 1999; Ratcliff 2002; Worcester and Whatley 2004). While the conventional model has eradicated diseases such as polio, it has also helped to facilitate ailments like HIV/AIDS by initially overlooking symptoms of HIV infection in women that were different from those presented in men (Campbell 1999; Goldstein 1997; McGovern 1997; Murrain 1997). Moreover, the biomedical model advances the notion that health maladies result from individual lifestyle choices (Singer 2001; Whelan 1998), however the more we learn about HIV/AIDS the more we recognize that it is an illness predicated upon social, political, economic, and gendered factors that are deeply intertwined with behavior (Fullilove 2006; Gilbert and Wright 2003). In regards to HIV/AIDS, the social determinants of health describe the interrelationship between cultural, economic, and political elements that facilitate vulnerability for HIV infection, and the way in which the social drivers of health limit choices for HIV/AIDS prevention, treatment and care.

Given that scientists have spent decades advancing research to eradicate HIV/AIDS, I thought it imperative to go to the source (women living with HIV/AIDS) to get an insider’s perspective on HIV prevention. I found it prudent to discuss inadequate HIV prevention strategies and ways to improve the system with those most impacted by the epidemic, the people living with HIV/AIDS. With a focus on HIV-positive Black women, I examine women’s prevention perceptions on effective preventative measure for HIV/AIDS. This article uses a human rights framework grounded in HIV-positive Black women’s health narratives in order to identify vulnerabilities for African American women. I consider if a rights-based agenda is pivotal to the reduction of rates of HIV infection among one of the most highly infected populations.

In the following section I review the changing models for health prevention with a particular focus on how traditional public health models and human rights based alternatives have conceptualized prevention, particularly HIV/AIDS prevention. Next, I examine methods and data, and the research and selection process. Following that, I present themes developed in the analysis of interviews with Black women living with HIV/AIDS whose perspectives can begin to build the foundation for
HIV-positive Black women’s standpoint on HIV/AIDS prevention. Examining these narratives through a rights-based lens builds toward the concluding section, which focuses on demonstrating the practical implications of African American women’s case for alternative HIV/AIDS prevention.

REVIEW OF CHANGING MODELS

Traditional Approach

Early research on HIV/AIDS followed the public health template of modifying one’s individual habits, patterns, and responses, known as the Health Belief Model (HBM) (Rosenstock et al. 1994). The most widely used framework for behavior intervention over the last 30 years, The Health Belief Model, was later updated to incorporate self-efficacy or the ability to successfully alter a pattern or bad habit (Bandura 1986). Initially configured to predict patient behavioral responses to various treatments, Bandura’s modification to the HBM integrated the concept of personal responsibility or what is commonly called lifestyle choices. Scientists using the premise of lifestyle choices designed HIV prevention interventions geared to change behavior (Rickert 1989; Cantania, Coates, and Stall 1992; DiClemente and Peterson 1994). Not all scholars, however, believed that individual behavior modification was the sole solution to eradicating new HIV infections. DeBeer (1986:70) argues that,

“a sick individual is regarded as a set of physical symptoms, rather than as a person who belongs to a social class in a particular society. This process turns our attention away from the political roots of disease, and conceals these roots by providing us with an alternative explanation. By and large this mainstream medical perspective assumes people are responsible for their own health.”

In sum, the social drivers of health are overlooked for a greater emphasis on personal responsibility and choice (Singer 2001:81).

Trends in infectious disease research emphasized behavior changes in the mid-1980s which led to the challenge in the mid-1990s by some scholars who contested notions of HIV/AIDS behavior interventions as the most viable and efficacious method to curtail the spread of HIV/AIDS; up to this point medical research prevention interventions focused solely on behavior modification. Social scientists who specialize in HIV/AIDS research using a gender, race, and class lens argue that individual actions are not created in a vacuum and must be contextualized (Akeroyd 1993; Fullilove et al. 1990; Glick Schiller et al.
Behavior, they suggested, is influenced by social, cultural, political, and economic factors (Fullilove and Fullilove 1991; Gilbert and Wright 2003; Sobo 1993; Wingood, Hunter-Gamble, and DiClemente 1993). The cusp of the twentieth/twenty-first century heralded an alternative trend, and infectious disease scholars designed interventions that take into account the myriad sociocultural, political, and economic aspects of behavior (Bowleg 2005; Gilbert and Wright 2003; Hammonds 1997; Sobo 1993). It was well into the 21st century before the Centers for Disease Control and Prevention (CDC) constructed a website exclusively dedicated to HIV/AIDS and the social determinants of health (June 2009); public health officials didn’t find the social drivers of health to be relevant in the fight against HIV/AIDS until approximately thirty years into the epidemic in the US.

