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"Work What You Got": Political Participation And HIV-Positive Black Women's Work To Restore Themselves And Their Communities

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African American women's rates of HIV/AIDS infection have skyrocketed in comparison to other racial and ethnic groups over the past thirty years. Today black women have twenty times more occurrences of new HIV infection than other women in spite of recent declines in new infections (CDC, 2012). Regardless of these statistics, HIV-positive Black women's perspectives are rarely sought regarding best practices to eradicate and interrupt HIV/AIDS among African American women, even though historically Black women have often proved phenomenal agents of social change (James, 2009; Springer, 1999). HIV-positive Black women's activism has been understudied, and given the nascent literature on HIV-positive Black women's standpoint on HIV prevention, this article focuses on their perspectives and stated concerns on effective prevention based upon their lived experience and situated knowledge. Through the narratives of thirty HIV-positive Floridian Black women (Melton, 2007), I present study results and the role of participant's personal agency in community-based political participation to thwart HIV/AIDS.

African American women have been on the front lines for justice as abolitionist and anti-lynching advocates, from rabble-rousing for political and social equality and freedom for citizens, to fighting for a woman's right to health (James, 2009; Guy-Sheftall, 1995; Springer, 1999). When it comes to HIV/AIDS, notes Hammonds (2009), "As in other eras, Black women are playing a large and diverse set of roles in confronting the AIDS epidemic—and they are doing so in the absence of institutions inside and outside of Black communities to address this difficult and growing health crisis" (p. 278). In this paper I situate HIV/AIDS into the larger dialogue about African American women's struggle for civil rights, equity and parity (Hammonds, 2009). In this vein, my work is informed by scholars such as Hine (1989), Hunter (1997), and Hammonds (2009), each of who has investigated how Black women have claimed and defined acts of self-assertion in the ongoing struggle for social justice. A sense of that type of political participation finds expression among HIV-positive Black women's social resistance in the current case.

Work What You Got

Black women's political participation might be considered an act of assertion because it can be accompanied by demands for justice and equality. Likewise, singer/songwriter Mary J.

Blige's sings about overcoming life's obstacles, personal transformation, and self-acceptance. In Blige's song "Work That" (Blige, Garret, & Feemster, 2007) she declares Black women need to "Work what you got." Her philosophy captured in rhythm and melody champion women asserting themselves and claiming personal authority over their circumstances rather than seeking societal affirmation and changing to suit the status quo. Embracing what you have to bring about positive change is a feature of African American women's activism. Black women for instance, have historically exerted the "Work what you got" philosophy as part and parcel of their political participation. During the period of enslavement Black women "Work What You Got," and they used quilts, songs, and blue paint to parlay various messages in their quest for freedom. Historically, using what you have to create something better may also be the bedrock of African American women's community work. Specifically, women living with HIV/AIDS in this study use and practice the "Work what you got" philosophy in the campaign to fight HIV/AIDS. Juxtaposed against the trajectory of literature on and about Black women, these narratives shed light on the post-civil rights activism of African American women in the new millennium.

Overview Of Community-Based Political Struggles

Black women's historical political participation has been well documented by scholars especially their activism during the twentieth century (Springer, 1999; Guy-Sheftall, 1995; Naples, 1998). Their efforts encompass both formal and informal public and political such as standard organizing and grassroots actions as well as working with feminist, multiracial, and/or co-ed associations (Guy-Sheftall, 1999). Often establishing themselves from groups of similarly situated locales, these activists formed associations from their circles as students, trade unions, professional sects, public assistance recipients, and sharecroppers to name a few (Guy-Sheftall, 1999). Scholars have contributed to an extensive body of literature on Black women's historical political organizing and participation and centrality to movements for social justice and equality. African American women's organizing also includes women's endeavors toward health and wellbeing for themselves, their families and communities (Grayson, 1999; Gilbert & Wright 2003; Berger, 2004). Despite the historical significance of Black women's political participation, HIV-positive Black women's activism is sometimes overlooked.

While the literature on Black women's activism is substantial, once unfettered by the boundaries of traditional definitions of political participation, activism, and advocacy African

Americans women's contributions to social justice projects and movements become even more extensive. These non-traditionally defined political activities are also chronicled in countless studies and research (Naples, 1998; Gilkes, 1994; Berger, 2004), and it is that definition I turn to in this paper. Berger (2004) suggests that women of color and economically insecure women involved in political activities did "not frame their meanings solely in political terms and often eschewed the realm of official, organized politics" (p. 83). Since women (especially those who are economically challenged) are often excluded from formal political institutional structures, they are politicized through their work on behalf of the community and neighborhood (Kuumba, 2001; Naples, 1998; Gilkes, 1994). These women use their informal kinship networks to organize due to the sexual division of labor. Women develop strong informal and kinship networks in opposition to the societal demands placed upon them by the expectations of performing normative gender roles; therefore, men and women enter political struggles based upon their societal gendered locations (Kuumba, 2001). Gender as a springboard for social resistance is tempered by structural factors and other dynamic variables linked to the execution of social protest (Naples, 1998).

Black women experience institutional and/or personal oppression and may be subjugated by these multiple locations simultaneously (Collins, 2000). Intersecting oppressions work to constrain Black women's agency, self-determination, and political participation (Berger, 2004) while at the same time being the reason *and* the catalyst for their social resistance (Naples, 1998). Although African American women deal with issues of interlocking oppressions, pockets of resistance exist where women create self-agency. Factors other than oppression mold African American women's experiences, allowing Black women to produce their own knowledge claims derived from their participation in or observation of their oppressed circumstances, known as situated knowledge (Collins, 2000). Exclusionary practices grounded in gender, race, and class bias inform Black women's lived experience and shape their ability to access mainstream strategies for justice and equality (Kuumba, 2001; James, 2009). Institutionalized sexism may hinder recruitment measures, mobilization tactics, organizing, and fighting strategies, if gender inequality is reproduced within formal political organizations (Kuumba, 2001). Thus, notes Kuumba (2001), gender bias influences women's ways of protesting.

