

## Taking It One Day at a Time: African American Women Aging with HIV and Co-Morbidities

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### Abstract

Self-managing HIV/AIDS presents challenges for anyone infected. These challenges may be further complicated for older HIV-infected African American women who acquired the disease at younger ages and now have co-morbidities. Little is known regarding how women's age identity, social responsibilities, co-morbidities, and romantic relationship status influence their HIV self-management. Five focus groups were conducted in Washington DC, with HIV-positive African American women aged 52–65. Topics included HIV and co-morbidity self-management, social support needs, medication adherence, and future plans for old age. A constant comparison approach was applied during data analysis. Co-morbidities, including diabetes and hypertension, were perceived to be more difficult to self-manage than HIV. This difficulty was not attributed to aging but to daily struggles such as lack of income and/or health insurance, an inflexible work schedule, and loneliness. Social responsibilities, including caring for family, positively impacted participants' ability to self-manage HIV by serving as motivation to stay healthy in order to continue to help family members. In contrast, inflexible work schedules negatively impacted women's ability to sustain medication adherence. Overall, this study demonstrates that HIV and co-morbidity self-management are inextricably linked. We can no longer afford to view engagement in HIV care as a single-disease issue and hope to attain optimal health and well-being in our HIV-affected populations. Optimal HIV self-management must be framed within a larger context that simultaneously addresses HIV and co-morbidities, while considering how social and cultural factors uniquely intersect to influence older African American women's self-management strategies.

### Introduction

#### *HIV and older African American women*

**A**FRICAN AMERICAN WOMEN are disproportionately impacted by HIV/AIDS. In 2010, African American women comprised 14% of the total population of U.S. women but accounted for nearly 64% of new HIV infections occurring among all women.<sup>1</sup> Additionally, African American women are also disproportionately impacted by the nation's leading chronic illnesses including diabetes, heart disease, and cancer.<sup>2</sup> With advancements in medication, HIV/AIDS has transformed from a fatal condition into a chronic, yet manageable condition.<sup>3</sup> The chronic nature of HIV/AIDS has resulted in increased life expectancy for many women who acquired the disease at younger ages and are now surviving into middle and old age. By 2015, it is

expected that 50% of HIV infected individuals will be aged 50 and over.<sup>4</sup> Based upon Centers for Disease Control and Prevention HIV/AIDS surveillance categories, persons aged 50 and over who are infected with HIV are deemed to be older adults.<sup>5</sup>

Due to the natural progression of aging, as well as accelerated aging caused by HIV, many HIV infected individuals will experience at least one other co-morbid condition such as diabetes, heart disease, or cancer.<sup>6–8</sup> These conditions often require additional treatment and can complicate HIV/AIDS medical regimens. For example, simultaneous treatment of HIV/AIDS with other conditions can pose challenges to selecting appropriate antiviral medications and can complicate patients' and providers' ability to discern the source of medication side-effects.<sup>4</sup> Nonetheless, concurrent treatment of co-morbid conditions is an essential component of optimal HIV self-management.<sup>9</sup> Thus, it

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is important to have an understanding of how aging influences the self-management perceptions and strategies of older individuals with HIV and co-morbidities. However, the majority of research that focuses on HIV and aging conceptualizes age only as chronological or biological age. Sankar et al. note that primarily discussing the relationship of chronological age to HIV has greatly limited understandings of how the social, behavioral, and cultural aspects of living with HIV influence the course and treatment of HIV among older adults.<sup>10</sup> In addition, it is important to note that age identity, how old a person feels, can have a significant influence on motivation to engage in chronic illness self-management behaviors,<sup>11,12</sup> as well as their expectations about health and aging.<sup>13</sup>

### *Chronic illness self-management*

Literature defines chronic illness self-management as the ability of the patient to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition.<sup>14</sup> Behaviors associated with chronic illness self-management may include adhering to a medication regimen, monitoring illness symptoms, managing diet and weight, seeking regular health care, and being physically active.<sup>15</sup> Several recent studies have been conducted that examine the self-management behaviors of women living with HIV.<sup>15–17</sup>

Overall, these studies indicate that it is important to examine the barriers and facilitators to illness self-management of women due to the unique experience that various intersecting factors including gender, social roles, poverty, race, and HIV stigma have on women's abilities to effectively manage their health. For example, Tufts, Wessell, and Kearney discern that race and gender are important social factors to consider when examining the HIV self-management behaviors of HIV positive women.<sup>17</sup> They conducted five focus groups with HIV-positive African American women ages 18–65. Findings reveal that African American women often place others in front of themselves when it comes to managing their own health. A prevalent racialized gender norm for African American women includes the Strong Black Woman/Superwoman role.<sup>18</sup> This role dictates that women place the needs of others in front of their own and that they cannot show any signs of weakness or of needing help. However, participants reported the realization that they had to go against racialized gender norms of placing others before themselves if they were going to optimize their HIV self-management behaviors. This includes reading self-help books, engaging in spiritual activities, and pampering themselves.<sup>17</sup>