Today, some segments of the scientific community support the “expanded response” model (Whelan 1998:22) that conjointly addresses behavior, the social determinants of health, and the repercussions of living with HIV/AIDS. Combating HIV/AIDS for African American women must include confronting the individual and institutional prevalence of social and economic injustices, specifically sexism, racism, and classism. Targeting HIV prevention strategies in culturally specific ways for Black women must be central to strategies for eradicating new HIV infections (Gilbert and Wright 2003; Kalichman and Cole 1995; St. Lawrence et al. 2001; Peter et al. 2008). Although medical research on HIV/AIDS became a consideration, it was not so well considered around dimensions of race and gender (Campbell 1999; Goldstein 1997; McGovern 1997; Murrain 1997). Black women, for example, have had limited participation in clinical trials in spite of their disproportionate vulnerability for HIV infection (Bayne-Smith, 1996; Campbell 1999; Corea 1992; Goldstein 1997; McGovern 1997; Murrain 1997). All in all, the sole focus on behavior often overlooked the needs and concerns of African American women in the conventional public health approach (Bayne-Smith 1996; Corea 1992; Duh 1991; Hammonds 1997; Scott McBarnette 1996).

Human Rights Approach

Changing and/or modifying life style choices are the cornerstone of the traditional public health framework. A human rights approach, on the other hand, is concerned with protecting the rights of citizens. The US standpoint leans more toward defending the human rights of others (internationally). There are certain segments of the population that believe that US citizens do not need the protection of human rights treaties or declarations. Concurrently, human rights have philosophically resonated with many disenfranchised communities in the US (Douglas 1855; King 1963). Resistance to applying a human rights framework to US situations, on the other hand, has been strong from segregationists in
the past, and more recently from those who uphold the worldview that 
America’s global mission is to bring liberty and democracy to other parts 
of the world (Shafer 1991; Bell 1989). Today, however, there is a 
growing domestic trend towards human rights, especially by those vested 
in civil, social, political, economic, and cultural rights (Daniels 2008). 
Human rights detractors still suggest that issues such as health care and 
housing are better left to the service of the free market (Friedman and 
Friedman 1979). With that said, the free market has not eliminated 
hunger, homelessness, unemployment, inadequate education, subpar 
healthcare, indecent wages and economic insecurity in the US. 
Therefore, an alternative method may be necessary to advance basic 
human rights and to govern in order to promote health and wellness for 
all.

*Universal Declaration of Human Rights* (UDHC). The 1948 UDHC 
is considered the cornerstone of international human rights law (United 
Nations 1998). There are four elementary components of most human 
rights documents: non-discrimination, equality, participation, and 
accountability (Gruskin et al. 2007). Articles twenty-three, twenty-five 
and twenty-six (in part) of the UDHC protect rights relevant to the 
placeholders of African American women living with HIV/AIDS:

(1) Everyone without any discrimination, has the right to 
equal pay for equal work (Article 23).

(2) Everyone who works has the right to just and favourable 
remuneration ensuing for himself and his family an 
existence worthy of human dignity (Article 23). …

(3) To a standard of living adequate for the health and well-
being of himself and 
his family, including food, clothing, housing, and 
medical care and necessary social services, and the right 
to security in the event of unemployment, sickness, 
disability, widowhood, old age or other lack of 
livelihood in circumstances beyond his control (Article 
25). …

(4) Everyone has the right to education (Article 26). (United 
Nations 1948).

The UDHR secures basic inalienable rights to a certain standard of living 
that includes health and wellness, satisfactory housing, education, equal 
pay for equal work, and access to opportunities for job mobility and 
economic growth (United Nations 1948). Although, the declaration was 
not set up originally to be a legally enforceable contract, “it has gained 
legal acceptance and legal enforceability through a series of international 
human rights conventions and charters” (Aniekwu 2002:33), however, 
the enforcement mechanisms are often considered to be weak (Patterson
These laws were set in place to ensure global compliance to preserving the observance of human dignity. The Declaration holds the state legally accountable to uphold, ensure, and satisfy the “enjoyment” of one’s basic rights. In this way, human rights can serve as an apparatus to frame the evaluation and formulation of national services, legislation, and policies, such as the integration of public health objectives and human rights standards (Gruskin, Ferguson, and O’Malley 2007; Patterson and London 2002).

Basic rights—the focus of the human rights agenda, rests on the obligation of the state (Gruskin, Ferguson, and O’Malley 2007; Stilz 2011). The marriage of the social determinants of health to a governing body of health care laws and policies is better known as the rights-based approach. Criticism of the human rights framework states that although the approach is expansive in bringing various components of wellbeing together, blending these factors can be challenging and may lack consistent and clear operational definitions (Gruskin, Bogecho, and Ferguson 2010). Rights-based proponents suggest that human rights can provide a platform to create legislation and public policy to redress the social determinants of health (Gruskin, Ferguson, and O’Malley 2007). A human rights agenda may be loosely defined so that it can be globally applicable and sensitive to issues of nation, culture, ethnicity, gender, race, and class in order to provide a legal foundation that decrees the design of measurable programs and services with the aim of HIV/AIDS prevention, treatment, and care, while at the same time creating accountability for the state, and even more importantly, public health institutions.

