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Still I Rise: The need for self-validation and self-care in the midst of adversities faced by Black women with HIV

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Abstract

Objectives—Psychosocial factors of trauma and abuse, racial discrimination, HIV stigma, and gender-related stressors (e.g. prioritizing others' needs) have been associated with antiretroviral treatment (ART) nonadherence and poor viral suppression among Black women living with HIV (BWLWH). To inform the development of an intervention addressing these psychosocial factors to improve ART adherence, we sought the insight of BWLWH.

Methods—Qualitative semi-structured interviews were conducted with 30 BWLWH to gather information on their experiences with trauma, racism, HIV stigma, gender-related stressors, ART adherence, and coping strategies, and their insights on the proposed intervention. Participants' interviews were audio-recorded, transcribed, and coded using thematic content analysis and grounded theory.

Results—Participants shared (a) their experiences with trauma/abuse, racism, HIV-stigma, gender-related stress, and medication adherence, (b) coping strategies they use (e.g. social support, awareness [acknowledging systemic racism], assertiveness, selective disclosure of HIV status, and prioritizing the self) (c) how each of these adversities relate to their medication adherence and how they found ways to self-validate and practice self-primacy and self-care, including medication adherence in spite of adversities, and (d) enthusiasm for the proposed intervention.

Conclusions—Culturally adapted interventions are needed to improve the health of BWLWH by enhancing coping strategies for the multiple adversities they face and promoting self-validation, self-primacy, and self-care in spite of adversities.

Keywords

Black Women; HIV; Trauma; Coping Strategies; Medication Adherence

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Introduction

Black women represent 62% of women living with HIV in the United States and HIV is the leading cause of death of Black women ages 24–35 (Centers for Disease Control and Prevention, 2016). HIV is a manageable and chronic illness that requires a high level of consistent adherence (at least $\geq 80\%$ depending on regimen) to antiretroviral therapy (ART) (Bangsberg et al., 2000). However, in samples of predominately minority women the estimated rate is 45% to 64% (Simoni et al., 2012; Howard et al., 2002). Risk of HIV virologic failure is higher among Black women compared to White and Latina women (McFall et al., 2013). Common adversities among Black women living with HIV (BWLWH) such as trauma, racial discrimination, HIV stigma, and gender-related stressors have been linked to medication nonadherence (Shacham, Basta, & Reece, 2008).

Rates of abuse/trauma and post-traumatic stress disorder (PTSD) are high among women with HIV. A meta-analysis of women with HIV (Machtinger, Wilson, Haberer, & Weiss, 2012) found a 55% rate of intimate partner violence more than double the US national average and estimated a 30% rate of recent PTSD over five-times the rate in a national sample. Abuse/trauma has been linked to negative health outcomes for women with HIV, including HIV medication nonadherence, antiretroviral failure, and increased mortality (Leserman et al., 2007; Machtinger et al., 2012).

Racial discrimination, which may also be traumatic, is also high among Black women (Kelso et al., 2013). The Black Women's Health Study found high rates of discrimination on a monthly basis with 66% of women reporting discrimination in one or more of three situations (on the job, in housing, and by the police) (Mouton et al., 2010). Black women also experience micro-aggressions, which are daily words and behaviors that are brief yet insulting to marginalized groups (Sue et al., 2007). Among BWLWH, researchers found that when racial discrimination was high, higher critical consciousness (an awareness that social oppression exists on a systemic level) was found to be related to higher CD4+ counts and lower likelihood of detectable viral load (Kelso et al., 2013). Researchers have also found that HIV and race-related discrimination is longitudinally associated with non-adherence to ART among African American men (Bogart, Wagner, Galvan, & Klein, 2010).

Beyond racial discrimination, BWLWH also face HIV-related discrimination, which have negative health correlates and behaviors. Researchers (Wingood et al., 2007) found that African-American women who reported HIV discrimination scored higher on stress, depressive symptoms, unprotected sexual episodes; scored lower on self-esteem; and were less likely to seek medical care for HIV.

In addition to HIV- and race-related discrimination, BWLWH are socialized with traditional female gender roles, which are higher among women with HIV (Brody, Stokes, Dale, et al., 2014). Traditional female gender roles include the coping strategy of self-silencing (self-needs are not expressed in order to avoid relational loss and conflict) and care-as-self-sacrifice (sacrificing self-needs in order to care for others) (Jack & Dill, 1992). Among Black women there is an integration of traditional and nontraditional gender roles (e.g. assertiveness) (Malson, 1983; Morris, 2007). Black women are also subjected to the strong

Black women stereotype, which expects them to “withstand male rejection, economic deprivation, crushing family responsibilities, and countless forms of discrimination” (Radford-Hill, 2002, p 1086)”. Traditional gender roles have been associated with higher depressive symptoms (Brody, Stokes, Dale, et al., 2014) and lower ART adherence for women with HIV (Brody, Stokes, Kelso, et al., 2014).

Despite predominantly quantitative research noting associations among trauma/abuse, racial discrimination, HIV-related discrimination, gender-related stressors and ART adherence (Logie, James, Tharao, & Loutfy, 2013), the literature has not captured the voices of BWLWH, for whom these issues are a lived reality, to elucidate how these adversities may be connected to ART adherence. Further, there might be unique ways of coping that BWLWH utilize to cope with these co-occurring adversities.