Women's political struggles at the local level, argues Naples (1998), are often in response to the activities of the state's government officials, or due to their inactivity on issues pertinent to

disenfranchised communities. Political participation for marginalized women include community work: women's non-electoral neighborhood work, organizing at the grassroots level, paid and unpaid activities to subvert and challenge oppression, and maintaining or rebuilding communities (Naples, 1998; Gilkes, 1994). Community work, notes Gilkes (1994), is broadly defined in African American communities in order to subvert oppression and suffering on multiple levels, and it is a continuous battle. For instance, community-based political work might include deconstructing stereotypes and oppressive ideologies because debunking stigmatizing images are vital to liberating and/or restoring communities of color (Collins, 2000; James, 2009; Gilkes, 1994). I use the terms political participation, organizing, social protest, social resistance, activism, political struggle, and community work interchangeably throughout this text to highlight HIV-positive Black women's political participation in fighting HIV/AIDS.

A Few Tenets of Black Women's Populist Struggles

Women of color struggling for justice in disenfranchised neighborhoods conceptualize and understand their efforts in non-conventional terms (Naples, 1998; Berger, 2004; Harris, 2012). The body of literature on economically insecure Black women's community-based political struggles substantiates the reframing of categories of analysis such as "work," "family," and "politics" (Naples, 1998; Gilkes, 1994; Berger, 2004). Mothering, for instance, is defined as the care and rearing of a blood-related child within the family home, but this term does not grasp the breadth or depth of women's community work in confrontations with systems of power. Conventional understandings of "mothering" minimize the radicalness of women's political activities and are in contrast with what they themselves believe about their political participation (Naples, 1998; Gilkes, 1994).

For African Americans a tenet of Black motherhood is acknowledgement that one woman being entirely obligated to raise one child may be impossible and/or misguided (Collins, 2000). "Othermothers," vital components of African/African American culture, are women (sisters, aunts, mothers, friends, co-workers, neighbors) who share in childrearing, temporary custody arrangements, and/or long-term or permanent child care (Collins, 2000). A present day example is the first family where Mrs. Robinson the first grandmother shares in parenting with her daughter, the first lady Michelle Obama. Collins (2000) notes, "the resiliency of women-centered family networks and their willingness to take responsibility for Black children illustrates how

African-influenced understandings of family have been continually reworked to help African-Americans as a collectivity cope with and resist oppression" (p. 83). Given the lived experience of race, class, and gender oppression for Black mothers the cultural understandings of cooperative parenting and the significance of women-centered networks are resources used to subvert oppression.

Collins (2000) argues that through Black women's acculturation as othermothers they develop an ethic of caring and personal accountability that extends beyond the nuclear family to the community-at-large. Some African American women believe that organizing is communal; it is not just about "me" the individual, but includes family, friends, and community. These women's philosophies are more often *I am my community,* an ideology that is central to their ongoing struggle for social justice (Collins, 2000). Therefore, "activist mothering" (Naples, 1992) occurs when African American women connect their various gendered roles to their struggle for liberation.

Some Black women may come to political awareness in response to an injustice suffered by their children, gradually becoming more politically astute until they reach a point where they recognize that their individual struggles are collective political issues (Collins, 2000). For example:

> As employees of state-funded community agencies, the community workers harnessed their paid work to support their community activism as well as their motherwork, thus blurring the boundaries between employment, politics, and mothering… It draws attention to the myriad ways these women challenged the false separation of productive work, socially reproductive work, and politics under changing historical contexts. (Naples 1998, p. 4).

Activist mothers integrate personal, professional, family, and community problems into a politicized standpoint for social change (Collins, 2000; Naples, 1998). Black women, however, do not reject formal means of political participation for informal organizing (Collins, 2000; Naples, 1998). Rather the effects of race, class, and gender oppression may impede their organized political activities with formal institutions that deny them spheres of influence, power and authority (James, 2009; Berger, 2004; Kuumba, 2001). Similar to the sentiments of Blige, community other mothers use the "Work What You Got" philosophy to change their circumstances when possible.

HIV/AIDS and Black Women

Gender, race, and class oppressions may constrain Black women's political participation, but it may also be the reason for their social struggles (Kuumba, 2001). Black women's susceptibility to rates of new HIV infections is disproportionate in comparison to other women (CDC, 2012) and a great cause of concern. Scholars investigating Black women and HIV vulnerability have conceptualized and investigated these major themes: condom use, multiple partners, and intercourse with intravenous drug users (Kim et al., 1993; Sobo, 1995; Wingood & DiClemente, 1998). Scholars have also critiqued HIV/AIDS studies for failing to contextualize studies and/or bias that skew the hypothesis and/or results of said reports (Akeroyd, 1994; Glick Schiller, 1992; Glick Schiller et al., 1994; Singer, 2001). Some researchers examine structural inequalities, HIV/AIDS, and Black women (Farmer, 1996; Lane et al., 2004), and others note that HIV prevention scripts and messages are more effective if they are gender specific and culturally relevant (Kalichman et al., 1993). Gender inequalities complicate prevention for women because intimate relationships may take the form of violence and subordination, where women may not be able to determine the timing or type of sexual contact, or the frequency and use of condoms (Sobo, 1995; Whitehead, 1997).