Human rights decrees and declarations can provide a foundation for the design of measureable programs and services. The 1994 International Conference on Population and Development, for instance, directs governments to provide “appropriate and quality sexual and reproductive health information and services to individuals (and couples) including adolescents, without discrimination” (Gruskin, Ferguson, and O’Malley 2007). Global decrees for universal nation state compliance that mandate the provision of non-discriminatory sexual health services, education, treatment, and care is the rationale from which public health institutions can craft rights-based initiatives and interventions that cater to the needs of its most impacted populations. Rare for traditional public health programming, the human rights framework may include directives for program enforcement because holding individuals or institutions accountable may stimulate results more readily than a basic goals and objective framework.

Comprehensive in its approach to health and well being is one of the positive aspects of the human rights framework, however, on the negative side are budgetary concerns. Fiscal matters are usually central to debates against changing the status quo, and governments may have to
re prioritize budgets to advance a rights based approach. By the same
token, budget reductions are made regularly for reasons not as exigent as
a global public health pandemic (Torres-Ruiz 2011).

**HIV/AIDS Declarations.** Justice and accountability were concurring
themes in the 2001 UN *Declaration of Commitment on HIV/AIDS*. A
new Declaration was deemed necessary, by member states, to build upon
the advances made by the UDHR because global HIV/AIDS prevention
was deemed inadequate. A new Declaration was penned in 2001 and
states in part that: “the full realization of human rights and fundamental
freedoms for all is an essential element in a global response to the HIV
pandemic, including in the areas of prevention, care, support, and
treatment” (United Nations 2001). The 2001 document is instrumental in
setting timeframes for the introduction of legislation and other actions to
protect specific fundamental rights.

Then in 2006 the *Political Declaration on HIV/AIDS* was written
for the express purpose of ensuring international access to care,
treatment, support, and prevention of HIV within a four-year period
(United Nations 2006). *The Political Declaration* also intensified
previous efforts to eliminate discrimination against vulnerable groups
including people living with HIV/AIDS. All of these documents were
written for the purpose of sustaining human rights within the specific
context of a global pandemic—HIV/AIDS.

More recently, the member states met again in 2011 and drafted the
*Political Declaration on HIV/AIDS: Intensifying our Efforts to Eliminate
HIV/AIDS*. The latest Declaration incorporates efforts to combat HIV-
related stigma, behavior, and vulnerability associated with HIV infection
(United Nations 2011). These Declarations on HIV/AIDS, although a
strong framework for approaching the design and implementation of
measures to thwart the pandemic, are “not self implementing” (United
Nations 2011). This signifies that action by health institutions, civil
society, and the state are also necessary to ensure that human rights are
safeguarded.

**A RIGHTS-BASED ANALYSIS**

Human rights start with the guarding of rights. Protection, however,
is only one of the benefits of this perspective. The human rights agenda,
unlike conventional models, has the potential to incorporate
accountability. But without an inherent accountability mechanism the
human rights framework is just a model for developing programs that is
weak in its power to change real world circumstances. South Africa is a
case study that illustrates the veracity of applying a rights-centered focus
to HIV/AIDS policy. South Africa’s success is based in part on
international human rights law and obligations. Therefore, if the State is
negligent in upholding international laws they may be held liable. Drug
patents prohibited South Africa from importing affordable generic
antiretroviral medication for citizens living with HIV/AIDS. The South African government could not afford to pay the rates requested by major pharmaceutical companies to assist in treatment and care of its residents. AIDS activists petitioned pharmaceutical companies to lower the cost of HIV/AIDS medications. In a lawsuit that employed rights-based language the government was pressed “to give human rights precedence over trade rights” (Patterson and London 2002:966). A pharmaceutical association (comprised of various major drug companies) alleged that national medicine reforms to lower the cost of drugs violated their rights. They argued that these reforms would amount to corporate pirating of their patented antiretroviral drugs. Activists living with HIV/AIDS and their allies (Treatment Action Campaign) who ardently protested against multinational drug companies were later granted leave to join in the lawsuit (George 2011; Patterson and London 2002). Treatment Action Campaign (TAC) also used right-based language in their suit asking for court consideration around “the rights to life, dignity and access to health care services” (George 2011:184).

“Acting up” in South Africa came in the form of educating the public about human rights laws. The turning point in the campaign to lower drug costs came when public discussion about rights-based laws and doctrines was injected into a sea of social unrest over the prohibitive costs of antiretroviral drugs. A civil society rebellion adopted a human rights platform shifting from corporate pressure (pharmaceutical) to pressuring the State in a lawsuit to uphold human rights declarations. International AIDS activists, alerted by the public discussions, joined in the struggle by hounding the campaign trail of then Vice President Gore’s bid for President. Because the Clinton Administration had passed legislation to impede South Africa from importing generic antiretroviral drugs and Gore supported his decision protestors chanted and held signs that read “Gore’s Greed Kills” at each campaign stop. International protestors were successful in getting Gore to stop his support of upcoming legislation that continue to prohibit importing generic drugs to developing countries. Realizing that there were rights-based mandates to support civil discontent, activism on the part of civil society and international communities led to “a major shift in national policy on HIV” (Patterson and London 2002:967), a change that was won in the court of public opinion first. The “events in South Africa changed the plot from a tale of pirates engaged in the theft of intellectual property to a story about the people and patients” (George 2011:187). Rights can be used by the marginalized or the privileged as seen in this case; ultimately a rights-based perspective allows for human rights instruments, public health objectives, community based organizations, positive people and civil society to protect human rights. If national and local efforts are to be successful at transforming destructive legislation, policies, programs, and their consequences, then human rights-based strategies must be
utilized in more than this one case (George 2011; Gruskin, Ferguson, and O’Malley 2007).