There is no existing intervention to address these adversities together as they relate to ART adherence, and women’s voices are needed to assess whether there is a desire for an adapted intervention. A limited number of studies specifically addressing trauma among individuals with HIV have shown significant effects on trauma symptoms and sexual risk, but not medication adherence. An 11-session Enhanced Sexual Health Intervention among women with HIV and a history of childhood sexual abuse by Wyatt and colleagues (2004) found a decrease in sexual risk, but no overall difference on medication adherence for women in the intervention compared to the control group. A cognitive behavioral stress management intervention among women with HIV also found a reduction in psychological symptoms (e.g. depression) and an improvement in health-promoting behaviors (e.g. medication adherence) (Jensen, Pereira, Whitehead, et al., 2013). Similarly an emotional disclosure intervention among women with HIV led to a decrease in trauma and depressive symptoms (Ironson, O’Cleirigh, Leserman, et al. 2013; Weiss, Tobin, Antoni, 2011). Trauma-focused and stress management interventions for women with HIV exclude critical discrimination experiences for Black women with HIV. Researcher have noted that discrimination (e.g. race- and HIV-related) is a key mediator of the relationship between posttraumatic stress symptoms and ART adherence among African Americans, with discrimination being the sole predictor of adherence when both PTSD and adherence were included in the model (Wagner, Bogart, Galvan, Banks, & Klein, 2012). In addition, several existing interventions incorporating gender empowerment have demonstrated efficacy in reducing sexual risk behaviors (DiClemente & Wingood, 1995; Wingood et al., 2004), but there is currently no efficacious intervention for women with HIV that incorporates gender roles and empowerment (e.g., assertive communication with providers) to address medication adherence.

We qualitatively sought the insights of BWLWH on how they cope with multiple adversities and their thoughts on a proposed adapted intervention. Findings may inform the development of a novel intervention (Striving Towards Empowerment and Medication Adherence [STEP-AD]) to enhance coping strategies for trauma, racial discrimination, HIV-related discrimination, and traditional female gender roles and improve medication adherence.

Methods

Participants

Participants were recruited in Boston, MA between June and September of 2015. Flyers and posters were distributed at local community-based organizations, community health centers and clinics, and community events. Once participants called the study research coordinator (a Black female) they were screened for eligibility via phone. To be eligible participants had to meet the following inclusion criteria (1) Identify as Black and/or African American (2) Age 18 or older (3) Biologically female (4) English speaking (5) Prescribed ART for at least the last two months and (6) History of abuse/trauma (i.e., responding “yes” to “During your lifetime have you experienced trauma or abuse?”). At the study visits participants gave informed consent prior to engaging in the study and were given \$25 to reimburse them for their time and efforts. All study procedures were approved by the Institutional Review Board of Partners HealthCare.

Measures

Self-report Sociodemographic Survey—Participants completed a self-report sociodemographic survey via Research Electronic Data Capture (REDCap, a secure web-based application; Harris et al., 2009). The survey asked for information on their age, number of children, relationship status, sexual orientation, country of birth, education level, employment status, living situation, years since HIV diagnosis, years on ART, self-reported ART adherence in the past two week, viral load, and CD4 count.

Semi-structured Interview—Individual, semi-structured qualitative interviews (60–90 minutes) asked about the following topics, with appropriate probes for follow up: (1) experiences with trauma, racism, HIV stigma, gender roles expectations, and medication adherence, (2) strategies to cope with adversities and promote medication adherence, and (3) perceptions about the need for and acceptability of a potential integrated treatment for trauma symptoms, racial discrimination, HIV discrimination, gender related stressors, and medication adherence for BWLWH. Table 2 lists sample questions from the interview guide.

Analyses

Interviews were conducted and audio-recorded by a Black female Clinical Psychologist with extensive training (over 10 years of experience) in conducting qualitative interviews. Audios were transcribed by a Black bachelor's level female research assistant. A coding manual for themes was developed by the Clinical Psychologist and research assistant by independently coding nine participant narratives, noting common themes that emerged, and then arriving at a consensus about the themes together. Themes were defined and accompanied by exemplary quotes in the manual. This manual was then used by the research assistant to code all 30 narratives (including recoding the initial 9) with NVivo, a qualitative data analyses program (Gibbs, 2002). All coded narratives were reviewed by the Clinical Psychologist.

Results

Thirty BWLWH were recruited and participated in this study. Participants' sociodemographic characteristics are presented in Table 1. In short, women's average age was 46 (range = 33 – 65), 73% reported an undetectable HIV viral load, 50% self-reported excellent ART adherence in the past two weeks, and their average years since diagnosis was 17 (range = 6 – 30).

Coding participants' interviews revealed informative themes on (a) BWLWH's experiences with trauma, racism, HIV-related discrimination/stigma, and gender-related stressors, (b) coping strategies that women utilize, (c) how women perceive the connection between their adverse experiences and their medication adherence, (d) general facilitators and barriers to medication adherence, and (e) women's desire for an adapted intervention for BWLWH.

Experiences of Adversity

As individuals who are simultaneously Black, women, and HIV-positive, the stories of adversities told by Black women living with HIV sometimes overlapped and reflected the intersectional nature of discrimination, trauma, and gender roles in their lives. For instance, one woman spoke of being mistreated at a hospital and attributing her treatment both to her race as a Black woman and being HIV-positive.

