



Published in final edited form as:

J Health Care Poor Underserved. 2017 ; 28(1): 389–405. doi:10.1353/hpu.2017.0030.

Life begins at 60: Identifying the social support needs of African American women aging with HIV

Lari Warren-Jeanpiere, PhD, Heather Dillaway, PhD, Pilar Hamilton, BS, Mary Young, MD, and Lakshmi Goparaju, PhD

At the time of the study, **DR. WARREN-JEANPIERE** was affiliated with the Women's Interagency HIV Study (WIHS) in the Georgetown University Medical Center in Washington, DC. **DR.**

DILLAWAY is an Associate Professor in the Department of Sociology and Associate Dean in the College of Liberal Arts and Sciences at Wayne State University in Detroit, Michigan. **MS.**

HAMILTON is a Project Assistant with WIHS in the Georgetown University Medical Center. **DR.**

YOUNG is Assistant Professor of Medicine, Georgetown University Medical Center and Principal Investigator of WIHS. **DR. GOPARAJU** is an Assistant Professor in the Georgetown University Medical Center and Project Director of WIHS

Abstract

HIV chronicity has resulted in increased life expectancy for many African American women who acquired the disease during the epidemic's peak years. As these women live longer and age, their social support needs may increase. Five focus groups were conducted in Washington, DC with 23 HIV-positive African American women aged 52–65 to explore women's perceptions about how aging and HIV chronicity affects their social support needs. Participants were recruited from the longitudinal Women's Interagency HIV Study (WIHS) participant pool. A constant comparison approach was applied during data analysis. Participants reported needing increased social support, especially emotional support from health care providers, family, and HIV-positive peers. The importance of providers and HIV-positive peers was discussed most frequently relative to meeting these needs. Health care providers in particular may need to increase their provision of emotional support when devising treatment plans to meet the social support needs of older HIV-positive African American women.

Keywords

HIV self-management; social support; African American women; aging

Advances in HIV treatment regimens have changed HIV from a fatal condition into a chronic, yet manageable condition.¹ These advances have led to what is known as *HIV chronicity*.² HIV chronicity has resulted in increased life expectancy for many people who acquired the disease during the peak years of the epidemic and recent HIV statistics indicate that people aged 50 and older accounted for 21% (8,575) of an estimated 47,352 HIV diagnoses in the United States.³ In addition, in 2015 and beyond it is expected that 50% of

HIV-infected individuals will be aged 50 and over.⁴ Based upon Centers for Disease Control and Prevention HIV/AIDS surveillance categories, people aged 50 and over who are infected with HIV are deemed to be older adults.⁵

African American women constitute 13% of the total population of U.S. women, but nearly 64% of new HIV infections among all female adults and adolescents.^{6, 7} In 2013, nearly 47,500 new HIV infections occurred among individuals in the United States, with 2,500 (5%) occurring in adults aged 55 and older.³ Twenty-three percent of these new HIV infections occurred among older women: 370 (15%) African American, 110 (4%) White, and 100 (4%) Hispanic women /Latinas.³ Keeping in mind that HIV chronicity is resulting in increased life expectancy for many infected people and African American women are disproportionately affected by HIV/AIDS, it is important to have a greater understanding of older African American women's social support needs and the specific formal and informal social relationships that facilitate their HIV self-management endeavors.

According to a recent qualitative study⁸ conducted with older HIV-positive African American women, HIV self-management is defined as adhering to a daily medication regimen, eating well, exercising, doing something good for others and self, and engaging in spiritual activities, (e.g., prayer, meditation). Research⁸⁻¹¹ also reveals that social support has a positive influence on older African American women's chronic illness self-management. For instance, older HIV-positive African American women report that daily emotional support received from intimate male partners helps them to remain medically adherent to their HIV medication regimens as well as their medication regimens for co-morbid conditions (e.g., diabetes, hypertension).⁸ A qualitative study conducted with older African American chronically ill women finds that informational and emotional support received from family members can have a positive impact on women's chronic illness self-care strategies.¹⁰