The analysis presented here seeks to unpack some of the complex issues of HIV prevention as it relates to African American women and their lived experience. Specifically, I consider HIV-positive Black women’s narratives and the degree of congruence between their prevention perspectives and that of a right-based perspective to eradicate HIV. This article presents poignant narratives and perspectives of African American women living with HIV/AIDS on: (1) access to affordable housing, (2) access to comprehensive job training and welfare reform, and (3) the lack of comprehensive HIV/AIDS prevention interventions and education designed specifically for heterosexual men. Based on these women’s narratives I suggest that a human rights framework might better encompass effective plans, policies, and accountability to curb the disproportionate incidence of HIV/AIDS for Black women in the US.

METHODS

A study was conducted in which I interviewed thirty African American HIV-positive women about their perceptions on effective preventative measures for HIV/AIDS. Focused on women living with HIV/AIDS, my overriding research inquiry was to examine Black women’s perspectives and stated concerns on effective HIV prevention as informed by their lived experience and situated knowledge. HIV-positive Black women’s situated knowledge...wisdom derived from being involved in a particular set of circumstances (Harding 1991), were gathered, evaluated, and used collectively to work towards a Black women’s standpoint on prevention of HIV/AIDS.

Presented in this document are poignant narratives and perspectives of African American women living with HIV/AIDS. Study participants’ “personal stories are self-conscious testimonies—what they have wanted to tell—about themselves as victims and as survivors who exist on the margins of American culture” (Scott 1982:7). Narrative analysis is a qualitative method that permits the social scientific study of systems from a holistic viewpoint (Reissman 1993). It investigates lived experience and meaning and the way in which participants construct their realities (Reissman 1993). These interviews follow the long-standing tradition of Black women’s oral narratives. Narratives can express various shades of meaning and this type of analysis may be useful to understanding the complexities of the HIV/AIDS epidemic.

Research sample

Because Black women are the population most heavily impacted by new rates of HIV infection, thirty HIV-positive Black women were recruited to participate in the study, which lasted seven months. These
women live in a Florida inner-city and range in age from 21 to 60. Participant observation and semi-structured, one-on-one interviews were carried out. Qualitative methods were employed in a narrative analysis (Reissman 1993) of ethnographic data. Each interview was audio recorded and, on average, interviews lasted from thirty minutes to an hour or longer. Interviews were conducted in a closed private room on site by a single investigator. While recognizing the limits of the generalizability of study results, this research drew upon Dorothy Smith’s (1987) argument that studies on discrete cases are portals into broader social and economic processes.

Selection process
The selection process to recruit participants was non-random and the interviews were non-compensatory. Names used in this article are pseudonyms to protect the anonymity of women in this study and the facility. Study participants were recruited through a women’s family medical clinic located in Florida. Recruitment measures included word of mouth, referrals, and the facility’s patient registry. Patients were asked by their social worker if they were interested in speaking with an onsite researcher. One staff member who fit the criteria secretly sought out the investigator to participate in the study. Participant observations included monitoring an African American women’s support group, interactions with HIV-positive women in the lounge of the facility (an area set up only for women living with HIV/AIDS), as well as a few casual conversations with employees at the facility. Eligibility criteria for these interviews were based upon participants self-identifying as being an HIV-positive woman of African descent. Not all of the women at the facility, including some of the participants, were under the care of a physician. Some of them were there only to obtain social services. Out of the forty women invited to participate, two refused to sign the consent form, thirty participated, and the remaining women refused to be a part of the research study. Although thirty women were investigated, the saturation point was twenty interviews. This study was approved by the Institutional Review Board and all the women who participated signed the consent form.

Narratives
The narrative segments were chosen based upon their significance to the research question regarding HIV-positive women’s perspectives and stated concerns on effective HIV prevention as informed by their lived experience and situated knowledge. Each interview was edited minimally for readability; participants’ speech patterns and dialect were preserved whenever possible. The investigator of this study transcribed the responses three separate times using various methods to ensure accuracy. The first stage was a literal verbatim
transcription of the data. Audio accuracy was double-checked by using different audio machines for the second phase, and in the third stage the study participant speech patterns, meaning, and interpretation were examined closely. The process of listening to the interview material repeatedly in addition to the time spent in participant observation assisted in the interpretation and analysis of narrations. The investigator also discussed some of the analysis and interpretations with various peer advocates (HIV-positive contract workers) to verify interview data.