Factors such as un/underemployment, high national rates of the imprisonment of Black men (Watkins, Fullilove & Fullilove, 1998), poor public health systems (Scott-McBarnette, 1996) and negative stereotypes of Black sexuality (Hammonds, 2009) have been contextualized in the socio-cultural construction of HIV/AIDS for African Americans (Gilbert & Wright, 2003). Berger (2004) argues that multiple stigmas related to HIV, when combined with interlocking oppressions create power hierarchies of stigmatization called intersecting stigmas. These hierarchies work together to create a unique position for HIV-positive women of color (Berger, 2004); and being marginalized from the margins is the place from which women in this study launch their social protests.

The prevention perspectives of HIV-positive Black women have emerged at a slower pace than the body of literature on HIV/AIDS. Gentry's (2009) ethnography is the only scholarly investigation for prevention that is grounded in the perspectives of HIV-positive Black women. The experience of women living with HIV has been documented in their personal memoirs and in ethnographic studies. Gilbert and Wright's (2003) anthology examines African American

women and HIV/AIDS by exploring community activism, policy, economic, and the political and sociocultural aspects of HIV/AIDS.

Women's early national grassroots organizing against AIDS has been written about primarily by activists (Banzhaf et al., 1992). Women's activism around HIV/AIDS has also been investigated using feminist approaches (Schneider & Stoller, 1995) and by exploring the AIDS activism of women of color (Berger, 2004; Harris, 2012). These remarkable works investigate women's work and perceptions around HIV prevention. Berger's (2004) work is groundbreaking in investigating the political participation of HIV-positive women of color. Intersectional stigma is a pivotal concept to understanding and examining HIV-positive women's political struggles. Berger's (2004) study however, does not focus solely on HIV-positive Black women. Harris (2012) examines Black women's AIDS activism and situates Black women's AIDS activism into the canon of Black women's historical community activism with her pilot study. As the only study of its sort, Harris plans to explore Black women's AIDS activism in a broader research study, but she does not focus specifically on HIV-positive Black women's political participation. There is not one specific text that examines the contributions, perspectives, and struggles of *only* HIV-positive Black women as they grapple with a chronic stigmatizing illness while simultaneously working to restore and re-claim their communities.

The study presented here seeks to explore the AIDS activism of thirty HIV-positive Black Floridian women. Analyzing these narratives using community-based political participation, Black feminism, and structural inequality as related to HIV/AIDS may establish a framework for incorporating the perspectives of Black women living with HIV/AIDS into existing literature on HIV/AIDS. These poignant narratives work to platform HIV-positive Black women's political participation around these emerging themes: 1) face-to-face activism; 2) activist mothering; and 3) publically coming out as women living with HIV/AIDS.

Methods

Participants

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. Study participants live in a Florida inter-city and range in age from 21 to 60. Study participants self-identify as women of African descent and as HIV-positive. Out of the forty women invited to

participate, thirty participated, two refused to sign the consent form, and the remaining women refused to participate in the research study. Names used in this article are pseudonyms to protect the anonymity of women in this study.

For the most part participants live in neighborhoods that have experienced declining socially organized communities of color, with increasing numbers of individuals and families becoming economically insecure (Gentry, 2009; Sharpe 2005). These areas have lost their middle-class base; businesses have moved to suburban locales; drugs and drug trafficking are rampant; residents have no legal means for earning a living wage, and institutionalized sexism and racism are pervasive (Gentry, 2009; Sharpe, 2005).

Research Design

Qualitative methods were employed in a narrative analysis (Reissman, 1993) of feminist ethnographic data over a seven-month period. The data emerged from narratives of HIV-positive Black women who were asked to share their perspectives and stated concerns on effective HIV prevention as informed by their lived experience and situated knowledge. Participant observations and semi-structured, one-on-one interviews were carried out. Each interview was audio recorded and interviews typically lasted from thirty minutes to an hour or more. Interviews were conducted in a closed private room at a women's family medical clinic in Florida, (called "the center" to further protect participant anonymity) by a single investigator. While recognizing the limits of the generalizing from smaller cases, I draw upon Dorothy Smith's (1987) argument that studies on discrete cases are portals into broader social and economic processes. In the broader study, I attempted to represent the many ways of living and being that constitutes the lives of HIV-positive Black women (Melton, 2007).

I carried out each interview using a set of pre-determined questions that were read to each participant during her individual interview. I also asked questions not on the form when I needed clarity, definition, or elaboration. The questionnaire begins with an opening statement, followed by three sections: demographic information (education, age, marital status, and household composition), perceptions and ideas for HIV/AIDS prevention, and participants' perspectives on relationships. Even though I interviewed thirty women, after twenty interviews many of the same themes were repeated and little to no new information was attained. The data suggested that all possible themes had been exhausted (saturation point). Participant observations included monitoring an African American women's support group, interactions with HIV-positive women

in the lounge of the center (an area set up only for women living with HIV/AIDS), as well as a few casual conversations with employees at the center. The Institutional Review Boards approved this study and all the women who participated signed the consent form.

Procedures

Study participants were recruited through a women's family medical clinic in Florida. The center advocates a one-stop shop philosophy and houses medical, dental, psychological, social services, and pediatric care in one building. All of the participants were not under a physicians care; some only received social services at the center. The selection process to recruit participants was non-random and the interviews were non-compensatory. Eligibility criteria for these interviews were based upon participants self-identifying as being HIV-positive women of African descent. Recruitment occurred daily; I routinely went to social workers for referrals. Social workers asked patients (by phone from the patient registry or during an onsite appointment) if they were interested in speaking with an onsite researcher. Other recruitment measures included word of mouth at the center and referrals from various divisions at the center. One staff member heard about the study via word of mouth and secretly participated in the study to maintain her anonymity because her co-workers were unaware of her seropositive status.

Interviews were conducted in the Social Services area of the center in a standard office. I bought a few pieces to warm up the office for a more intimate setting. I bought a bright silk plant and decorative tray as a centerpiece for the interview table, air freshener, and a radio tuned to a smooth jazz station. These accouterments were put in place to summon the feminist kitchen table ritual (Lorde & Smith, 1980). The table in the kitchen is representative of a safe space for women to let down their guard and commune with one another. I hoped to symbolically evoke this ritual during these interviews.