“I experienced it not only because I was Black but because I was HIV [positive]. I had my knee replacement and I was on my period...The nurse came in and she threw the pads at me, I felt like she felt like I was contagious... The guy [staff] came in and he's like 8 “Well you got the virus and you need to take your meds and he was at the door yellin' this, everybody else can hear.” - 1012

Similarly, another participant talked about being treated poorly (due to her race and HIV status) by police officers after a traumatic experience in which her roommate physically assaulted her.

“I got scratched all on my face, blood was runnin' down my face, ...and in the middle of that when the police was called you know they just stood there and looked at me...I'm the victim and nobody acknowledged that being an African-American woman who has HIV. I was traumatized.” -1023

While women experienced their adversities as intersectional beings, they often shared stories that were specifically about trauma, racism, HIV-discrimination or gender roles.

Trauma—The majority of women shared stories of experiencing sexual, physical, and verbal/emotional abuse/trauma that occurred both in childhood and in the context of intimate relationships (i.e. intimate partner violence) as adults. In addition, many women talked about witnessing intimate partner violence at home as children, witnessing violence in their communities, and losing loved ones to community violence. It was more often the case that women had experienced multiple traumas/abuse and rarely the case that they only experienced one instance of trauma. For instance, one woman shared how she was molested in childhood by a stepfather, witnessed her mother being physically abused by her stepfather, and was physically abused by her own partners as an adult.

“My step-father used to molest [me] when I was young. And [I’ve been] in abusive relationships too.... my oldest daughter’s father he used to beat on me... I don’t see my moms beaten so bad by my step-father.” – 1010

Another woman lost her son who was a young adult to community violence and another participant and her young adult daughter witnessed the killing of a boy.

“I didn’t see the actual shot and everything but I still lost a child. Had to come down to the yard [outside the home] and find my child lying on the grass dying, do you understand what I’m saying?.. You know somebody took my son’s life and I’m mad about it still.” – 1018.

“Me and my daughter just seen this boy get killed right in front of my doorstep... We were coming out the door and all I heard was gun shots right in front of my door step. My daughter called 9-1-1 and they [police] moved us that night so we’d be protected.”- 1001

Discrimination—Women shared stories of being discriminated against due to their race and HIV-positive status. Women spoke about experiencing racial discrimination at the institutional level (e.g., law enforcement, health institutions, retail stores) and the interpersonal level primarily from white individuals (e.g., strangers, acquaintances). Similarly, women shared stories of being discriminated against based on their HIV status at the interpersonal level by family, friends, and others who knew their status as well as at the institutional level by those in law enforcement, housing, healthcare, and churches. Many women shared explicit instances of racial discrimination from the past and subtle behaviors and microaggressions in their current lives.

One participant (who was a nurse) spoke about attempting to perform CPR on a child who had fallen in a pool and having the child’s mother yell at her to not do CPR because of her race.

““Hell no oh no, don’t you put your Black a** lips on my child’...And that rocked my world. I looked at the mom, tears coming down my face “I’m trying to save your daughter.” She said “don’t put your black lips on my child.” -1030

Another woman shared how children threw rocks at her. “They was throwin’ rocks at me ‘cause I had AIDS. Young kids.” -1029

In regards to the subtler forms of discrimination/microaggressions one participant described that she was often followed while shopping in stores based on her race and another participant talked about hearing conversations that others have about not wanting to associate with persons with HIV.

“As recently as a couple of months ago this guy a security guard followed me around Walgreens. I said [to him] ‘if I was gonna steal something let it be a Brinks truck. I’m not gonna go to jail for no hair dye or something like that. [laughs] I’m not gonna be banned from a store over a bottle of shampoo’.” -1014

“You could hear ‘em other convos [conversations] like, ‘oh I don’t wanna be around anybody who got AIDS’.” -1009

Gender-related Stressors—In conjunction with the aforementioned adversities, as women participants also faced gender-related stressors that they shared. Many of the stress and expectations were experienced in their gendered roles as mothers, intimate partners, sisters, and daughters. Women talked about the overall stress of being a caretaker for children, partners, and other family members, as well as expectations to (a) put others first and neglect themselves, (b) complete domestic chores, and (c) be “lady-like” in their behavioral presentations. As two women briefly stated “They expect me to be perfect ... They expect too much of me sometimes.” -1004 and “Being clean, being mindful, courteous, sensitive to and nurturing to other’s needs.” – 1022 Another woman spoke in-depth about the impact of gender roles on her well-being:

I took care of my mother for three years during the whole time that she had cancer. So I was getting my kids ready for school, going to her house, getting her ready, taking her to the doctor, going back to her house, cooking for her and then cooking for my kids. For three years I did this and all along I wasn’t taking care of myself. I was losing weight, I wasn’t eating because I was too busy running. So the next best thing for me to do that I thought was taking care of myself was to use drugs just to keep me energetic and going back and forth. I’m a caretaker...but nobody takes care of me... My family... expect me to go above and beyond.” – 1011

Coping with Multiple Adversities

Women reported various strategies to cope with trauma/abuse, Black-related discrimination, HIV-related discrimination/stigma, and gender-related stressors. For trauma and abuse common strategies included social support, spirituality, counseling/psychotherapy, adaptive activities, and avoidance. A participant talked about avoiding people and the traumatic memories – “Have a good drink and go for a walk. I stop socializing with other people. And then I just forget.”-1019. Another participant explained that she used spirituality and social support to cope with trauma “I pray, I used to use drugs. But I pray, I pick up the phone and I use my support.”-1012 Similarly, another woman spoke about using spirituality in conjunction with receiving psychotherapy and seeing a psychiatrist to cope with past trauma.