Social support is often separated into three distinct domains: instrumental, informational, and emotional.¹² Instrumental support can encompass concrete support such as transportation and financial assistance. Informational support often refers to support which is given through a transfer of information by verbal or written communication. Emotional support generally refers to non-tangible support and maybe provided through providing encouragement, discussing a problem, and giving positive feedback about a problem.¹²

Much of the research regarding social support and chronic illness self-management among older adults focuses on informal sources of social support, such as care and support provided from family members, friends, neighbors, and religious communities.^{13, 14} In contrast, formal social support may be defined as help from formal services including professionals, paid helpers, or companies who provide caregiving help.¹³ There are times when older adults depend on formal sources of support to provide instrumental as well as emotional support.¹⁵ Shippy and Carpiak¹⁶ note that many older HIV-positive adults may be disconnected from informal sources of support and must rely on formal sources of support for care. For instance, a qualitative study conducted with 63 African American, Latino, and White older HIV-positive adults identified several perceived barriers to informal social

support.¹⁷ These barriers include ageism, unavailability of family, non-disclosure of HIV status, HIV stigma, and not wanting to be a burden.

There is a dearth of literature on older HIV-positive women's social support needs because the majority of studies which examine HIV self-management and/or the social support needs of HIV-positive women have been conducted with women younger than age 50.¹⁸ This research aims to address this literature gap by answering three questions. First, what are the social support needs of older HIV-positive African American women? Second, what social relationships do women deem most valuable in helping them to self-manage HIV? Third, what types of support do women receive from various social relationships? Findings from this study can provide insight into the social relationships that influence older HIV-positive women's illness self-management strategies, and serve to inform the development of age-/gender-appropriate and culturally relevant interventions to improve HIV self-management among older African American women.

Theoretical Framework

This study is guided by an intersectional theoretical framework which examines how intersecting forces including race, class, gender, age, and HIV stigma interact to produce health effects.^{19, 20} In accordance with this framework, we argue that these inequalities serve to shape the realities of living with HIV.¹⁹ For example, among women living with HIV, Black women are more likely to experience real and perceived HIV stigma compared with other women as well as their Black male counterparts.²¹ This heightened level of HIV stigma is a result of historical and existing class, race, gender, and sexuality inequalities.^{19, 21, 22} Furthermore, a reciprocal relationship exists between these intersecting forces because HIV stigma reinforces these inequalities and these inequalities in turn reinforce HIV stigma.²² Finally, mainstream societal views regarding the hypersexualization of African American female sexuality²³ combined with an increased risk of economic insecurity among older African American women²⁴ may converge to produce HIV stigma and limit older women's access to social support.^{19, 25} Social support for HIV management is critical for anyone infected; however both informal and formal social support may be particularly critical for the promotion of the HIV self-management strategies of older African American women who face unique experiences and challenges resulting from intersecting oppressive forces.^{8, 26}

Methods

Design

Focus group methodology was deemed the most appropriate method of data collection given that very little data exist regarding the lived experiences pertaining to older HIV-positive African American women's social support needs. Focus group methodology has some unique advantages including facilitating an environment where participants may feel more comfortable expressing certain views about embarrassing or sensitive topics when they are in a group setting as opposed to individual interviews and allowing for ideas to emerge as a result of synergistic energy.²⁷

Since our goal was to examine the social support needs of only older HIV-positive African American women, a single-category focus group design was deemed the best method of data collection.²⁸ Single-category design is ideal for exploring the experiences of one particular type of group rather than comparing across different groups. Thus, we only aimed to gather information from HIV-positive African American women aged 50 and over. Single-category design allowed us to reach theoretical saturation by making within-group comparisons.