The majority of studies examining the HIV self-management of women largely focus on the experiences of younger women. Research, however, is emerging that recognizes how age is an important social factor to consider when examining the HIV self-management behaviors of HIV-positive women. Plach et al.<sup>19</sup> conducted in-depth interviews with nine culturally diverse HIV-positive women ages 50–56. They report that women's definitions of HIV self-management are shaped in large part by their life experiences over time, which serve as a buffer for managing the health effects of HIV. As noted by Plach et al., women viewed their advanced age to be a source of wisdom from which they could rely upon to cope with chronic illness as well as life challenges.<sup>19</sup> That is, older women with HIV have a lifetime of self-management experiences from which to draw. Ultimately, they purport that

mature age is viewed as a strength to simultaneously manage HIV and other co-morbid conditions.

Self-managing HIV/AIDS presents challenges for anyone infected, and these challenges may be further complicated for older HIV infected individuals with co-morbidities. This is particularly problematic for older African American women who are at increased risk of living in poverty and/or being unmarried.<sup>20</sup> Furthermore, reduced income due to retirement or loss of employment may serve as an additional barrier for many older African American women to access needed health care in order to optimize their self-management behaviors.<sup>21</sup> Marital status is significant to consider regarding older African American women's chronic illness self-management because research demonstrates that marriage may be a protective factor against poverty for many women<sup>20</sup> and spouses can be an important source of social support for chronic illness self-management.<sup>22,23</sup> A qualitative study conducted with five HIV positive African American women ages 29–49, reveals that women's perceptions of receiving emotional support from their spouses positively contributes to women's HIV coping and self-management strategies.<sup>24</sup>

It is also important to note that many older African American women commonly assume traditional gender roles including that of family health manager and often place their health care needs behind the needs of other family members including spouses, children, and grandchildren.<sup>16,25</sup> In addition, Pearson et al.<sup>26</sup> note that persons aged 50–64 who experience co-morbidities are also providing informal care to family members with similar conditions.<sup>26</sup>

Despite growing numbers of older African American women living with HIV, research is scant that examines older women's experiences of self-managing HIV with other co-morbidities. The purpose of this study is to add to the literature by describing how age identity, co-morbidities, social responsibilities, and relationship status of older HIV-positive African American women influence their HIV self-management. Four questions guide this research. First, what does HIV self-management mean to HIV-positive African American women aged 50 and over? Second, how does age identity or how old the women feel influence their HIV self-management? Third, what influence, if any, does a co-morbid condition have on women's HIV self-management strategies? Fourth, what role, if any, does romantic male companionship play in women's self-management perceptions?

## **Methods**

### *Design*

Focus groups were deemed the most appropriate method of data collection for this study. By employing focus group methodology, we aimed to encourage open conversation about aging and women's HIV and co-morbid illness self-management strategies. Our intent was to highlight women's attitudes, priorities, language, and framework of understanding<sup>27</sup> related to their HIV and chronic illness self-management and perception of how the aging process has impacted or is impacting their self-management behaviors. Given that we aimed to examine the HIV and co-morbid experiences of older African American women, a single-category focus group design was deemed the most appropriate method of data collection.<sup>28</sup> Single-category design is ideal for exploring the experiences in one particular type of

group rather than comparing across different groups.<sup>28</sup> This design has several advantages including allowing researchers to conduct focus groups until they reach theoretical saturation by making within group comparisons.

#### Sampling and recruitment

Purposive sampling was used to recruit participants. Following approval from the Institutional Review Board Georgetown University, 23 participants from the Washington DC Women's Interagency HIV Study (WIHS) were recruited to participate in one of five focus groups, between November 2011 and December 2011. The WIHS is the largest prospective, observational study of HIV-infected and at-risk HIV non-infected women in the USA with an original enrollment in 1994–1995 of 2056 HIV-positive and 569 HIV-negative women.<sup>29</sup> WIHS study sites are located in Bronx, NY, Brooklyn, NY, Washington DC, Los Angeles, CA, the San Francisco Bay Area, CA, and Chicago, IL. At the time of the study, the Washington DC site was actively following 292 (210 HIV-positive and 82 HIV-negative) women. At the time of recruitment, Washington Metropolitan WIHS had 55 HIV-positive women who were aged 50 and over. Among the 55 women who were HIV-positive, 50 were identified as African American. All African American women eligible for inclusion were approached for study participation. They range in age from 50 to 78 years.