**Feminization of Poverty**

Health is linked to human rights while health disparities are closely aligned with financial disparity. Economic parity was a pertinent issue for most participants I interviewed and their questions included: Why aren’t there more programs that create viable opportunities for women? Why aren’t women who are in positions of power more willing to groom other women for upward mobility? Why is economic empowerment readily available to some, but not to others? These concerns and others were shared in most of the health narratives. These women are at risk on several levels because they exist under economically challenged conditions that can exacerbate the incidence of HIV/AIDS. What is common among these participants is a financial situation that resulted in either homelessness or the threat of homelessness. Women and their children are vulnerable to endangering and/or jeopardizing their health because of a lack of housing or the threat of being without shelter.

The following section presents three themes that emerged from the analysis of HIV-positive Black women’s narratives. When juxtaposed with a human rights framework these themes illustrate how women living with HIV/AIDS envision a rights-based approach to HIV prevention.

**Comprehensive Job Training/Welfare to Work Programs**

The feminization of poverty notes that some women live on the fringes of the economic system as the disenfranchised and dispossessed, while oftentimes their underpaid labor/service enhances the massive profit margins of many corporations (Fukuda-Parr 1999). The manifestation of the feminization of poverty experienced by many Floridian women showed up during the outsourcing of the 1980’s and the welfare reforms of the 1990’s (Dennis et al. 1995; Jones and Kodras 1990; Mink 1995). Many women who lost welfare assistance with the 1990’s reforms lacked skills and some were not readily job trainable. Some women had only minimal education, had not completed grade school, or had never held a job. Moreover, according to study participants, welfare reform policies of the 1990’s had minimal provisions for women who: (1) worked long hours, had more than one
job, and did not have enough money to meet basic needs, (2) were quick studies and easily trained but, having soon became bored with their initial position, desired advancement that was not available in the frequently dead-end welfare reform jobs, (3) needed more time to move towards a full employability status.

Welfare reform in Florida also decreased the amount of cash assistance to families. Hannah is in a double-bind, she receives public assistance but not public housing and is left in a financial conundrum. Hannah, age twenty-eight, has three children and is HIV-positive.

They don’t let the Black community know about certain things. [I think that leads to people doing other things to get money, like] stealing. I was getting $171 for my youngest child, $171 in cash and $90 in food stamps. I still had to get more money, I had to go out and make more money. You can't afford daycare. Daycare is like $175 a week. That’s my whole check right there. Rent is $700-800 a month, just for a one-bedroom. Three kids. Now they’ve got it where two kids or more, you only get $300-and-some for two kids. If you have another kid, [it’s] “No, we’re not going to give you no cash assistance.” You’ll get food stamps for it. But no cash assistance.

Hannah admits that $171.00 is not enough for daycare or rent for a one bedroom apartment. She also refers to the cap on cash assistance and discusses the need to engage in alternative illegal income activities such as stealing in order to have food and shelter. Hannah recognizes that the new changes in the welfare laws have made women’s plight for survival even more egregious. Ultimately, public policy can be critical to and for women’s empowerment but particularly for those women living on the margins. Likewise, lack of relevant legislation for the disenfranchised may also be a catalyst for HIV vulnerability.

Another aspect of the feminization of poverty is underemployment. Many women want to work and are simply looking for an opportunity. Others may have employment but they are working in dead-end jobs where there is no personal fulfillment. Some women desire a position with the potential for upward mobility. Tammie also lives with HIV/AIDS, and is 33-years old with two children. She suggests, “It’s a lot of good women in the ghetto who want to make it, who want to be somebody, who want to go somewhere, but don’t know how to get there. All they need is the right guidance. I was one of them.” Tammie advocates “Sister Power,” (Reid-Merrit 1996) wherein women empower each other. She and others like her, however, do not have strong professional support networks. Tammie suggests that women in positions
of power train and mentor other women who also would like to secure fulfilling or viable employment.

Tammie discusses her experience with job training programs that move women from entitlement programs and/or disability to work. She states, “what I'm trying to say is that if you going to develop these types of programs, don't develop these types of programs to stop.” "We're going to train these people," then whatever field they're in, "yeah, we're going to move them along so we can hire more." I mean, don't you want to see what you do-grow? You don't want to see it stagnate in one place... And they're not doing that..." Tammie had a desire to make something of herself; she knew she had untapped potential but needed guidance.

More employment choices and opportunities are what Tammie would like because, she argues, the government develops training programs that result in dead-end jobs rather than vying for programs that promote new opportunities and upward mobility. She condemned the government for training women for positions with no potential for advancement or self-actualization. Tammie reached out to government programs that professed to help her enhance her economic status and they failed her. Fukuda-Parr (1999) argues that human poverty is gauged by the choices and opportunities available at any given time, and that these choices are gendered because men have more options than women. In short, economically challenged individuals have fewer options in life, but if you are financially disadvantaged and a woman your opportunities are even worse. Tammie’s experience with the feminization of poverty illuminates the way in which choice and opportunities are embedded with gender and class bias.