“I was beaten very bad. I was sexually abused and everything with this- with this man...I was so afraid of being around men. Of them coming near me, I would panic... I got myself in therapy. I have a psychiatrist that I see...I pray on it, I started to go back to church.” -1013

Social support was also a common coping response for racial discrimination and HIV-related discrimination. Social support was obtained via conversations with family, friends, community members, and professionals (e.g. psychotherapists), as one participant shared - “there’s people that I can go talk to” and “I go to groups so then I’d see a lot of people that made me change. I felt like I wasn’t alone.” -1004 Similarly another woman talked about seeking support from her family when she experiences racial discrimination, but not police officers because they were unhelpful to her son when he sought their help. “I call my children first if anything bad happens to me. Law enforcement? No, I’m not calling them... They heard what everybody else said but my son.” -1005

Ignoring the perpetrator was also a way that women dealt with being treated unfairly based on their race and HIV status. For instance, a participant talked about experiencing interpersonal racism from a White woman in a store who refused to move her cart to make space for her.

“I just walk away. I go up to the next place. It’s not worth- I’m not gonna get my blood pressure up and stuff like that over nonsense when I can just avoid it and just go to the next place. That’s how I see it.” -1010

Another participant described how her aunt did not want her to eat next to her because of her HIV status and she ignored her and continued sitting and eating. “I was out here with my aunt .. she didn’t want me to eat near her...And I was like “oh I’m gonna sit right here whether she like it or not.” -1001

Unique to the way in which our sample of BWLWH talked about coping with racial discrimination was a blend of awareness, assertiveness, and caution. Women talked about being aware that racism exists in America, that it will continue throughout their lifetimes, and that it is a burden that they share with other Black and nonwhite individuals. As one woman stated “I lived in a boarding school growing up, yeah there was always...my color has always been an issue.” -1019. However, women were not simply resigned to the existence and fate of racism. Instead they strategically chose whether and how they responded in situations. Many women also talked about being assertive. For example, one participant explained how she asserted herself with a store employee who followed her.

“She’s following me around the whole store so finally I asked her. Why are you following me around? She told me ‘cause I’m a Black person and Black people steal. I said now hold on, not all Black people steal.” -1016

Women also exercised caution in the presence of perpetrators and were mindful of the tone of their voices and related behaviors in order to avoid escalation, fearing that perpetrators of discrimination would call the authorities on them. As two women stated “I had to learn to watch my mouth, what comes out of it now.” -1005 and “Because if I hit them, they may call the police. You know, it’s with White folks. They easy to talk about you or try to put you down.” -1019

In discussing the coping strategies that they used to cope with HIV-related discrimination women often talked about selective/non-disclosure of their HIV status, education/ knowledge, and avoidance. For instance, some women spoke about choosing to selectively disclose with family members and intimate partners, but not others such as neighbors/ roommates or police officers. As two participants individually explained: “I just feel that long as my family know and if I’m in a relationship they know, I’m good. That’s how I look at it.” -1010 and “You’re just the arresting officer. I don’t have to tell you...No, I don’t have to tell anybody. It’s my choice to tell.” -1015

Other women elaborated on how they sought out knowledge about HIV and related discrimination in order to educate others and cope with the stigma. “Educating yourself and spreading knowledge regarding the impact of HIV, stigma, and/or discrimination.” - 1027 Some women also avoided certain places that are traditional spaces for healing in Black

communities out of fear that they will be stigmatized based on their HIV status. “They’re hypocrites...That’s why I don’t go to especially Black churches.” -1027

Commonly reported coping responses for gender-related stressors were prioritizing the self, spirituality, helping others, self-love, and self-sacrifice. Specifically, when faced with gender expectations such as sacrificing their needs to care for family or partners, women talked about focusing on themselves (“I refuse to put myself on the backburner for anybody anymore.” -1012), connecting to their spirituality (“Maybe it was a spiritual awakening...I have to help myself first or I can’t help anyone.” – 1011), and continuing to help others and sacrifice for others as a way to show they care. A participant explained that “to take care of [her] son” is very important to her and “during the winter [she] was walking around in his hand me down shoes...because [she] couldn’t afford a pair of shoes for [herself] because he was walking around in the best pair of shoes.” -1014 Other women also spoke about having the awareness that they prioritize others and working to change that gradually. As one women stated “I will give someone my last and go without and I’m a work in progress. I’m trying to work on that because I shouldn’t do that to myself.”-1011

While the use of alcohol and drugs was not a coping strategy commonly discussed in the present interviews by women as a way of coping with trauma, racial discrimination, HIV-related discrimination, and gender roles, a couple of women did draw a connection between their history of substance use and coping with adversities. For instance, one woman described drinking to cope with the memories of being raped “I used to drink like 6 [drinks] basically every single day. I would buy a gin for \$5.99 and that’s how I just solved my problems. But then I had to stop.”-1002