Sampling and recruitment

Following approval from the Georgetown University Institutional Review Board, 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 U.S. with an original enrollment in 1994–1995 of 2,056 HIV-positive and 569 HIV-negative women.²⁹ The WIHS study sites are located in the Bronx, NY, Brooklyn, NY, Washington, DC, Los Angeles, CA, the San Francisco Bay Area, CA, Atlanta, GA, Miami, FL, Birmingham, AL, Chapel Hill, NC, 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 and 50 of the HIV-positive participants were both African American and aged 50 and over. All 50 HIV-positive African American women aged 50 and over were targeted for study participation.

A recruitment flyer was sent to all eligible WIHS participants regarding a voluntary study. Study goals were explained in more detail when the participants expressed interest to the research staff, and again during the informed consent process prior to the start of focus groups. 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 three to seven participants each and discussions lasted between 90 and 120 minutes. A semi-structured interview guide was used to generate conversation across all groups. Topics of discussion included identifying the social support needs of women as they age, facilitators and barriers to acquiring needed social support, and identifying the social relationships most critical to meeting women's social support needs. These topics were addressed in all 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 highlighting recurring comments and important quotations were also taken during each group discussion. The moderator (LWI) reviewed notes taken from previous focus groups before moderating subsequent focus groups to help stimulate early insights about how themes in the data were unfolding and to probe further into those areas if needed.³⁰

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.³¹ 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 10 software to facilitate data management.³² 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 sub-categories found repeatedly in the data.³³

The first author (a medical sociologist) 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 (HD 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 sub-categories identified during open coding. Finally, we engaged in selective coding where we decided on the core concepts that explain the social support needs and corresponding social relationships that women deem necessary to meet these needs.

Rigor and trustworthiness

Throughout the analysis, we refined our thoughts through on-going discussions in an effort to arrive at a coding consensus in order to achieve a minimum 85% inter-rater reliability, and to identify central codes and themes in the data. To ensure inter-rater reliability further, a qualitative research consultant and gerontology health expert (HD) scrutinized the core concepts identified by (LWJ) to identify any idiosyncrasies with coding and evaluate whether the final coding scheme accurately reflected what was found in the coded text segments. Further discussions were held between the first author and the consultant to identify and resolve any inconsistencies with the coding scheme.

Results

Sample profile

Theoretical saturation was achieved with five focus groups, for a total of 23 participants. Despite the fact that eligible participants were still expressing interest in study participation, we ceased our recruitment efforts as a result of reaching theoretical saturation. The mean age of focus group participants was 57 (range 52 - 65). Nine participants reported being single/never married, three were married, one lived with her male partner, six were divorced, and four 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 six months to 17 years) and the average length of time participants have been taking HIV medications is 13.1 years (range zero to 17 years). Six women had detectable HIV viral loads at the time of the focus group. Nine of the participants reported ever having AIDS.

Our analysis revealed four central themes. The first theme, *Life begins as 60*, marks a positive shift in participants' identity, in that they have reached a point of self-acceptance in

life, despite their HIV status. The second theme, *Stop worrying about everybody else*, marks participants' realizations that they desire the instrumental and emotional support that can facilitate self-empowerment and, in turn, improve HIV self-management. The third theme, *The silence is killing us*, points to participants' need for emotional support in order to withstand HIV stigma. The fourth theme, *I need something more*, signifies participants' need for continued emotional support and instrumental support as they age with HIV.

Life begins at 60

Participants were asked to describe their social support needs as well as their ideal sources for acquiring support. In these discussions, there was a general consensus among women in all five focus groups that life was "just beginning" due to a renewed outlook on life. After living for many years with HIV and also as a result of natural shifts in identity because of aging, participants found themselves at a time of life when they knew what was important to them and wanted to start living life more fully. Excerpts from four participants demonstrate this sentiment.

Focus Group A Participant: They say life begins at 50. I say it's a lie... I say life begins at 60... until we can feel good about ourselves. If you look good you feel good, you know... To learn to love us says that you're okay no matter what.