Other participants analyze the relationship between welfare reform and the increase in HIV-positive Black women, accusing the government of mishandling welfare reform by making changes too quickly thereby increasing some women’s vulnerability for HIV. Since women were not adequately prepared for life without subsidies, Grace argues, some did whatever they had to do (trading/exchanging sex for money) to make ends meet, increasing their chances of becoming infected with the virus. Grace is forty-one, has grown children, and is living with HIV/AIDS:

There are some women who think that because the government is not supporting them like they used to, then the government has done whatever. I’m not saying that the government needs to keep on keeping them. But there should have been a way that if a person was so used to being on the system, give them options to go out and work, or be in job programs where they get paid. Then they won’t have to feel that they need to be with so many different men, depend on men that probably ain’t
no good for them. ...Some of these programs, I think it’s a program that they got called wages or...Those people, even if they in those programs, the government don’t even much help them enough for them to get their education, or to give them child care, or to give them medical assistance until they can become productive working people, or productive tax-paying people. The government falls short in that aspect.

Public policy is pivotal in the lives of marginalized people and can facilitate women’s vulnerability to HIV/AIDS. Prevention, treatment, and care for HIV-positive women are more complex than the current emphasis on individual lifestyle choices and behavior changes. A human rights approach may be more efficacious in resolving issues of health, public policy, and self-determination.

Affordable Housing

Much of the literature on HIV/AIDS has focused on class, arguing that financial need is an impetus for unsafe sex. Of all the oppressive forces by which study participants feel disempowered, perhaps the most damaging is the lack of affordable housing and/or the threat of homelessness. Based upon participants’ narratives the lack of affordable housing is the driving force behind many African American women’s engagement in discreet sexual encounters. Micki, a twenty-eight year old study participant, tells her story:

I can’t see laying on my couch saying, “I want to go have sex.” I can’t see it that way. But money plays a part in it. “I need money. I know this man’ll pay me this for this.” I’m just going to be honest. I thought about it the other day… I sure thought about it the other day because I’m $300 short on my rent. I been behind ever since February and I’m still behind. I thought about it, but I said, “Where you going with that?” I’m trying to work it out. Today was my deadline, but I’m going to write them a note when I put the other money I do have in there. I’ll write them a note, see if they can work with it. [I’m] trying not to go that route.

Micki’s average monthly income is about $1300. She works and has one child. She doesn’t receive food stamps and she is not receiving housing assistance. Micki’s situation would be greatly improved if she could afford her rent. As study participants report, some women trade sex for money, employing an “I did what I had to do,” strategy for self-determination. Discreet sexual encounters create self-agency, especially
for Black women who have cut out the pimp, and are able to make all the
decisions and money for themselves. These narratives about financial
issues are ultimately concerns about housing or the lack thereof. Even
though other women use low-paying service sector jobs, food stamps,
section eight housing, Medicaid, or other sources of assistance as a band-
aid for the societal ill of monetary marginalization, finding affordable
housing is pivotal, argue participants, to Black women’s wellbeing and
HIV prevention.

Lack of affordable housing can be taxing for single women with
no children, especially if they are HIV-positive. Kilah, an HIV-positive
participant states:

I’m 26. I have no kids. I receive SSI; my income is like
$585.00. $585.00 is not enough to pay bills anywhere.
Then I think with my little income I’m not able to work.
Yet, I can’t get housing [section eight] because I don’t
have any kids. If you got kids, then housing get thrown
at you. I have worked all my life until, I don’t know. I
worked when I was 17 all the way to I think 20, 23, 24
or 25. All I want is housing. All I really want and
nothing else. I could care less about food stamps. I don’t
have any kids. I can care less about everything. I can get
food stamps right now. I choose not to. I could care less
about all that. I just want housing. It’s hard, including
the only housing that they could give me right now since
I am HIV is in, it’s a building. Everybody in the building
is HIV. I’m 26 years old. I don’t want nobody to know
I’m HIV. …They feel it’s AIDS, and HIV when they see
you, they are going to get it.

Women in this study professed that in addition to their already
marginalized status as African American women, they face stigma that
may alienate them from vital support networks. What happens when a
Black woman is consigned to the margins of an already marginalized
group? This is the position of many Black women living with
HIV/AIDS. Study participants’ narratives of stigma and discrimination
describe the overwhelming negative experiences that they have had and
continue to have as Black women living with HIV/AIDS. Kilah’s
perspective is aligned with the rights-based approach that calls for an end
to stigma, discrimination, and lack of confidentiality because these erode
HIV prevention efforts and harm vulnerable populations (United Nations
2001).