Connections between adversities and health

Women shared ways in which trauma, HIV stigma, racism, and gender roles related to their self-care and medication nonadherence. Women also shared how they continue to take their medications in spite of trauma, racism, and HIV-stigma. Women explained how trauma, racism, and HIV-related discrimination led to depression, anger, a sense of resignation, not practicing self-care (i.e., not taking their HIV medication), and disengagement from medical care (e.g. not attending appointments). As one participant said,

“He would act so...he would act so funny towards me. That’s right and he used to treat me so bad [emotional/verbal abuse]. He used to put me out at 2 o’clock in the morning in his house.. I mean he messed with me. At one certain time I was so, when he hurt me I was in big. I just didn’t even wanna take my medicines. I was depressed.” -1001

Another woman talked about not wanting to take her medication because of HIV stigma and the medication serving as a reminder of her status. “It tears me down ‘cause if I don’t have the medicine I don’t have the virus. The whole world picks on me so I don’t wanna have it no more 16 so I don’t have to take that med.” -1029, Similarly, another women spoke about not attending appointments or talking medications because of internalized HIV stigma

“I would skip appointments and miss appointments because I didn’t wanna deal with the subject [HIV]. You know, it was just basic blood work you know where

they check me out. I was angry inside. I couldn't deal with the fact that I had it. You know and I didn't wanna take it, I hate pills.”-1019

When asked how a racial discrimination experience affected her medication adherence, one woman explained how she would go into a negative mood and stop taking her medication.

“I find myself not like liking my skin. It kind of made me not wanna go out. This is like okay, nobody likes dark skin so I might as well stop doing what I'm doing and just deteriorate yeah, that's true. I would just go on a F***-it mood. Like F*** everything, I don't care about nothing until I get real sick and then I'm like okay, I do care.” -1030

In terms of gender roles, women shared how gender role expectations led to them sacrificing their own needs and neglecting their self-care (e.g. taking medications, attending appointments) in order to care for others. As two women poignantly stated

“I wouldn't keep my appointments...Because I was doing something else for someone else... I wanted their approval and I wasn't taking care of myself.” -1020

“Cause I'm too busy taking care of them and other people, I don't have time to take my medication. 'Cause I felt like a little slinky. Like boing, boing, you know, back and forth. It only takes 2.5 seconds to pop a pill and I didn't. Because I felt that was too much time I was takin' away from them.” -1011

Beyond noting the negative connections between the adversities and not taking HIV medications, women also shared how they continue to take their medications in spite of trauma, racism, and HIV-stigma. Despite histories of multiple traumas women explained that they were able to draw on an internalized self and sense of power, put their needs first (self-primacy), take their health seriously, and view their children and grandchildren as a source of purpose/motivation to keep taking their medication and live a healthy life.

A woman spoke about having an internalized power and focusing on taking her medication and managing her HIV in spite of trauma.

“I don't need to worry about whether I'm gonna come in the house and you're gonna punch me in my face... That's not what I wanna worry about...I got other things. To make sure I take my meds between 7:30 and 9:30 in the morning and at night. ...I will get hit by a mack truck before I allow the HIV to kill me.” -1015

Women also talked about owning their internalized self/power as a way to thrive in the face of racism and keep taking their medications.

“I'm a strong individual and I'm gonna continue to be strong, continue to live no matter what you think about me or my color. I'm gonna show them you know. I'm gonna try to look good, be healthy, be active, regardless of what nobody thinks. I'm gonna do what I got to do to survive with this HIV. I'm gonna pay attention to what the doctors tell me, go to the doctors on cue, and take my medicine on time.”-1006

Similarly, women noted that practicing self-primacy and taking their health seriously helped them to take their medication in spite of HIV-related discrimination or stigma.

However, unique to coping with HIV-related discrimination, women talked about how HIV-wasting may lead to potential discrimination so they take their medications in order to avoid HIV-wasting. Two women shared these sentiments below.

“It’s very important (ART adherence) because as long as I’m healthy, and I look healthy...the people that don’t know or they soon find out...it’ll blow their minds.”
-1019 “I take care of myself in part to keep myself healthy looking so that I don’t have to deal with people who look at me and say do you have AIDS? Do you have the virus? It’s not that I’m ashamed of it or anything, it’s just that I don’t want to live my life with people walking around and pointing fingers. So I take care of myself, I go to my doctors, I very seldom miss an appointment, and I do the best I can with my meds”- 1003

General Facilitators and Barriers to Adherence

In general women also talked about common facilitators and barriers to their medication adherence independent of trauma, HIV-related discrimination, racism, and gender roles. Commonly reported facilitators for adherence among the women were (a) having family members (e.g. children, siblings) who provided social support and reminders to take their medications, (b) having a set routine/schedule for taking their medications (e.g. meal-time), and (c) having convenient/organized pill storage. For instance, one participant talked about her mother and sister reminding her to take her medication on a daily basis.