The above participant's comment denotes the importance for older HIV-positive women to focus on their physical appearance as one way to facilitate self-acceptance. This participant also implies that with self-acceptance women are able to transcend the intersecting limitations of such characteristics as age, HIV stigma, gender, and race in order to engage in successful HIV self-management. The following quotation from another participant also speaks to the importance of pampering for women as they age.

Focus Group E Participant: I know, what my main thing that I didn't have for me was learning to love myself. Because as I learned to love myself, that's when I start doing things... So it's things that we need to do...now to pamper ourselves. Like massages and acupuncture, you can help yourself, and eating right and taking vitamins... and that's the key - learn to love yourself, cause you learn to love yourself you'll do anything for yourself.

Both of the above participants suggest that it takes time to "learn to love us", meaning that HIV-positive women often have to spend time learning how to manage their HIV status and learn a new way of living before they "can feel good about [themselves]." In the following quotation another focus group participant also makes it clear that HIV status has to be "accepted" and managed, because "that's all you can do."

Participant: I know [HIV-positive status] ain't going nowhere and the only thing I can do, all this many years, I keep on accepting it and take my medication. And it ain't too much you can do about it, you know. You do the best you can....That's all you can do. Accept it and go on along with life. You can't dwell on it.... Just like I was born to live, I was born to die.... I can't stop how I came here. The only reason I can stop death is right now [is if] I have my personal relationship with the God of my understanding...But the main thing is enjoy my life. These ain't my golden

years yet. This is my, I'll say these are, I probably say these [are] still my teenage years, you know.

Self-support, in the form of self-love and pampering is identified as being important to participants' health and wellbeing as they begin to live their "golden years." The following theme highlights the necessity of receiving instrumental, emotional, and informational support from formal and informal sources in order to strengthen this self-support.

Stop worrying about everybody else

During each focus group, participants expressed the need to be able to put their own needs in front of others' needs, in order to maintain health and wellbeing. Despite living with HIV/AIDS for many years, several participants reported serving as the matriarch of their families. Family members therefore expect participants to fulfill social roles that require them to prioritize others' needs. The following quotation represents one participant's need for instrumental support (e.g., preparing family dinners) from family members in order to engage in self-support.

Interviewer: So, you're helpful to your family members?

Participant: Yes, helping everybody. But this, like last year I, they thought I was [going to] cook. I told them [at the] beginning of the year I wasn't gonna cook.

Interviewer: For Thanksgiving?

Participant: Yeah, they didn't believe me. I said, "I'm retired...I pass it on. Everybody know how to cook. I done taught all of you." And they, they was callin' around..., "Ma ain't cook, Ma ain't cook!" No. I left the house.

The following exchange illustrates that an important part of effective HIV/AIDS self-management is having informational and emotional support in place for HIV-affected family members, so that women can focus on their own healing without having to worry about the emotional well-being of their loved ones.

Interviewer: What would be your ideal system of support to help you manage your health and your HIV as you age?

Participant: Well, like I said, good doctors, of course. Support groups and also... family support groups. I think that would be good too to offer because I never was able to tell [my son] that I had the virus. He died. He got killed. And he never knew. He thought I had cancer. So the vehicle of allowing them to,... once they find out, because my daughter, she still has issues. She's thirty-five... but she still has, not issues of me, but her concerns about me, my health and how it makes me feel. Sometimes shell see me sitting down looking sad. And shell say, "Ma, what's going on?"... So, just a vehicle for them [to learn and talk about HIV] too.

This mother's story illustrates how formal social support services that are inclusive of family members could allow women to stop worrying as much about the effects of their HIV status on loved ones, so that they can continue to focus on self-acceptance.