A recruitment flyer was sent to eligible WIHS participants regarding a voluntary study. The specific topic and goals of the study were explained in more detail when the participants expressed interest in the study to the research staff and prior to the focus groups during the informed consent process. Participants were provided with transportation, refreshments and \$40 cash as compensation for their time.

#### Focus groups

The focus groups were conducted at the Washington DC WIHS study site in a private conference room. Focus groups had between 3 and 7 participants each and discussions lasted between 90 and 120 min. Focus groups were co-moderated by the first and fourth authors who are experienced HIV/AIDS researchers. A semi-structured interview guide was used to generate conversation across all groups where the primary topics of discussion included women's definitions of HIV and co-morbid self-management, the influence of age on illness self-management behaviors, and barriers and facilitators to self-managing HIV and co-morbid conditions. The main topics were always addressed in the groups. Additional probes were added as needed based upon the collective responses of the women. Focus group discussions were audio-taped to ensure accuracy and transcribed verbatim by a professional transcription service. Detailed notes were also taken during each group discussion.

#### Participants

The mean age of focus group participants was 57 years (range 52–65). Nine participants reported being single/never married, 3 were married, 1 lived with her male partner, 6 were divorced, and 4 were widows. As measured by number of years that participants have been enrolled in WIHS, the average length of time women have been living with HIV/AIDS is 14.5 years (range 6 months–17 years). See Table 1 for participant HIV status and co-morbid conditions based on clinical data collected during a WIHS study visit. All participants were provided a pseudonym to ensure confidentiality. Among the 23 women who participated in the study, only 1 woman did not have any co-morbidities. The majority of the women were managing 1–5 co-morbidities. Arthritis, cancer, depression,

TABLE 1. RESPONDENT HIV and CO-MORBIDITY STATUS

| Pseudonym | Age | Years living with HIV in cohort | Years on HIV medicine | Co-morbidities  | HIV RNA PCR (viral load) copies/mL |
|-----------|-----|---------------------------------|-----------------------|---|------------------------------------|
| Peggy     | 65  | 17                              | 17                    | Arthritis, high blood pressure, hepatitis                       | 48                                 |
| Alisha    | 53  | 16                              | 16                    | Arthritis, high blood pressure, heart disease, hepatitis        | 48                                 |
| Wanda     | 53  | 16                              | 16                    | Diabetes, heart disease, hepatitis                              | 48                                 |
| Beth1     | 56  | 16                              | 16                    | Arthritis, diabetes, hepatitis                                  | 48                                 |
| Jane      | 63  | 16                              | 16                    | Diabetes, high blood pressure, cancer                           | 48                                 |
| Ruth      | 57  | 16                              | 16                    | Heart disease   | 48                                 |
| Karen     | 58  | 16                              | 16                    | Diabetes, high blood pressure, heart disease, hepatitis, TB     | 48                                 |
| Kendra    | 56  | 16                              | 16                    | Hepatitis   | 48                                 |
| Dana      | 56  | 16                              | 16                    | High blood pressure, hepatitis, depression                      | 48                                 |
| Rena      | 58  | 16                              | 16                    | High blood pressure,  | 48                                 |
| Ilene     | 55  | 17                              | 17                    | High blood pressure, hepatitis, cancer, depression              | 48                                 |
| Julia     | 53  | 17                              | 15                    | High blood pressure, hepatitis                                  | 48                                 |
| Deirdre   | 55  | 16                              | 16                    | Cancer  | 68                                 |
| Liza      | 64  | 16                              | 14                    | Arthritis, diabetes, high blood pressure, heart disease         | 2740                               |
| Fran      | 52  | 16                              | 16                    | Arthritis,  | 48                                 |
| Elena     | 57  | 16                              | 16                    | Arthritis, diabetes, high blood pressure, hepatitis, depression | 48                                 |
| Judy      | 59  | 16                              | 12                    | High blood pressure,  | 832                                |
| Ethel     | 60  | 16                              | 15                    | High blood pressure, depression                                 | 3760                               |
| Monica    | 53  | 16                              | 3                     | Arthritis, high blood pressure, heart disease                   | 48                                 |
| Mimi      | 60  | 16                              | 0                     | Arthritis, high blood pressure, hepatitis, depression           | 4800                               |
| Sophia    | 58  | 9                               | 13                    | High blood pressure   | 656                                |
| Mae       | 55  | 1                               | 1                     | None  | 48                                 |
| Anne      | 53  | 0.5                             | 4                     | High blood pressure   | 48                                 |

diabetes, heart disease, hepatitis, high blood pressure, and TB were the co-morbidities reported. High blood pressure was the most common co-morbidity reported by 16 women, followed by hepatitis (11 women). Six women had had detectable HIV viral loads at the time of the focus group. Twenty-two participants have at least one additional co-morbid condition including diabetes, hepatitis, high blood pressure, arthritis, cancer, heart disease, and depression as defined by the Center for Epidemiologic Studies Depression Scale (CES-D)<sup>30</sup>. Nine of the participants reported ever having AIDS.