“My mom and my sister. Did you take your meds today? Yes I did. Did you take your meds because me and my mother have a thing. My mother’s not good at taking her medication so we remind one another, you know? My sister she does it out of concern ‘cause my sister works in the medical field and she just wants to make sure you know, I’m taking my medication. ‘Cause she knew about the breaks, you know? The med vacations,.”-1020

Many women also spoke about the importance of having a set time or routine for when they take their medication. For instance, mealtime (“I just know when I eat supper I take it.” -1004) and TV programs may serve as reminders (“They usually have a talk show until 8 o’clock. So after 8 o’clock, a movie comes on. Pop it [medication] in, lay down and look at the TV.” -1008)

Factors that served as barriers to women’s adherence included (a) being busy and feeling tired from completing daily tasks, (b) being tired of taking the medications and (c) being active substance users. One women stated “I’m tired of being little Miss pill popper” and another said “I used to say no I don’t want no medication I’d rather get high.” -1023

Desire for an adapted intervention

After being provided with an overview of the proposed intervention (Striving Towards EmPowerment and Medication Adherence [STEP-AD]) to address the discussed adversities and facilitate medication adherence, participants expressed overwhelming enthusiasm for the proposed intervention. For instance, participants stated “This is exactly what people need” and “I think that it would be an excellent idea and I think it would be very very very

beneficial.” Another participant spoke in-depth about why this adapted intervention is needed

“That would be perfect and by me sharing my experiences and my strengths and my hopes, just now and revealing my life in that just little bit of time that it would help other women to let them know that they’re not alone. And have somebody, somewhere they can go to express that, deal with it, so that they can heal.” –1012

Participants also talked about the importance of having a Black woman as the interventionist because participants would feel more comfortable talking with another Black woman especially about racial discrimination and gender roles. As some participants said “talking to someone Black or of color would make people open up” and “would probably be inviting if you’re dealing with another Black woman.” Another woman explained that they would also be able to identify with a Black female therapist and identifying with their providers (in terms of race and gender) is often rare given the low number of racial minorities providers. As two participants stated “I think with everything that’s going on, they would respond more with the Black woman...I would really like it to be a Black woman because she knows more of our situations, of the way we are.” -1030 and “Another psychologist like you. It’ll work. You don’t see too many Black psychologists. You the first I seen.” -1009

Discussion

Our present study interviewed BWLWH about their experiences with (a) trauma, racism, HIV-related discrimination, and gender-related stressors, (b) coping strategies, (c) connections between adversities and their medication adherence, and (d) desire for an intervention adapted to the needs of BWLWH. Several major themes emerged from the interviews. Most of the women shared multiple experiences of trauma/abuse in the form of sexual, physical, verbal and emotional trauma/abuse, intimate partner violence, and community violence. These qualitative reports of trauma/abuse are consistent with previous literature on the high prevalence of abuse and trauma among women with and at risk for HIV (Machtinger et al., 2012). In addition to the abuse/trauma, women talked about being discriminated against due to their race and HIV-positive status at the institutional (e.g., law enforcement, health institutions, retail stores) and interpersonal (e.g., strangers, friends) levels. Some of their stories on discrimination reflected the ways in which they were discriminated against based on their intersecting identities as BWLWH. Many women shared overt acts of racial discrimination from the past and subtle behaviors and microaggressions in their everyday lives. While the types of discrimination (e.g. overt versus covert) and the perpetrators of racial and HIV-related discrimination (e.g. individuals at the institutional and interpersonal levels) have been well documented (Hunt, Wise, Jipguep, Cozier, & Rosenberg, 2010), the intersecting experiences of both racial and HIV-related discrimination has been discussed less (Logie, James, Tharao, & Loutfy, 2013) especially among BWLWH. Our women spoke of moments when they were treated negatively by police officers and hospital staff and attributed this to being BWLWH. As Black women, participants also spoke of the compounded stress of gender roles expectations to put others first, do everything, and be “lady-like.”

In response to the various traumas and adversities women used a range of strategies to cope, some of which are supported by existing literature (Blakey, 2016; Stevens-Watkins et al., 2014). For instance, social support, spirituality, avoidance, and selective disclosure of HIV status were common coping strategies. In the face of racial discrimination awareness (acknowledging systemic racism) and assertiveness were common responses coupled with using caution depending on the situation. Authors such as Carter and Forsyth have discussed these strategies and found associations between awareness and less mental health distress (Forsyth & Carter, 2012). While there is no definitive explanation as to why assertiveness would be more common in response to racial discrimination than other traumas (e.g. sexual abuse/physical abuse), HIV-related discrimination, and gender related stressors, it may be that racial discrimination experiences are likely to occur outside of relationships (e.g. strangers) that woman may feel pressured to maintain and therefore self-silence. In contrast, woman experience abuse, HIV-discrimination, and gender-related stressors from partners and family members and may not assert their emotions, thoughts, and needs in order to maintain harmony. In discussing gender-related stressors (e.g. expectations to put others first and “do everything”), women said that they coped by prioritizing the self and practicing self-love as well as continuing to help others, and at times sacrifice their needs in order to help. Helping others and self-sacrifice was tied to a sense of altruism and being the matriarch of their families, which is consistent with the view of the Black women historically and within their families (Collins, 2002).