Similarly, adolescents and teens also have problems with
housing, especially runaways who may end up in homeless shelters.
HIV-positive twenty-one year old Serenity is the mother of two and discusses her experience and perceptions about homeless shelters:

The nearest homeless shelter is not enough. You say they have places to go, but people don’t want to be with addicts. That’s not trying to change. That’s why I say we need a [shelter] in our neighborhood for all these people. The first 50 people ain’t good enough [after 50, people are turned back onto the street]. … I say if I ever make me some money, I’m going to make my own [shelter]. My [shelter] ain’t going to be for no age range for adolescents, it’s going to be for any and everyone. My [shelter], and it’s going to be 24 hours, that’s 24/7 rain, winter, snow. If everything on fire besides me, I don’t care. It’s going to take everybody, and I hope to have floors so that I can separate the addicts from normal, because we don’t want to have no disturbance or no confrontations. I’m going to have floors. I don’t care if that means I sleep there to keep that thing open, I will. If it means that I have to take some into my own home, I will. I believe in my heart that’s what we really need.

Here, Serenity is arguing that everyone (including drug addicts) has the basic right to a safe shelter because human rights are not a luxury. The Political Declaration on HIV/AIDS “expresses grave concern that young people between the ages of 15 and 24 years account for more than one third of all new HIV infections, with some 3,000 young people becoming infected with HIV each day” (United Nations 2011). In sum, young men and women are particularly vulnerable to new infection by HIV for a variety of reasons. In this study African American women living with HIV/AIDS reveal that lack of housing and inadequate homeless shelters put them in a perilous situation.

EDUCATION DESIGNED SPECIFICALLY FOR HETEROSEXUAL MEN

Similar to the previous themes on economic inequality, Black women can also face gender inequality. A crisis of the proportions of HIV/AIDS needs an all hands on deck mentality and yet women are being blamed for doing what the government has failed to do adequately. Because gender bias is rooted within public institutions and society at large, condom use and education (in heterosexual relationships) are still considered women’s “responsibilities.” Sexual health and education campaigns have lacked sufficient focus on educating and training heterosexual men (Bowleg and Raj 2012; Higgins, Hoffman and Dworkin 2010; Dworkin, Fullilove, and Peacock 2009). Gay men have
been targeted for prevention campaigns and rightfully so. But HIV/AIDS is now a crisis outside of men’s same sex relations, and the public health system has shirked its responsibility to heterosexual men (especially those who do not use drugs, who have not been incarcerated, or who have not engaged in bi-sexual relations). Even those public interventions for heterosexual men (drug users and men who sleep with both men and women) rarely speak to gender dynamics, gender norms, gender politics, relationship negotiations or the power dynamics in African American heterosexual relationships.

Power dynamics, such as expecting the oppressed to educate their oppressor, are problematic. African American women living with HIV/AIDS hold a unique position of being marginalized based on race, gender, and possibly class. When combined with HIV-related stigma HIV-positive Black women are in the unique situation of being marginalized from the margins and these women may not be in a position to liberate/educate heterosexual men. Study participants discussed the difficulties they faced with the societal expectation that women should control the behavior of men when, in fact, gender inequality and male privilege is pervasive. Questions such as: Why aren’t men educated about HIV/AIDS? Why is it always the woman who must take responsibility? Why are men not held more accountable? These were some of the questions heard from respondents during the interview process regarding HIV prevention education and training. Mikki, for instance, became very agitated about men not being held accountable for HIV prevention and expressed her concern:

This is killing me, your whole thing is women, women. I understand this is a woman’s thing, but it’s two-sided, and I don’t ever see the male side unless they’re talking about gay men. There’s more than gay men in the world that are HIV-positive. There are more than just women that are HIV-positive. We talk about kids every so often, not, I mean, outspoken like...It’s always women, women, women...I feel men should be in on it too, because that way men will have knowledge that they so-call try to instill in us women. Right now we’re fighting a battle. We got to be the ones to try to let this person know or the man know. I feel everyone should be educated about it. … Everybody needs to know. Right now it feels like we’re being put in a place to educate the world and I don’t feel women should have to educate everybody. Everybody should know...It’s not up to us to educate. We [women] can educate some. We can't educate everybody, and right now we have to educate
everybody. Everybody you run across, [its] “you got to stop and think for everybody.”

Seal and Ehrhardt (1999) suggest that studies on monogamy and intimate partner negotiation initiated by women are subject to cultural and community gender norms which may hinder women’s sexual assertiveness and simultaneously encourage multiple sexual partners for men. Serenity, mother of two and the youngest participant at age twenty-one, weighs in on the subject. She says, “We have a conversation with that, every girl have a conversation, try to have a conversation about monogamy with these men. These men don’t want to hear it.” Some women in the study expressed the opinion that all men cheat. If one agrees with that statement, then there is no reason to leave a good relationship with someone you love because, as some women reason, the next man will also cheat.

Thirty-two year old Princess is also unsettled about the dilemma of the dearth of HIV/AIDS education for men who sleep with women:

We’re not educating each other on this thing. We need to, even in churches, there’s a lot of things not being discussed. It’s a lot of things. The whole body, the whole church body. Not just women, but African American women and men. Teach the men, too, to be honest with the women. We’re sleeping with the men, the men need to be educated, too…A lot of the Black men didn’t have fathers there with them to teach them to respect the woman, to love her. If I have something that I know can hurt her, I would tell her, give her that choice. Have the men be educated, too. It’s not just the women, it’s the men need to be educated, because they’re picking up these vulnerable women who just want somebody. Most women just want somebody to love them and to see them for who they are but they’re not being honest.