#### Data analysis

We employed the constant-comparison technique of data analysis. This is an inductive methodological approach that involves a continual comparison of themes, concepts, and experiences within and between the data sets.<sup>31</sup> The transcripts were read while listening to the audio files to check for accuracy. Upon verifying accuracy of the transcripts, they were imported into NVivo 9 software<sup>32</sup> to facilitate data management. Following procedures for the constant-comparison technique, the investigators engaged in open, axial, and selective coding. Open coding consists of reading transcripts line-by-line in order to identify, name, and describe what is happening in the text and to identify categories and subcategories found repeatedly in the data.<sup>33</sup> The first author engaged in open coding independently in order to create a coding structure for the co-investigators to follow. The open codes were then used by two of the authors (LWJ and PH) to develop more focused codes also known as axial codes. In this step, we engaged in independent coding in order to draw relationships between categories and subcategories identified during open coding. Finally, we engaged in selective coding where we decided on the core concepts that explain the influence of the social, cultural, and behavioral aging process on participants' chronic illness self-management.

#### Rigor and trustworthiness

Throughout the analysis process, we refined our thoughts through on-going discussions in an effort to arrive at a coding consensus, and to identify central codes and themes in the data. To ensure inter-rater reliability, a consultant with the research team (HD) scrutinized the core concepts identified by LWJ and PH without examining the transcripts line-by-line in order to identify any idiosyncrasies with coding and to make a judgment as to whether the final coding scheme accurately reflects what was occurring in the coded text segments. Further discussions were held between the research team and the independent consultant in order to identify and rectify any inconsistencies with the coding scheme.

#### Results

Four central themes emerged during data analysis. The first theme, "*Taking it one day at a time*," denotes the meanings attached to HIV self-management and the social roles that influence women's self-management behaviors. The second theme, "*Age ain't nothing but a number*," indicates that women do not place chronological boundaries on their age and that age is a state of mind. The third theme, "*Forget the single life*," describes women's perceptions of the influence of romantic male companionship on their self-management behaviors and outlook on the future. The fourth theme,

"*Daily life struggles*," illustrates the barriers that many women face in their everyday lives, including lack of income and health insurance that influence their ability to self-manage their HIV and other co-morbidities to their satisfaction and suggests that HIV is not women's primary concern when it comes to self-managing their overall health. Data on all four themes indicate that many factors intersect to affect older women's illness self-management. Age identity is paramount to women's self-management strategies and perceptions.

#### "Taking it one day at a time": Women's definitions of HIV self-management

Participants were asked to define what HIV self-management means to them. There was a general consensus across all focus groups that HIV self-management consists of adhering to a daily medication regimen, eating well, exercising, doing something good for others and self, and engaging in spiritual activities (i.e., prayer, meditation). Women described that the most effective way for them to self-manage their health was to take it *one day at a time* so as not to become overwhelmed with trying to manage HIV along with their other co-morbid conditions and family commitments.

**Interviewer:** *What does HIV self-management mean to you?*

**Elana:** What it means to me, I'm taking it one day at a time.

First, since my kids are grown, I gotta put me one number first. I gotta stop thinking about, you know, a mother gone always raise they kids...I still worry about my kids...And...sometimes it's still hard for me to live by myself without my kids 'cause they grown, out on they own. But my baby son he still live with me cause he got a mental condition...He still like to be underneath me 'cause he's the baby...But take it one day at a time. Make sure I'm taking my medicine. Make sure I'm number one, taking my medicine, I help somebody along my way, long as no strings attached. Long as I can help somebody, then I can help myself, you know. I know this journey that I'm going on, it's not gon' be in vain... That's what it means to me, taking it one day at a time 'cause I don't know what the day gone bring. Just one minute at a time, one second at a time.

**Beth:** Just taking care of myself one day at a time to manage it...But just help me to manage it and live a productive life to a well-being as I possibly can. Just help me to manage like I do the rest of my ailments and carrying on to, you know, to be a balance in everything...

The self-management of HIV and co-morbid conditions also means "[making] sure I'm number one," according to Elena, and to balance this self-management with other social roles like motherhood. Self-management also meant achieving "balance in everything," according to Beth. In addition, participants such as Beth reported that getting older led them to slow down and take their overall health into greater consideration, choosing themselves over "the silly stuff." In Beth's case, then, the ability and desire to self-manage her health increased with age.