To our knowledge no existing literature has qualitatively captured the connection between these traumas and adversities to HIV medication adherence and health among Black women living with HIV. Women explained that experiences of trauma/abuse, HIV stigma, and racial discrimination led to depression, anger, resignation, disengagement in care, and medication nonadherence. Similarly, gender-related stressors led to medication nonadherence via self-neglect. Our women’s stories collaborate and help to clarify the quantitative links that have been noted in the literature between trauma/abuse, racism, HIV-stigma, gender roles, and depression and negative emotional states with HIV medication nonadherence (Bogart et al., 2010; Brody, Stokes, Kelso, et al., 2014; Dale et al., 2014). However, as a testament to the resilience of women living with HIV noted in previous literature (Dale et al., 2014) these BWLWH also shared how they continue to take their medications in spite of trauma, racism, HIV stigma, gender roles. Women shared how having an internalized sense of self and power and prioritizing their self and needs allowed them to cope with the adversities and adhere to their HIV medications. Essentially women were practicing self-validation (e.g. viewing their power as coming from within), self-primacy (putting their needs first), and consciously choosing to practice self-care despite adverse experiences that were invalidating. Believing in one’s power and recognizing that it comes from within irrespective of society (e.g. racism, stigma, prescribed gender roles) may be linked to self-efficacy in taking care of one’s health and reaching goals overall (Johnson et al., 2007). Women also cognitively viewed their health as important, children as motivation to take care of their health and live longer, and HIV medication adherence as way to prevent HIV wasting and anticipated discrimination.

Several practical strategies also helped women to adhere to their medications including (a) reminders from family members, (b) set routines/schedules for taking their medications (e.g.

meal-time), and (c) convenient/organized pill storages. In contrast, other factors that served as barriers to women's adherence included feeling tired from completing daily tasks, tired of taking the medications and substance use. The literature is abundant on substance use as a barrier to medication adherence (Dale et al., 2016) and attempts to address it, however very little exists on how to best address the burden of daily tasks and fatigue from taking medication over time (Lima et al., 2009).

When provided with an overview of *Striving Towards EmPowerment* and Medication Adherence (STEP-AD) – an intervention aiming to enhance coping strategies for trauma, racial discrimination, HIV-related stigma/discrimination, and traditional female gender roles and improve medication adherence – participants were excited about the possibility of having an intervention that would be adapted to their experiences and needs as BWLWH. Scholars have discussed the importance of having adapted and culturally congruent interventions to tackle HIV disparities among communities of color (Wyatt, Williams, Gupta, & Malebranche, 2012). Participants also spoke of the importance of having a Black woman as the clinician delivering the intervention to make women comfortable to speak about their adverse experiences especially racism. Existing interventions specifically for Black women utilize Black women facilitators for this reason (Wingood & DiClemente, 2006; Wyatt, 2009).

The women provided invaluable insights about their experiences and coping strategies and there are a few study limitations to note. The sample consisted of women residing in and around the Boston area and their thoughts may not represent other women in other regions of the US or abroad. Some qualitative research scholars prefer the use of completely open and unstructured interviews, and we utilized guided interviews (i.e., semi-structured interviews with open-ended questions) as a way to obtain women's experience and thoughts on particular content areas (e.g. trauma, racial discrimination, HIV stigma/discrimination, gender roles, and medication adherence). In addition, a large portion of the women (50%) reported excellent ART adherence and were fairly educated (43%), which may limit the generalizability of these qualitative findings. Despite these limitations, women shared experiences and insights that may inform future interventions.

BWLWH shared multiple experiences of trauma/abuse, racial and HIV-related discrimination, gender-related stressors, ways that they cope, and how their adverse experiences and coping are connected to their HIV medication adherence or nonadherence. The women's stories and insights will directly inform the ongoing development of *Striving Towards EmPowerment* and Medication Adherence (STEP-AD) and may inform the development of other interventions that aim to enhance adaptive coping strategies for multiple psychosocial adversities faced by BWLWH or those at risk. For instance, helping women to self-validate, enhance their internalized sense of power, and practice self-primacy and self-care may be especially beneficial. Cognitive Behavioral Therapy (CBT) strategies (Barlow et al., 2010) may be used to help BWLWH cognitively view adherence to medications as a way to thrive, be resilient to adversity, and behaviorally practice self-care in the face of numerous adversities. CBT strategies have been effective in promoting medication adherence among individuals with HIV and other chronic illnesses (Dale et al., 2016). Elements of Dialectical Behavioral Therapy (e.g. distress tolerance tools, focus on

values/goals) (Harned, Korslund, & Linehan, 2014) may also be beneficial in helping women to cope with the negative affect that result from multiple adversities. Ultimately the best solution to these adversities negatively impacting self-care behaviors (e.g. medication adherence) among BWLWH will be a systematic approach to ending violence/trauma, racism, HIV-discrimination, and prescribed gender roles. Until then, BWLWH are eager for interventions that are delivered by members of their community (i.e. gender and race matched), and that address health behaviors from the nexus of real-world adversities that they face.