Data Analysis

HyperRESEARCH is a qualitative software analysis program that I used to help sort through the data from my fieldwork. I loaded all of the original unedited transcriptions into the software program and read all thirty interviews line by line; as I read them I created codes to categorize data. Once the data was grouped by the various themes, I examined the data for similar and divergent viewpoints. The themes were chosen based upon their significance to the

research question. I transcribed the responses three separate times. 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 participants' speech patterns, meaning, and interpretation were examined closely. I also discussed some of the analysis and interpretations with various peer advocates (HIV-positive contract workers) at the center to ensure accuracy and minimize bias. Each interview was edited minimally for readability; and participants' speech patterns and dialect were preserved whenever possible.

Results

Face-To-Face Activism

Springer (1999) argues that Black women's activism can take the form of "direct action" that involves face-to-face exchanges with community members. Springer (1999) suggests that face-to face interactions can include approaching people in venues they typically frequent. HIV/AIDS direct action can include paid advocacy in HIV/AIDS organizations, information booths set up in the community, passing out condoms and information at bus stops, and visiting congressional representatives to advocate for HIV- related legislation, to name a few. Women in this study argue that HIV prevention is more difficult to dismiss, when confronted with repeated and consistent messages from a friend or a peer.

Thirty-year old Tracey is an HIV-positive mother of three, and an HIV advocate. She declares, "I just left a place now, forty-five minutes ago, and they was actually doing outreach in an HIV center, and they should be trying to take it and do outreach somewhere where there's no HIV or people don't really know about it and, spread the word or talk to people, communicate, just have conversations." Tracey works for an institution that treats women with HIV/AIDS. She is frustrated by the exclusionary practices of another institution, one that she visited because they do not go into neighborhoods like Tracey's where HIV education and prevention is needed. Tracey's situated knowledge suggests that direct contact, face-to-face interactions with specific communities are critical to curtailing the virus.

Odessa, a mother of three who lives with HIV, laments the changes that have occurred at the center she frequents for treatment. Odessa frequents a different institution than the one that Tracey was visiting. Odessa recalls when she was initially diagnosed the center encouraged community participation in their prevention workshops regardless of seropositive status, so "you

get to learn about the virus and stuff." The center used to be in a trailer and the atmosphere was very informal. Since that time the center has moved to a state of the art facility with door codes for entry and infrequent on-site visits by donors. Odessa recalls some of their activism:

> …They weren't doing their job in here! They was out! And about in the streets! Even at the gas station! Even when the gas station was telling them you can't set up there. They were standing there! There were handing out condoms. "Come get this!" …But when they got here [new location], they stopped doing it, and it's like all the women that used to do it on their free time, they're not here, they quit. … Our goal was, it's outreach to tell these young women, it's another way. If you're gonna have sex, use condoms. If you gonna use condoms go get checked first. Because condoms do bust. …They had one girl, she was so pretty here, and then she would tell you "I'm positive too." "Do I look like I'm positive?" She was telling the kids, and that was, that worked so much. But they took it away.

Odessa feels excluded and is frustrated that the staff is expected to work at their desk rather than engage in face-to-face activism on the streets; therefore, Odessa and the others quit volunteering. In addition to Odessa's perspectives of being excluded is the possibility that budget cuts reduced resources for community outreach and peer advocates. Odessa's standpoint suggests that face-to-face intervention is pivotal in her community to HIV prevention campaigns.

Fifi, a forty-five year old divorcee and mother of a little girl, shares her experiences with prevention advocacy in her community:

> My husband and I had our little organization in Florida, where we was testing and everything. You get some to come by, but you don't get them to come back. [I started the program] to reach out to the Black community since we both. And no one else was doing it and with us being Black and young ourself, maybe we could get that attention.

Fifi notes that formal prevention interventions did not target the Black communities, and she and her husband were compelled to start something themselves as a result of being excluded. Fifi identifies the reason she is passionate about working in this community: "To show them that it ain't all about the White. You got some Blacks that can help or put you in the right direction too."

Fifi highlights that her community was not targeted with HIV prevention campaigns, and that African Americans were not considered as central to the struggle against HIV/AIDS even in their own neighborhoods. Fifi found it important enough for people in her community to see people similar to themselves as leaders in HIV prevention, so she became involved and favored face-to-face interactions in her political participation.

Activist Mothering

Activist mothering as mentioned earlier, is a technique used in particular by economically insecure African American women in their community-based political struggles. Women use this technique as radical social resistance (Naples, 1998). The process of becoming politically constituted for these Black women means understanding that one person cannot be liberated until their communities are restored and liberated. In some instances motherwork is fluid combining paid and unpaid advocacy.

Newlywed Bobbi is twenty-seven years old with three kids and her activist mothering is with her children. Bobbi's situated knowledge informs her to use a multilayered approach to educate her children about HIV/AIDS. She talks to them and leaves out condoms, with permission to use them; and she has repeated dialogue with them around sex education.

> "You want to look like that?" "No, mama." "So you know what you better do. Use these condoms right here." He say, "Okay mama I'm going to use them when I start having sex. I'm gonna use this condom." "You better, cause that's how you'll look if you don't." And I don't laugh with them when I talk to them like that. I let them know it's serious. It is serious. Sometimes we go up, when we go to visit my mother-in-law in the hospital and we go to hospice, and it be a lot of sick people at hospice.
> …They let you walk down the hall, but you can peep in the room.