**Beth:**...I never thought I would live to be 56 years old. I really didn't cause the lifestyle of drugs and all that stuff, I thought I'd be dead or somebody would kill me [inaudible]...I'm living life like it's golden. And I, I love getting older because as I get older I get better with wisdom more so than not the silly stuff that I used to do, that I wouldn't dream about thinking about doing now. I just want to grow old gracefully.

**Interviewer:** *What do you mean by that?*

**Beth:** Gracefully? To be able to do the things and still just live life like it's golden...Cause I'm never in a hurry to be nowhere, see nobody or do nothing.

On the other hand, a focus group conversation among multiple women made it clear that, while co-morbidities and aging meant that self-management of their health “had to change,” participants balanced the need for this change with their need to “love” themselves.

**Liza:**...With the co-morbidity there’s also the awareness that things need to change. And here comes age. Age creeping up behind you [cross talk among participants].

**Beth:** You can’t eat some things you used to. [cross talk]

**Jane:** You know what, I’m gonna tell you something right now...I’m on dialysis, I’m not supposed to eat this, I not supposed to eat that...I’m a diabetic, I’m not supposed to drink this, I’m not supposed to drink that...I’m not trying to say that, you know, I don’t want to live or anything like that but, like, okay...I eat a lot I’m not supposed to eat. I, I do it. And, and I don’t know why. It’s not like I’m trying to kill myself or anything because I love me. But I just, I, I, I, I, I just can’t say, okay, this is not diet, I’m not gone drink it. I don’t do that. I, I just can’t do that. Sometimes I follow a, a diet, and then sometimes I don’t.

Managing HIV and co-morbid conditions while aging required considerable negotiation on a daily basis. Beth told her doctor, “[D]on’t tell me nothing else I got...I make do with what’s going on and just do what I can about it and what I can’t, leave alone.” The idea that self-management includes a daily negotiation of HIV-related conditions, co-morbidities, social responsibilities, and feelings about aging are clear from these quotes.

#### *“Age ain’t nothing but a number”*

Participants in all five focus groups were asked to describe what it feels like to be older. Overall, there was a general consensus across all groups that they did not self-identify as being older. This is partially due to the fact that they did not have expectations of growing older due to having HIV/AIDS. In addition, they defined age as a state of mind as opposed to a chronological number based on years of life. In addition, several participants indicated that their adult children still needed various types of social support from them as mothers. The feeling of still being needed by adult children contributes to a mindset of being younger and forgetting about being older. As voiced by participant,

**Ruth:** Sometime people forget your age because, back in the day, when you was like 57 and 60, you looked it and you felt it. But I guess because of the mindset that we have now, you know, you are what you think, what you eat, how you feel and how you take care of yourself...like my kids sometimes, they always have me doing, going running here and there. I’m like, look, I don’t feel like it today but I’ll do it, you know. But overall I forget sometimes, all but ‘cept that I gotta take my medicine.

Multiple participants also felt that they need to take life slower and make their health a greater priority. At the same time, caregiving responsibilities—here, of adult children—may not subside as women grow older. Nonetheless, women in this study also understood that in order to help themselves, they sometimes have to place the needs of important others behind their own. The comment from one participant illustrates this finding.

**Interviewer:** *So how is it like to be middle-aged?*

**Elena:** Well, I feel good to reach the age I am now. The way I was brought up and stuff like that, I feel good, you know. I

thank God that first, that I got to see this age. And to live to see me raise my kids and stuff like that. But like they say, age ain’t nothing but a number. That’s true, too, and in a way it’s not true...I gotta act my age. I gotta do things in moderation. I know I can’t do the things that I used to do when I was 25 and 35 years old, you know...At my age, you know, I still like to do things to help people but I know mostly, I got to help myself, you know what I’m saying?

The following exchange from two participants indicates that women are feeling confident in their older years and place importance on maintaining their physical appearance. It also denotes an optimism regarding their overall health.

**Wanda:** Feel fantastic, baby. Fifty and fly.

**Fran:** Oh yes. Diva.

**Wanda:** A diva [inaudible]. Okay, and I told you earlier I try to keep it sexy all the time. Feel me. Sometimes I just can’t stand myself. Alright, but other than the occasional physical aches and pains, you know what I mean, fifty is not bad. Fifty is the new thirty, boo. Don’t get it twisted. The new thirty. Not the new forty, but the new thirty.