The silence is killing us

Relatedly, focus group participants explained how their desires for additional emotional support included, in part, their desires to talk about their HIV and general life concerns with others who could empathize and not be judgmental. Women reported wanting to voice their concerns, thoughts, and experiences about aging with HIV and seek advice from others, including “good doctors,” therapists, family, and HIV-positive peers. The following participant illustrates the silence and stigma surrounding HIV/AIDS that she experiences, despite living with HIV/AIDS for years. Her declaration that “everybody’s making us feel bad” and the “hush, hush” issue she refers to implies a lack of real conversation about their illness and a lack of emotional support from non-HIV-positive individuals.

Participant: What we talk about in a lot of the support groups and when we’ll go to conferences is the... stigmatism of not talking. The silence is killing us. You’re HIV-positive. You may be suffering with Acquired Immune Deficiency Syndrome - AIDS, [inaudible] It’s an illness. You are not the illness. And so and, and everybody’s making us feel bad because we have an illness. So, once we work with that, you know, because it’s a painful thing....So, you know, the hush, hush, I mean,...and that’s been the key issue, when do you disclose and who [to] disclose to...I am my own person today. If you love, you love me. If not, fine, someone else will.

The following quotation suggests that the participant would feel more comfortable seeking support from HIV-positive female peers than from family members or other, non-HIV-positive friends. A second participant makes HIV-related stigma and unavailability of informal emotional support even clearer during her focus group.

Participant: I mean, I’ve only known you [referring to other participants in the focus group] for less than an hour. I would depend on you quicker than I depend on anybody else in my family.

Focus group discussions also revealed that women sometimes decided to care less about others’ opinions of their HIV status in order to maintain their health. The following participant expressed arriving at a life stage at which she is now better able to cope with HIV/AIDS stigma because she other people’s opinions “don’t matter.”

Participant: I’m being honest with myself. It doesn’t matter what people think about me. And it does matter and it don’t matter. ‘Cause I’m living for me. You see what I’m saying? I’m doing my life in spite of what’s going on, you know? People gon’ talk about you whether you have HIV or whether you got anything else going on with your life.

Others’ opinions “matter and don’t matter” as this woman decides she is “living for [herself].” Despite feeling good about herself, this participant’s response is indicative of the need for emotional support from informal sources as she confronts societal HIV stigma.

I need something more

Although most participants reported attending some sort of organized support group, there was a general consensus among all five groups that their social support needs have evolved over time. Many participants indicated that they would like to have more support groups composed of homogeneous groups of older, HIV-positive women (similar to our focus groups), because the challenges that they face differ from those that younger women with HIV encounter.

Participant: Well, if you living for HIV for 28, 27 years and it's the same subject matter, you know,...And you're living it, done lived it [cross talk].... I need something [different], you know, more.

In addition to attending social support groups with their peers, participants expressed the desire for a mental health care provider to also be a part of these groups. There was a general consensus among all five focus groups that mental health counseling is important for all people living with HIV (PLWH), especially for aging women who may be thinking about issues of chronic illness and death. The following exchange represents this sentiment.

Interviewer: What is it that you need now and in the future to maintain your health?

Participant: I think these organizations [support groups] should have a therapist. I mean, it's not easy when you're young or old. But in the in the progression of, your life cycle, you know, people are dying all around you, your family members. I'm the oldest one. I'm the [crosstalk] matriarch.

Several participants indicated that participating in retreats for HIV-positive individuals has provided much needed emotional and informational support. The following focus group exchanges demonstrate the importance of participants being able to transcend the everyday challenges of their lives and convene with other women who are experiencing similar challenges.

Focus Group A:

Participant 1: I think [retreats are] a valuable tool..... I go to retreats.

Participant 2: I like the retreats.

Participant 3: I go to [name of retreat]...

Participant 1: Yes. [suggesting she attends the same retreat] **Interviewer:** And that helps you?

Participant 1: You know, it helps me a lot...

Participant 3: Yes.

Participant 1: Because sometimes I'm so wounded up and... **Participant3 :** You know, you just want a relief.

Participant 2: Just living and then the fact that [cross talk] I have an illness and I go to the retreats with HIV people [a] lot like myself.