Bobbi wants her children to see first-hand the more devastating effects of HIV/AIDS and when she visits her mother at the hospital she uses it as an opportunity to go to the infectious disease or hospice unit so her children can see the final stages of AIDS. Bobbi uses the "Work What You Got" philosophy with her kids to scare them. Bobbi's standpoint is similar to "Scared Straight" the documentary program that took juvenile offenders to prison to speak to convicts and experience prison first hand. During the Black World AIDS Day 2014 in Miami FL vulnerable

adolescents (similar to Bobbi's children), were brought together for a lecture where a white casket was the centerpiece of the program. Platform speakers that included a mortician discussed HIV/AIDS and utilized raw, frank terms with the audience of teens. These speakers employed "Scared Straight" tactics similar to Bobbi's methods with her children.

Twenty-seven year old Tess, mother of two, discovered she was HIV-positive at sixteen. Tess questioned God, wondering why she was seropositive:

> I always ask God, "why in the hell did I get this?" "What did I do wrong?"
> I'm not the worst, so I am thinking, everyday I think I have this for a
> reason and my reason is to educate my family 'cause they're stupid, they
> are. My family judged people before getting to know, so everything I
> learned, I teach them and they're much better now.

Tess' standpoint is that she has the responsibility to save her family, to educate them about HIV/AIDS. Her family stigmatized people with HIV/AIDS but did not practice any form of HIV prevention in their interpersonal relationships. Tess takes on the role of othermother with her family and nurtures her nieces, brothers, and uncles. As an activist mother, Tess' standpoint is that family is integral to HIV prevention.

Tammie is a thirty-three year old woman living with HIV/AIDS who has two children and works at the center (facility that treats HIV-positive women). As a community othermother, Tammie is a nurturer. Her political participation may range from paid to unpaid advocacy with no set hours and includes family, kin, clients, and the community-at-large.

Tammie states:

> Seems like I'm a counselor, I'm a sister, I'm a brother and whatever I have
> to be to the clients who come in. Spiritual counselor because a lot of
> people come in depressed, upset or worried about something, and I just try
> to be that shoulder for them to be on, to lean on. A lot of times I think that
> I'm basically, just try to encourage them and give them the strength that
> they need. Because a lot of them don't have faith just to believe they can
> make it.

Tammie *mothers* the clients that come into the center. She nurtures them and allows them to "lean on" her for strength, support, and comfort.

Scholars argue that neighborhoods similar to study participants have experienced declining socially organized communities of color, with increasing numbers of individuals and families becoming economically insecure (Gentry, 2009). These areas have lost their middle-class base; businesses have moved to suburban locales; drugs and drug trafficking is rampant; residents have no legal means for earning a living wage and institutionalized sexism and racism are pervasive (Gentry, 2009; Sharpe, 2005). In this context, Tammie, Bobbi and Tess' activist mothering is radical. Tammie, in particular, is a role model for social resistance. She does not allow HIV to prevent her from living a full life. Tammie works, helps others, raises her children, and embraces living a full life. When Tammie counsels people waiting in the lobby or gives them advice on employment opportunities she may be assisting women in subverting exclusionary processes that keep them from accessing basic resources for living.

Publically Coming Out as Women Living with HIV/AIDS

Living out loud (publically coming out as HIV-positive) means being unapologetic and unashamed, accepting one's strengths and weaknesses, and living openly as a woman with HIV/AIDS. To reconstruct or reconstitute one's life means "to signify the specific identifiable processes that allow women to construct, expand, reshape, or begin anew what it means to be a *woman with* HIV" (Berger, 2004, p. 16). Some Black women living with HIV/AIDS reach a stage where they live out loud; they are at a certain phase in life and have been able to reconstruct their lives. Berger contends that HIV-positive women who have reconstituted their lives usually do so on two fronts: 1) rehabilitation from substance abuse; and 2) the development of a greater sense of themselves as women.

Although significant, the journey to reconstruct one's life after a HIV diagnosis is not always a straight path and it may be imperfect and incomplete. Sometimes women relapse and/or lose hope and this may happen more than once (Berger, 2004). Some women have built and employed various resources (mostly nontraditional) and utilize their personal agency, experience, and wisdom to politically participate in their communities and to live out loud. Living out loud is particularly noteworthy because HIV-positive Black women's political struggles do not necessarily make it safe for them to publically reveal their seropositive status. Yet, some reconstituted women have publically come out with their seropositive status, because they recognize the gravity of living in silence.

Thirty-six year old Hattie is single, childless, and lives with HIV. She expresses her standpoint on living a reconstituted life:

> I deal with a lot of different people with the virus. But they will look at me and say, "How could you be so open like that?" I tell 'em, I say, "Honey, cause I'm not the only one!" I'm not the only one. Until you open, you're gonna stay stressed. …I say, "Baby, you can't do it alone. You need support. We need support." I just try to make my little meetings or whatever. If I don't talk. Maybe something I've been done heard I will take with me. What I don't need, I'm gonna leave it. …Life is beautiful, especially when you have recovered from drugs and alcohol and your right mind has come back with the help of the Lord. I wouldn't change it for the world.

Hattie reconstructed her life; she's recovered from substance abuse and conceives of life on her own terms and not by the dictates of others. Gentry (2009) suggests that public drug rehabilitation facilities are predominantly driven by treatment procedures for heroin rather than crack cocaine. Crack cocaine is linked to the incidence of HIV/AIDS in African American neighborhoods (Gentry, 2009; Sharpe, 2005). Black women are disadvantaged by treatment centers with best practices for rehabilitation geared towards a drug they are not using as well as by a lack of gender and cultural sensitivity (Gentry, 2009). Given that context, Hattie's statement is powerful; she has recovered from drugs and alcohol despite the odds and has reconstructed her life and now lives out loud as a woman with HIV.