As presented in these quotes, women report feeling younger than their chronological age. This perception can be attributed to wanting to remain “youthful” and spry in order to meet the social support demands of important others. In addition, women expressed a sentiment of gaining a deeper sense of self-confidence that they may not have had during their younger ages. This strengthened sense of self may contribute to women’s desire to maintain their physical appearance, for themselves as well for a male partner/potential male partner. Wanda’s comment that fifty is the new thirty suggests that getting older does not decrease the desire to have an intimate male partner. Rather, wanting a relationship and engaging in fun activities (i.e., dating) that are typically associated with younger ages is still very important to these women. The following theme “*Forget the single life*” provides greater insight into the role that romantic male companionship has on women’s HIV self-management strategies.

#### *“Forget the single life”*

Although participants were queried on the various familial relationships that served to facilitate their illness self-management, they emphasized the important role that an intimate male partner can play in helping them to optimize their illness self-management as they grow older. This intimacy not only included wanting and needing sex but also emotional support and companionship that can be an integral part of a loving romantic relationship. The topic of romantic male companionship arose throughout four of the five focus groups. Several single participants commented on how being single and lonely contributes to the difficulty of managing their HIV. In contrast, participants in committed relationships expressed that their male partners are very supportive and provide them with emotional support on a daily basis. Participants reported that companionship received from male partners serves to inspire them to self-manage their HIV and other co-morbid conditions. In addition, the hope of finding romantic love with a male partner seemed to inspire women in the study to engage in self-management behaviors including having a positive outlook on their futures. Many of the single focus group participants described wanting to grow older with

a male companion who could assist them with their daily life routines and provide emotional support for them as they age.

**Mimi:** A lot of people may not be aware of the trials and challenges a person who lives alone goes through living with HIV and AIDS...So you know I'm talking 'bout this loneliness...Forget the single life, you know. It's nice to have someone to bring you a cup of tea. Like we said, again the stigmatism. Who would want you if you...disclose that you HIV positive? I just have a gusto for living. Excuse me, I love life, I enjoy life. And what happened there has come over the years of maturing...But I'mma tell you what the main problem I personally was dealing with was loneliness. Not having brothers and sisters. Not having children. Not having a husband. Always feeling nobody would want me so the psychological aspect of living with HIV was more devastating to me than the physical aspects...I do as much as I can to enjoy myself but I still have those lonely moments. I'm not...burdened with children...[U]nfortunately I don't have children. So I have this freedom of time. I have this down time. I'm in the house by myself...I don't know, will a man accept me? The caliber of a man that I need to complement my style of woman? And it's rough just in the natural dating scene. Can you imagine HIV?...So I understand a lot of us are afraid. We afraid of fear, of rejection. But I do have one friend. I been working with him and I told him up front, "You probably get hit by a Mack truck before you get infected by me."

**Interviewer:** *Oh, so what I'm hearing is that it's important to have a relationship?*

**Mimi:** Absolutely, because you know what? All that crap they talking 'bout '[D]on't nobody need no man, and you could make it by yourself, and you could do bad by yourself'...This is my motto today: I don't give a flying fruit fly. We can do bad together just as long as you're with me. And you respect me. Appreciate me. We'll work the rest out. The loneliness. I'm tired. So that's what I been working on.

The following comment from Beth, a married participant, illustrates how her spouse contributes to her positive outlook on life and helps her to remain adherent with her HIV medication regimen.

**Beth:** I got a life and I got a husband. I been married 20 years...I never thought nobody would want me being positive. And he's not positive...He keeps me in stitches. Laughing about something...He will call me, he used to always remind me or like if we in the car or something, he'll say Boo, did you take your medicine this morning, and stuff like that so.

Beth and Mimi, along with others, suggest, then, that self-management of HIV and co-morbid conditions is facilitated by support from intimate others. Mimi suggests that she yearns for this support as she ages, hinting at the fact that women's loneliness (and, by default, need for this support) might increase with age. Being single was alright in youth and in good health, but women preferred to be partnered in old age and as they were dealing with chronic illnesses.

#### *Daily life struggles*

Several participants expressed great concern over their ability to continue to effectively self-manage their health due to a lack of income and/or health insurance as a result of job loss, decreased income, and lack of health insurance. There was a general consensus among all focus group participants that seeking regular health care is critical to promote successful self-management. Despite the importance of seeking regular care, some participants expressed anxiety or fear

about not being able to access care due to a loss or reduction of health insurance.

**Rena:** You know, I'm listening to everybody say, "Go to the doctor." I have a concern now that many of you seem like you may not have. I was downsized from actually working at [name of employer] in 2009 to now. And I don't have good insurance. So my concern, I think, that I'm dealing with now is, I just came out the hospital for 6 days and I don't know who's really gon' pay this bill.