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Table 1**Sociodemographics and Characteristics of 30 Black Women Interviewed**

Characteristic	Mean (<i>SD, range</i>) or n (%)[*]
Age	46.5 (11.6, 33–65)
Place of Birth	
U.S. Born	26 (87%)
Non-U.S. Born	4 (13%)
Parents of Children	29 (97%)
Number of Children	3.0 (1.4)
Religion	
Religious/Spiritual	28 (93%)
Baptist	8 (27%)
Christian	12 (40%)
Catholic	3 (10%)
Islamic	1 (3%)
Other	4 (13%)
Education	
Less than high school diploma	8 (27%)
Completed high school	7 (23%)
Some college	13 (43%)
College degree	1 (3%)
Graduate degree	1 (3%)
Relationship Status	
Single	15 (50%)
Married	3 (10%)
In a Relationship	4 (13%)
Divorced	5 (17%)
Widow or Loss of Partner	3 (10%)
Employment Status	
Full-time Work	1 (3%)
Part-time Work	2 (7%)
Full or Part-time School	3 (10%)
Neither Working or in School	9 (30%)
On Disability	20 (67%)
Living Situation	
Lives with Self	14 (47%)
Roommates	1 (3%)
Partner or Spouse	5 (17%)
Children	9 (30%)
Group Home or Residential Treatment	2 (7%)
Other	2 (7%)
Sexual Orientation	

Characteristic	Mean (<i>SD, range</i>) or n (%) [*]
Exclusively Heterosexual	19 (63%)
Heterosexual, some Homosexual Experience	6 (20%)
Bisexual	2 (7%)
Chose Not to Answer	3 (10%)
Medical Characteristics	
Years since Diagnosis	17.23 (6.19, 6–30)
CD4+ count	695.32 (277.35, 280–1209)
Viral load	
Undetectable	22 (73%)
Detectable	6 (20%)
Don't know	2 (7%)
Years taking antiretroviral medications	11.7 (7.35, 1–31)
ART Adherence Self-Report	
Excellent	15 (50%)
Very Good	8 (27%)
Good	4 (13%)
Fair	2 (7%)
Poor	1(3%)

^{*}
Note: Percentages do not equal 100% due to rounding.

Table 2

Sample Questions from the Interview Guide

Theme	Corresponding Questions
Experiences with Trauma/Abuse	1. Sometimes things happen to people that are extremely upsetting—things like being in a life threatening situation like a major disaster, very serious accident or fire; being physically assaulted or raped; seeing another person killed or dead, or badly hurt, or hearing about something horrible that has happened to someone you are close to. We have, when doing the informed consent, discussed that you have had these kinds of experiences. What, specifically, have happened to you? 1b. How do you think the traumatic experiences you just shared affect how you care for yourself and your health now? Medication adherence?
Experiences with Racism - Interpersonal Level*	2. What about a time, in the past 12 months when another person was not nice to you, was disrespectful, or mistreated you because you are Black? Think about times when you were ignored, excluded, or avoided by people you know because of your race, or when you were treated with hostility or coldness, or people acted like you couldn't be trusted. It could be someone you know well—like a friend or partner—, an acquaintance, or someone you don't know or just met—like someone in a store or your neighborhood—or a coworker. It could also be a person at church. 2a. What happened? 2b. What did you do to cope? 2c. How do you think the racism you experience (/d) affect how you care for yourself and your health? Medication adherence?
Experiences with HIV Discrimination/Stigma - Institutional Level*	3. What about a time, in the past 12 months when you felt discriminated against by institutions or systems in society because you are HIV-positive? For example, in the past 12 months, have you felt mistreated by the police or law enforcement, at work or by an employer, in healthcare or by a healthcare provider, or at church? Were you ever treated poorly or made to feel inferior at any of these places or by any of these people? For example, were you denied a job or did you lose a job due to your HIV-status? Also, have you been denied housing or not been able to get a place to live because of your HIV-status? 3b. What happened? 3c. What did you do to cope? 3d. How do you think the HIV discrimination/stigma you experience (/d) affect how you care for yourself and your health? Medication adherence?
Experiences with Gender Roles Expectations	4. As a woman do you think they are certain ways that others expect you to behave? Others such as family, friends, peers, partners, children, other. 4a. Expectations around: Communication? Maintaining relationships? Putting others' needs ahead of your own? 4b. How do you think these expectations and relationships affect how you care for yourself and your health? Medication adherence?
Experiences with Medication Adherence	5. How long have you been prescribed HIV medications (i.e. ART)? 5a. What are things that make it easier to adhere (keep taking) to your medications on time? 5b. What are things that make it hard to adhere (keep taking) to your medications on time?
Thoughts on Proposed Intervention	6. "We are thinking of offering a program through [hospital name] in which we would provide individual sessions for Black women living with HIV, to discuss ways to improve medication adherence and cope with trauma, discrimination, and gender-related stress. The program would last about 10 weekly sessions, and it would include discussions about similar experiences, and take-home activities to help practice skills you learn in the program" What are your initial thoughts about such a program? Would you be interested in attending this kind of a program? Why or why not? Do you think other people living with HIV would be interested in attending such a program? Why or why not?
Suggestions for recruitment and retention	7. What do you think would make women willing to come to the program? What specific things should we do to make the program more attractive? How should we recruit women to come to the program? Online, in person, specific places? Why these methods and not others? 7a. What kind of person do you think would be the best facilitator for this program? How important is it that the person is a member of your community—that is, Black, female, etc.?

* Note that questions on women's experiences of racism and HIV-related discrimination/stigma were asked at both the interpersonal and institutional levels. These questions were adapted from Bogart, et al. (2016).