Focus Group B:

Participant 1: Really true support.

Interviewer: Would [a retreat] help you? Do you think it would help you?

Participant 1: It will help me. Yeah, and I think that ‘cause when I revealed it, a couple of women came to me and hugged my neck and said, “You know, I have HIV and thank you so much for sharing that.”

Although retreat attendance provided emotional and informational support to some women, retreat attendance was reported to be an exception and not the norm.

In addition to acquiring emotional and informational support from therapists and their same-age, HIV-positive female peers, participants expressed a need for getting additional emotional and informational support from their physicians. However, participants noted that in order to acquire the needed support from their providers, they had to be completely open and honest about their health behaviors. The following excerpt denotes this point.

Participant: For me, it’s good for me to have a good personal relationship with my doctor. Which I do. I tell her what I do. I don’t hide nothing from her because it ain’t gone do me no good and it ain’t gone do her no good.

Overall, there was a general consensus among focus groups that having a close relationship with a health care provider(s) that includes open and honest communication is critical to HIV/AIDS self-management as well. The following excerpt demonstrates the role that a long-term patient-provider relationship has played in helping the participant to remain medically adherent.

Participant: Okay.... Doctor XXXX, bless his heart, is great.

Interviewer: Good.

Participant A: And I mean, we are close, close.

Interviewer: Oh, that’s very good.

Participant A: I mean, I mean, I mean, closer than close... You know, when we talk we are buddy buddies... But, you know what? That’s what keeps me undetected, by taking my medication, ‘cause I’m sure I’ve seen people that come off medication and they viral load shoots way up there... Doctor XXXX, bless his heart. I tell you, we talk. You know, when he explained it all to me [inaudible]..., [I said,] “Okay, okay.”

From this excerpt we can glean that the above participant is receiving both instrumental (e.g., medication information), and emotional (e.g., friendship) support from her doctor. An excerpt from a final participant demonstrates a reliance on hospital staff for both emotional (e.g., pampering) and instrumental (e.g., transportation) support, in the absence of support from informal sources.

Participant: So I had to call a[n] ambulance on myself. Okay. Nobody went with me. So I was in the hospital. Bless their hearts. I’m thinking I’m a be in the hospital

for a coupla days, eat some hospital food, and get some pampering. That lady popped up and say, “I’m giving you medicines to give you oxygen treatment.” They gave me the antibiotic drip. I’m laying up there, say, “Oh, okay, I guess I’ma spend the night over.” [But they say,] “Oh, no, Ms., you could leave [in] about a hour.” I say, “How I’ma get home?” [They say,] “Oh, hold up, I got that for you.” Came up with a [bus] token.

Data in this section suggest participants’ need for both instrumental and emotional support from formal sources (e.g., doctors, hospital staff, and age-segregated, HIV-positive support groups). Emotional and instrumental support from formal sources may be critical to women’s self-support efforts given a lack of both types of support from informal sources.

Discussion

This study explored older African American women’s perceptions about how HIV chronicity affects their social support needs. As voiced by the African American women in this study, participants are redefining themselves in positive terms as they age, in order to transcend the intersecting demands of HIV stigma, gender and race constraints and to concentrate on self-management. Participants also expressed that advancing into older age with HIV has served to facilitate a greater self-awareness of their social support needs. Women in this sample place emphasis on the identity shifts they are experiencing at age 50, 60 and beyond as they are finally ready to accept themselves. They desire support from others as they “begin” life again in their “golden years.”

Women’s social support needs are varied and change with age, and HIV status can shape aging women’s social support needs in unique ways. Participants reported needing emotional support (e.g., talking with others, feeling close to others, pampering), informational support (e.g., on medication side-effects, information about family support groups, information from mental health providers), and instrumental support (e.g., transportation assistance, health care insurance). Health care providers and HIV-positive peers were identified as key individuals to provide emotional, informational, and instrumental social support.