Rena highlights the conflict between the lack of income and insurance and the need for regular health care when diagnosed with HIV. Alisha further commented on how she had to choose between her job and being able to follow her HIV medication regimen.

**Alisha:**...I'm doing what I'm supposed to do. I tried to choose a job over the medicine and I knew I couldn't do that.

**Interviewer:** *Okay, so now you're not working.*

**Alisha:** No, I'm not working. And, like I say, when I was working at [name of employer], I stopped taking that medicine for a whole year, trying to keep the job 'cause I was having lotta side effects from the medicines and I couldn't do both.

Alisha's comments suggest that the effects of medication often conflict with the very structure of paid work, making it necessary for women like herself to choose self-management over paid work.

The topic of medication fatigue also arose in three of the five focus groups. Many of the women also expressed that they are tired of taking medication for their multiple ailments because they have been doing so for many years.

**Elena:** One time I had stopped taking my medicine for a whole month, you know...I'm tired of taking medicine. I been taking medicine over the last 20 years since the pills came out, AZT, you know...So women as we aging...it's a blessing for us to take the opportunity that we get now to take medicines. But when you start getting old like I am, you know, getting up in age like I am, and I don't know if anybody's gone feel like I do...You get tired of taking the medicine. But still we want to live and enjoy life. It's not that we're ungrateful, that's how it is with me.

When asked to describe the easiest and hardest aspects related to managing their HIV, several women commented on how advancements in HIV medication regimens have helped them to overcome difficulties with HIV medication adherence and decreased the fatigue associated with self-management. However, some also reported having difficulty keeping up with management regimens for their other co-morbidities. Importantly, participants often expressed that co-morbidities required more effort to control than HIV.

**Karen:** I think mine is my pressure [i.e., high blood pressure] and, you know, things that I have to deal with every day. HIV is there. It affects my immune system in some ways but lot of times I forget that I even have it. I have never been sick. I take my medication and I just take it so religiously that it's like okay you take the medicine. So that's not a problem. So it's not like it stands out like a sore thumb for me...But the pressure and things like that I have to really pay attention to every day. What I eat and how I eat. Exercise and things like that. Those are more...[cross talk]

**Elena:** And even before I became HIV[-positive] I was stressed out. I'm saying like this. I can't put everything on HIV...Things was happening to me before I even got this way.

But I feel good right now. I have my good days and my bad days, you know. But it don't all get back to HIV.

Fran, who struggles with depression as well as other co-morbidities, explained "I'm just like, you know, working towards where I know I shoulda been, and...the way I feel now, [HIV] is not what I'mma die from. I don't think it's HIV. I don't feel as though it's HIV because the medicine is really working. It's always one thing you think you gone die from and...it turn out something else..."

Thus, women in the focus groups were very aware of the fact that they could live long lives with HIV if they managed it well, and that managing co-morbidities might prove more challenging. Women in the study talked about how their doctors confirmed this as well. Mature age may have helped them move past unhealthy lifestyles in their youth and manage their HIV, but co-morbidities and other life circumstances (e.g., job loss) still forced many participants to endure daily struggles.

## Discussion

Our findings suggest that neither aging nor HIV are always at the forefront of women's concerns when they discuss their illness self-management. Co-morbid conditions, specifically diabetes and hypertension, were perceived to be more difficult to self-manage than HIV. This difficulty was not primarily attributed to aging or HIV, but rather to daily life struggles such as reduced income and health insurance and the very nature of paid work. Current life circumstances likely contribute to women's emphasis on "taking one day at a time" and the importance of managing co-morbidities ("It's not all HIV"). Women reported that they had not expected to live as long as they have and are grateful for each day as it comes. This finding suggests that women may not be focused on how getting older may impact their self-management strategies, rather they are focused on living well in the present. This present time orientation is similar to findings from Zollinger et al. regarding breast cancer screening and awareness among African American women aged 40 and over, who were more likely to be present time oriented in comparison to younger women.<sup>34</sup> Lukwago et al. also report that present time orientation may be a significant factor in the health behavior of African American women regarding breast cancer screening.<sup>35</sup> They conclude that women's social circumstances (i.e., income, education, employment) contribute to them not actively planning for the future due to meeting the demands of daily living.