Likewise, Norma is engaged to be married, has one child, and she and her child are both seropositive. Spirited Norma declares that she is going to live and survive:

> I know what my situation is. I'm not, and when I tell a person my status, and they don't like it. There go the door. I'm a grown woman. I take care of myself. I'm not gonna be around here wondering, okay, I got to hide this from this person. I got to hide my medicine. My medicine sit as big as day on my bed, and my son medicine in the cabinet. …And if you don't want to be in my house you don't have to be here. You don't wanna eat my food, you don't got to eat my food. I'm gonna live. I'm gonna survive.

> …My doctor said, "Whatever I been doing continue to do it cause it works
> for you," and I'm doing exactly that.

Norma's standpoint is to live out loud, to be open about her seropositive status, to come out, because it creates peace and long life. Norma also notes that she intentionally moved away from her old neighborhood (where women in this study live) to change her life. Williamson (2003) argues that transformation is dynamic and changing and may or may not improve an individual's life and the results may or may not be lasting. Transformation is also impacted by race, class, and gender practices experienced in daily life (Williamson, 2003). Norma and other participants who grew up with income inequality, numerous tenacious stressors throughout their lives, and several traumatic events, fall outside of traditional concepts on stress and coping (Williamson, 2003). But scholars note that HIV-positive Black women living in circumstances similar to women in this study who remove themselves from their stressors may have more success in sustaining their transformation or reconstituted lives (Williamson, 2003; Gentry, 2009).

Mary is thirty-three and works as an HIV/AIDS advocate. She thinks that HIV-related stigma is so overarching that even those who work in facilities dedicated to preventing, treating, and caring for people living with HIV/AIDS will still experience discrimination at work:

> There's women who work in the [HIV/AIDS] place I work in who are living with HIV, and even though they're working in this field, it doesn't mean that they're open to speak about it to other people. [Thus,] I think it should be like the gays and lesbians, having a Coming Out Day. And we all just walk in the park. …Have a Coming Out Day or something to make it unify [to create unity and subvert HIV-related stigma].

Mary laments the fact that even while working to treat and prevent HIV/AIDS, women living with HIV hide their seropositive status because they fear the negative impact of HIV-related discrimination and stigma (Berger, 2004; Melton, 2007). The connection between failing social structures for Black folk and multiple HIV-related stigmas constrain Black women's political participation (Berger, 2004).

HIV-positive women in a Detroit study by Berger (2004) placed strong emphasis on HIV-positive people speaking their truth publically, stating: "I always say you can turn a negative into a positive. I say the same thing what you did out there [on the street, or in the life], you can do it in recovery, but you just do it in a different way… You got to use everything you

know when you're HIV-positive" (p. 182). HIV-positive women encourage other women to be assertive and to use whatever they have to live fuller lives and to facilitate social change. This is an example of the "Work What You Got" philosophy where Blige encourages women to be proud and to work with what they have to improve their circumstances. Similarly, Mary (participant) encourages women to be assertive, to be bold, to come out, and to use social resistance to stand up to HIV-related stigma.

Discussion

In this paper, I situate HIV/AIDS into the larger dialogue about African American women's struggle for civil rights, equity and parity (Hammonds, 2009). In-depth qualitative interviews of thirty HIV-positive Floridian Black women were analyzed to establish HIV-positive Black women's populist struggles to eradicate HIV/AIDS. Participants' poignant narratives demonstrate that African American women living with HIV/AIDS are engaged in social resistance to find solutions to restore themselves and their communities from the effects of HIV/AIDS. By analyzing HIV-positive women's activities through the lens of Black women's political participation (James, 2009; Berger, 2004; Naples, 1998), Black feminism (Collins, 2000), structural factors (Glick Schiller, 1992; Glick Schiller et al,. 1994; Singer, 2001), and Black women's vulnerability for HIV infection (Gilbert & Wright, 2003; Gentry, 2009; Sharpe 2005), a *new* picture emerges of HIV prevention work and organizing. Given the context of study participants lived experience, these women could be engaged in HIV/AIDS activism while fighting and organizing against the increase of gender-based public school suspensions of Black girls, medical discrimination, food deserts, and not just condom distribution.

Study participants accounts also reveal an aspect of Black women's political participation that may be unique to HIV-positive Black women activists. I believe that living out loud—to publicly come out as a Black woman living with HIV— is a political act unto itself. In contrast to African American women activists of the past, the act of publically coming out as a seropositive Black woman is revolutionary and in and of itself a radical and subversive political act. HIV-related stigma and discrimination can be so damaging that it can disrupt women's efforts toward solidarity by positioning some Black women as seemingly deserving of a seropositive diagnosis and others as victims (Hammonds, 1997). To proudly stand up to these stereotypes, harsh character judgments, gender/class hierarchies and to challenge patriarchal

constructs is a subversive. As such living out loud is a technique specific to HIV-positive Black women's activism, a new activist strategy that can be added to the literature on Black women's community-based political participation.

Tammie's, Tess', and Bobbi's AIDS activism is similar to legions of African American women foot soldiers before them who lived in areas where income inequality was pervasive and where community-based political participation was grounded in nurturing and motherwork (Naples, 1998; Collins, 2000). Black women's organizing at the community level typically engages with power structures, their social networks such as family and friends, and the larger community to which they are connected. When it comes to activist mothering and HIV/AIDS activism, Bobbi and Tess' standpoint in particular, indicate that families can be pivotal in intervening and preventing HIV/AIDS (Gilbert & Wright, 2003). Gilbert & Wright (2003) note that developing work suggests that "family-based" prevention are essential for successful interventions among African Americans, especially programs that target mothers for prevention while simultaneously instructing them on teaching their daughters (Gilbert & Wright, 2003).