The Political Declaration on HIV/AIDS: Intensifying our Efforts to Eliminate HIV/AIDS of 2011 specifies for instance, “Note with concern that national prevention strategies and programmes are often too generic in nature and do not adequately respond to infection patterns and the disease burden; for example, where heterosexual sex is the dominant mode of transmission, married or cohabitating individuals, including those in semi-discordant relationships, account for the majority of new infections but are not sufficiently targeted with testing and prevention interventions” (United Nations 2011). Focus on intensifying efforts toward heterosexual prevention interventions is just one aspect of the 2011 Declaration where the creation of enforceable legislation and policy
with a rights-based strategy for HIV prevention could actually transform the health outcomes for African Americans. If these tenets were upheld and enforced, human rights centered models have the capacity to incorporate programs designed to measure the efficacy of HIV/AIDS prevention interventions and to hold officials (state and public health) accountable for protecting and promoting health for every population (Gollub 2100; Patterson and London 2002).

CONCLUSION

To mention human rights abuses and the twenty-first century United States in the same breath might be considered a sacrilege by health practitioners, but the narratives of African American women living with HIV/AIDS tells another story. Their stories expand our awareness of the reality of what it means to be HIV-positive, African American, and women in the US. A clearer picture emerges of the ways in which Black women are disadvantaged by male privilege and the expectation that women, rather than health officials, provide HIV prevention education to heterosexual men, how welfare reform and its corresponding job training failed Black women leaving a disenfranchised segment of the population even more vulnerable, and finally Black women’s narratives illuminated the connection between the lack of affordable housing and/or the threat of homelessness and susceptibility to HIV infection.

Medical research has provided some relief from the HIV/AIDS epidemic, however, the pandemic continues to spread. The heterosexual transmission of HIV brings with it a host of problems that are social, political, economic, and gendered in nature…social ills that facilitate health disparities. Given the nature of HIV/AIDS, traditional public health frameworks may not have the breadth and depth necessary to eradicate the HIV virus (Gruskin, Ferguson, and O’Malley 2007; Patterson and London 2002; Whelan 1998). As such, the traditional health belief and biomedical models are stretched thin trying to meet the needs of vulnerable populations. The United Nations has convened on numerous occasions to tackle the challenge of HIV/AIDS globally. There are three Declarations penned in 2001, 2006, and 2011 on HIV/AIDS that lay a legal foundation for nations, governments, non-governmental and community based organizations, and civil society to create measurable programs so they can hold powerbrokers accountable. Human rights advocates propose a rights-based approach to the elimination of HIV/AIDS that encompasses enforceable international policies and legislation, develops efficacious prevention interventions, and holds governments and health officials accountable for protecting the health of all populations. Moreover, the rights-based approach encourages civic participation and is inclusive of coalescing with impacted communities and people living with HIV/AIDS.
Gender, or the case of gender is problematized in the global response to HIV/AIDS with recommendations for action in all of The Declarations on HIV/AIDS, but having as yet to be actualized in civil society. What we see globally and is corroborated by study participants is that discrimination and bias negatively impacts the health of women. For Black women this has especially shaped access to education and employment (Aniekwu 2002); inaccessibility to affordable housing has also had disastrous effects on African American women and has increased their vulnerability for HIV infection disproportionately (Gollub 1999). Furthermore, gender bias has set the expectation that women in heterosexual relationships must control the behavior of men, rather than public health officials creating HIV/AIDS prevention interventions geared specifically to educate and modify the actions of heterosexual men (Aniekwu 2002). Exner et al. assert that “men’s heterosexual behavior should not be an afterthought: it should be the starting point for intervention development” (1999:357). Some scholars suggest that prevention interventions have to be more attuned to heterosexual men’s sexual patterns and programs created that are centered around vaginal intercourse, the irregular use of condoms, numerous sex partners, and gender role adherence that varies by culture (Exner et al. 1999). African women and those of African descent argue that the participation of heterosexual men is mandatory to the wellbeing of Black women, because heterosexual men also need to be targeted for HIV/AIDS prevention interventions and education (Aniekwu 2002). Therefore a rights-based approach has the flexibility for gender, race, class and cultural sensitivity that is paramount in combating HIV/AIDS. Furthermore, as evidenced by the changes that emerged in South Africa as a result of a rights-based approach in combating HIV/AIDS, this method may hold the state and the public health system accountable in the prevention, treatment, education, and care for impacted populations.

REFERENCES


CDC, Centers for Disease Control and Prevention. 2009. Social Determinates of Health (website created)


CDC, Department of Health and Human Services 2013. "HIV Among Women." Centers for Disease Control and Prevention, Atlanta


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United Nations. 2006. "Political Declaration on HIV/AIDS."

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