However, in contrast, women's desire to find romantic male companionship as they grow older suggests that they are planning for their romantic futures. Although aging did not appear to be an explicit concern regarding women's HIV and co-morbid self-management, they did seem to implicitly place more value on aging when talking about finding love or being in a committed relationship, in order to avoid loneliness in their later years. This finding is not specific to HIV-positive older adults. For example, Luanaigh and Lawlor report that loneliness is common in older people and can negatively influence physical and mental health outcomes.<sup>36</sup> However, participants suggested that their HIV status makes it more difficult for them to find male companionship. Despite this perceived difficulty, participants remained hopeful about finding love, which served to inspire them to maintain their

overall health. Over time, the advancements in HIV treatments may have inspired the women to hold less fatalistic attitudes regarding their life expectancy. Thus, present time orientation may be buffered somewhat by women gaining hope that they will be able to enjoy life more fully with a romantic male partner. This finding is supported by research which suggests that intimate sexual relationships positively influence the quality of life of older women living with HIV.<sup>37</sup> Recognition of older age status and confirmation that HIV may not be the cause of their mortality may also encourage women in this study to think about the future.

Women reported that, over time, HIV has become easier to manage in comparison to their other illnesses based on advancements they have experienced in their HIV treatment regimens. Nonetheless, given that the majority of women in this sample have been living with HIV and taking medication for many years and are now experiencing additional chronic conditions that require medication and behavior modification, some reported growing tired of taking medicine. Being tired of taking medicine while simultaneously developing co-morbidities, may contribute to women's sense of daily struggle. Experiencing a heavy pill burden, especially over a course of years, could contribute to older women's risk of becoming non-adherent to some or all of their medication regimens. This finding is supported by research conducted with HIV-positive African Americans that identifies cultural rationales that guide HIV medication adherence.<sup>38</sup> Growing tired of taking medicine may be one contributing factor to an individual adherence rationale (IAR). Individuals' IARs are additionally influenced by popular culture, alternative medicine, "street" knowledge, and folk medicine when constructing their meanings of antiretroviral therapy adherence. We expand on the findings of Sankar by suggesting that age identities and supportive romantic partners are additional sources of authority that may contribute to women's IAR.

Participants' accounts of wanting to do for others as a vital part of self-managing their HIV suggests that as women age they feel valued and young if they are able to continue caring for others. When women in the study talked about caring for their children (even adult children), they were also more likely to discuss self-management in positive terms. This finding is supported by research which suggests that older minority women hold positions of prominence within their social networks and this is an important cultural aspect which may influence women's self-management behaviors.<sup>25</sup>

Although findings from this study may provide important insight regarding the HIV and co-morbidity self-management behaviors of African American women aged 50 and above, it is not without limitations. The participants for this study are all active participants in a longitudinal study regarding HIV among women in the United States. Consequently, the cohort effect may have influenced women's perceptions of how aging is influencing their HIV and co-morbid illness management. Thus, these findings may not be generalizable to all older African American women living with HIV. Furthermore, 9 of the 23 participants reported ever having AIDS. This is important to note because variations in AIDS status could influence women's perceptions and practices regarding their HIV and co-morbid illness self-management.

The women in this study are all coping with life-threatening illnesses, as well as race and class positions that contribute to their daily life struggles which increase the difficulty of

self-managing HIV. However, despite these difficulties, these women seem to be persevering in their efforts to self-manage HIV. This perseverance may be due in part to a mature age standpoint of knowing that HIV self-management is critical to one's survival and that successful HIV self-management is dependent upon simultaneous management of co-morbidities. As highlighted by the women in this study, self-management of co-morbidities like diabetes and hypertension pose more challenges for optimal management compared to HIV self-management. Given that HIV self-management and co-morbidity self-management are inextricably linked, providers could enhance their treatment plans and conversations with older HIV-positive African American women in an effort to provide more coordinated care. These enhanced treatment plans could offset some of the structural challenges (i.e., poverty, loneliness, HIV stigma, marital disruption) that negatively impact older women's ability to engage in optimal HIV self-management. By identifying patients' concerns, providers could adjust medication dosage and timing in an effort to combat medication fatigue. In addition, providers could recommend that patients seek out age-specific social support groups, especially for patients who express that loneliness negatively contributes to their self-management practices. Findings by Nokes et al.<sup>39</sup> note that older HIV-infected individuals can learn how to cope better with issues such as HIV and co-morbidity medication management, by participating in a telephone peer support group.<sup>39</sup> In addition, many African American churches provide social support for HIV-infected individuals, as well as individuals who are single, through their HIV/AIDS ministries and singles ministries.<sup>40</sup> Previous research<sup>41</sup> has demonstrated the positive influence that religious engagement has on the HIV coping strategies of older persons living with HIV. Thus, providers could collaborate with local churches in an effort to link older women to services and social supports that could assist them with illness self-management.

Finally, and perhaps most importantly, we can no longer afford to view engagement in HIV care as a single-disease issue and hope to attain optimal health and well-being in our HIV-affected populations. Therefore, to ensure that patients receive optimal health care, HIV specialists should continually consult with their patients' general practitioners in order to stay abreast of patient treatments and prescriptions regarding co-morbidities.

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