Life reconstruction is to redesign, enlarge, and start anew as a woman living with HIV (Berger, 2004). Living as a reconstituted woman argues Berger (2004) can initiate the emergence of a personal "public voice" (p. 16). Personal voice is crafted by women who embrace their serostatus, accept the political and gendered consequences of speaking out, name their oppressor(s) and claim their identity; a decidedly feminist principle (Berger, 2004; Collins, 2000). Norma named her oppressor (people who do not want to get close to her because she is HIV-positive) and regardless of being alienated, she makes the claim that she is a survivor. Mary named some of her co-workers as oppressors and suggests that positive people collectively come out and claim their identity as subversives. Ultimately, standpoints that call for women to come out are feminist (even if the women do not self- identify as feminist themselves). I believe that one of the most radical things that an economically challenged HIV-positive Black woman can do is to come out. Reconstituted participants note that the best way to politically participate is to rebelliously oppose the status quo of shame and silence in order to restore themselves, to "live," to "survive," and to have a "beautiful" life.

Conclusions

The canon on Black women's activism argue that definitions of political participation encompass the wide range of activities that African American women engage in including grassroots organizing, direct action, community work, and activist mothering. This project focuses on the political participation of HIV-positive Black women living in communities that already lacked an economic base, social capital, resources, and institutional structures before the HIV/AIDS epidemic, working to restore themselves and their communities. I illustrate the personal agency of seropositive Black women through the narratives of thirty HIV-positive Floridian Black women and situate their political participation in the fight against HIV/AIDS within the canon of Black women's political participation around these emerging themes: 1) face-to-face activism 2) activist mothering, and 3) publically coming out as women living with HIV/AIDS.

Gay men's AIDS activism is documented in the literature and they are in decision-making positions in organizations and institutions in the community, government, public health, and so forth, as it pertains to HIV/AIDS. HIV-positive Black women are mostly missing from the equation. Since gay seropositive men hold high positions in formal prevention and intervention, HIV-related stigma is not the culprit in the dearth of seropositive African American women. If stigma is a non-issue, then is it possibly gender, race, or class discrimination? Is it possible that overlooking HIV-positive Black women is due to fear that they will demand a larger share of the already too small HIV/AIDS budget? Regardless of the reason, I submit that since the major players in HIV/AIDS prevention and intervention rarely partner with HIV-positive African American women it has hindered their ability to find viable solutions. Black women have historically been at the forefront of major community crisis and have used the tenets of Black women's political participation to address and sometimes resolve community crisis; Black women's political participation works.

Study participants' narratives demonstrate that vital work is being done even though it may be invisible to many in the public health arena. African American women's organizing around HIV/AIDS, however, is an emergent topic and might be useful with multiple and more extensive studies. Participants' standpoints are similar to that of Mary J. Blige; calling on public health officials, the medical community, research scientist, and interventionists to "Work What You Got." To use the situated knowledge of HIV-positive Black women already on the ground

fighting to reconstitute their lives and reclaim their communities and turn around the HIV/AIDS pandicemic in Black America. Just like President Obama used the tenets of Black women's political participation from "Obama's Mama's" and won an unprecedented election so too can health professionals gain a foothold in HIV reduction by incorporating HIV-positive Black women and their tenets of community-based political participation as central to prevention in the African American community.

References

Akeroyd, A. (1994). Gender, race, and ethnicity in official statistics: Social categories and the HIV/AIDS "numbers game." In H. A. & M. Maynard (Eds.), *The dynamics of 'race' and gender: Some feminist interventions* (pp. 63-81). London: Taylor & Francis.

Banzhaf, M. et al., (Eds). (1992). *Women, AIDS, and activism by the ACT UP/New York women and AIDS book group*. Boston: South End Press.

Berger, M. T. (2004). *Workable Sisterhood: The political journey of stigmatized women with HIV/AIDS*. Princeton: Princeton UP.

Blige M. J., Garret, S. & Feemster, T., (2007). *Work That*. Retrieved March 23, 2014 from: http://en.wikipedia.org/wiki/Work_That

CDC, Centers for Disease Control and Prevention. (2012). New HIV infections in the United States. Retrieved March 22, 2013. From: http://www.cdc.gov/nchhstp/newsroom/docs /2012/hiv-infections-2007-2010.pdf.

Collins, P. H. (2000). *Black feminist thought: Knowledge, consciousness, and the politics of empowerment*, 2nd ed. New York: Routledge.

Farmer, P. (1996). Women, poverty, and AIDS. In P. Farmer, Connors, M. & J. Simmons (Eds.), *Womenp poverty and AIDS: Sex, drugs and structural violence* (pp. 3-38). Monroe: Common Courage.

Gilbert, D. J., and E. M. Wright. (Eds). (2003). *African American women and HIV/AIDS: Critical responses*. Westport: Praeger.

Glick Schiller, N. (1992). What's wrong with this picture? The hegemonic construction of culture in AIDS research in the United States. *Medical Anthropology Quarterly*, New Series, 6 (3), 237-254.

Glick Schiller, N., Crystal, S., & Lewellen, D. (1994). Risky business: An examination of the cultural

construction of AIDS risk groups. *Social Science & Medicine*, 38 (10), 1337-1346.

Gilkes, C. T. (1994). "If it wasn't for the women…": African-American women, community work, and social change." In M. Baca Zinn & B. Thorton Dill (Eds.), *Women of color in U.S. society*, Philadelphia: Temple University Press.

Grayson, D. R. (1999). "Necessity was the midwife of our politics": Black women's health activism in the "post"-civil rights era (1980-1996). In K. Springer (ed.), *Still lifting, still climbing: African American women's contemporary activism*, (pp.131-48). New York: New York University Press.

Guy-Sheftall, B. Ed. (1995). *Words of fire: An anthology of African-American feminist thought.* New York: The New York Press.

Guy-Sheftall, B. Preface: African American women redefining activism for the millennium." In Kimberly Springer (Ed.) *Still lifting, still climbing: African American Women's contemporary activism*. New York: New York University Press.

Hammonds, E. M. (2009). "AIDS the secret, silent, suffering, shame." In S. M. James, F. S. Foster & B. Guy-Sheftall (eds.), *Still brave: The evolution of Black women's studies*, (pp. 268-280). New York: The Feminist Press.

Harris, A. (2012). Black feminist AIDS activism: A profile in Afrocentric humanism. August, 16 Paper presentation. American Sociological Association Annual Meeting, Denver, CO http://research.allacademic.com/one/www/www/index.php?cmd=www_search& offset=0&limit=5&multi_ search_search_mode=publication&multi_search_publication_fulltext_mod=fulltext&text field_submit=true&search_module=multi_search&search=Search&search_field=title_idx &fulltext_search=Black+Feminist+AIDS+Activism%3A+A+Profile+in+Afrocentric+Hu manism

Hine, D. C. (1989). *Black women in white: Racial conflict and cooperation in the nursing profession, 1890-1950*. Bloomington: Indiana University Press.

Hunter, T. W. (1997). *To 'joy my freedom: Southern black women's lives and labors after the civil war*. Cambridge: Harvard University Press.

James, J. (2009). Resting in the gardens, battling in the deserts: Black women's activism. In S. M. James, F. S. Foster & B. Guy-Sheftall (eds.), *Still brave: The evolution of Black women's studies*, (pp. 363-371). New York: The Feminist Press.

Kalichman, S. C., Kelly, J. A., Hunter, T. L., & Murphy, D. A. (1993). Culturally tailored HIV-AIDS risk-reduction messages targeted to African-American urban women: Impact on risk sensitization and risk reduction. *Journal of Consulting and Clinical Psychology*, 61 (2), 291-295.

Kim, M. Y., Marmor, M., Neil, D., & Wolfe, H. (1993). HIV risk related sexual behaviors among heterosexuals in New York City: Associations with race, sex, and intravenous drug use. *AIDS* (7), 409-414.

Kuumba, B. M. (2001). *Gender and social movements*. Lanham: Rowman & Littlefield Publishers, Inc.

Lane, S. D., Rubinstein, R. A., Keefe, R. H., Webster, N., Cibula, D. A., Rosenthal, A., et al., (2004). Structural violence and racial disparity in HIV transmission. *Journal of Health Care for the Poor and Underserved*, 15.

Melton, M. L. (2007). *Positive perspectives on prevention: Southern women's voices on HIV/AIDS in an African American community*. (Doctoral Dissertation). Available from ProQuest Dissertations and Theses database. (UMI No. 3278530)

Miami Herald, (2014). Role models reach out to Miami-Dade youths for black world AIDS day. Retrieved March 23, 2014 from: http://www.miamiherald.com/2014/02/06/3917870/role-models-reach-out-to-miami.html

Naples, N. A. (1992). Activist mothering: Cross-generational continuity in the community work of women from low-income urban neighborhoods. *Gender & Society*, 6 (3): 441-63

Naples, N. A. (1998). Women's community activism: Exploring the dynamics of politicization and diversity. In N. A. Naples (ed.). *Community activism and feminist politics: Organizing across race, class, and gender*, (pp. 327-349). New York: Routledge.

Reissman, C. K. (1993). *Narrative Analysis (Vol. 30)*. Newbury Park: Sage.

Schneider, B. E., & N. E. Stoller. (1995). *Women resisting AIDS: Feminist strategies of empowerment*. Philadelphia: Temple University Press.

Scott McBarnette, L. (1996). African American women. In M. Bayne-Smith (Ed.), *Race, gender and health* (pp. 43-67). Thousand Oaks: Sage.

Springer, K. (1999). Introduction: African American women redefining activism for the millennium." In Kimberly Springer (Ed.) *Still lifting, still climbing: African American women's contemporary cctivism* (pp.1-16). New York: New York University Press.

Singer, M. (2001). Health, disease and social inequality. In I. S. & T. C. Patterson (Eds.), *Cultural*

diversity in the United States (pp. 76-100). Malden: Blackwell

Sharpe, T. T. (2005). *Behind the eight ball: Sex for crack cocaine exchange and poor Black women*. New York: The Haworth Press.

Smith, B. & Lorde, A. (1980). Interview with Barbara Smith. In *Alexis Pauline Gumbs Talks about Kitchen Table: Women of Color Press* (by) Harriet Staff. Retrieved March 23, 2014 from: http://www.poetryfoundation.org/harriet/2012/06/alexis-pauline-gumbs-talks-about-kitchen-table-women-of-color-press/

Smith, D. (1987). *The Everyday World as Problematic.* Toronto: University of Toronto Press.

Sobo, E. J. (1995). *Choosing unsafe sex: AIDS risk denial among disadvantages women*. Philadelphia: University of Philadelphia.

Watkins, B. X., Fullilove, R.E., and Fullilove, M.T. (1998). Arms Against Illness: Crack Cocaine and Drug Policy in the United States. *Health and Human Rights, 2(4)*, *HIV/AIDS and Human Rights. Part I: The Roots of Vulnerability*, 42-58.

Williamson, M. (2003). Life transformations of HIV-positive African American women: Theories and evidence of change. In Gilbert, Dorie J., and Ednita M. Wright. (eds.) *African American women and HIV/AIDS: Critical responses* (pp. 107-139). Westport: Praeger.

Wingood, G. M., & DiClemente, R. J. (1998). Partner influences and gender-related factors associated with noncondom use among young adult African American women. *American Journal of Community Psychology*. *Special Issue: HIV/AIDS Prevention Through Community Psychology*, 26 (1), 29-51.

Whitehead, T. L. (1997). Urban low-income African American men, HIV/AIDS, and gender identity. *Medical Anthropology Quarterly*, 11 (4), 411-447.