For some women in our study, health care providers represented the only reliable source of support. A majority of women in our sample reported relying heavily on formal sources of support for HIV self-management -- not only for informational support but also emotional support. The current reliance on formal versus informal support for HIV self-management could be a function of the development of emotional coping skills resulting from HIV chronicity,³⁴ in that women often have well-established relationships with doctors and face considerable stigma and silence surrounding HIV once they leave doctors’ offices.³⁵ Participants’ heavy reliance on formal sources of support (especially for emotional support) is noteworthy and deserves further research.

Findings on the four central themes (*Life begins at 60*, *Stop worrying about everybody else*, *The silence is killing us*, and *I need something more*), demonstrate that emotional support needs might ebb, flow, and change throughout women’s lives, perhaps more so than instrumental and informational needs do. This finding is supported by a recent study

conducted with 1,300 chronically ill patients regarding their changing social support needs.³⁶ van Houtum et al.³⁶ conclude that patient perceptions of their chronic illness and actual changes in their self-rated health are predictive for their need for support for self-management activities.

Earlier in their HIV-positive experience, instrumental and informational support may have been more critical as the women were learning to accept their initial HIV-positive diagnosis and self-manage HIV. At midlife, however, participants largely report that they have stable HIV self-management strategies⁸ and feel good about themselves. In fact, older HIV-positive African American women in this sample perceive that their mortality will result from a non-AIDS comorbid condition, such as diabetes and/or hypertension, because they are self-managing well.⁸ This finding of participants' optimism within HIV chronicity stands in stark contrast to research that purports that, over time, chronically ill people may begin to question their own self-worth and view their limitations as losses.³⁷ Yet, regardless of good self-management and more positive self-images, older women in this sample still require substantial emotional support as they continue to confront HIV stigma and a lack of informal sources of support.

While individuals with chronic health conditions often find informal sources of support to be more helpful than formal sources^{38, 39} the exact opposite situation was described by our participants. Our findings also reveal that because of the simultaneity of HIV stigma and societal ageism,⁴⁰ older HIV-positive women may find it more difficult to seek support from informal sources to aid them with their HIV management in comparison with other chronic illnesses. Poindexter and Shippy⁴¹ report a similar conclusion in a study conducted with HIV-positive African American women aged 50–83, that reveals women regarded their families to be an unreliable source of social support.

As a result, participants constructed “alternative families” with HIV-positive female peers that they met via an AIDS social service organization.⁴¹ A few women in our sample did note that adult children could be supportive if provided enough information about HIV, but these informal sources of support were few and far between— partially because family members were not educated themselves about HIV. This finding aligns with research that notes that older adults often rely on formal sources of support due to a lack of available informal support.^{15, 35, 42}

Increased emotional and instrumental support from family members may be especially significant for older, chronically ill African American women who commonly assume the role of family matriarch.^{38, 43} Similar to our findings, Cagle, Kelly, and Carter-Edwards⁴³ note that older African American women with type 2 diabetes need emotional and instrumental support from family members, by way of family members “sharing head of household” duties. Participants reported that this additional support would enable them to optimize their chronic illness self-management strategies because they would not have to worry about the well-being of significant others. The authors conclude that health care providers could facilitate informal support for older chronically ill African American women by providing women and their families with emotional support (e.g., verbal positive reinforcement) regarding chronic illness management.⁴³

These findings have several implications for the design and implementation of appropriate clinical care and social support programs for older HIV-positive African American women. Older HIV patients have social and psychological needs that extend well beyond the clinical visit.⁴⁴ Consequently, providers could enhance coordination of HIV care with social service organizations, to assess and possibly increase the available informal support that their patients have. There are a number of strategies that providers could employ in order to assist older women with HIV self-management, including: creating a positive clinical environment within which women can more fully support their own emotional and physical wellbeing; involving family members in appointments; offering HIV educational and social support programs for families to help remove HIV stigma and enhance the informational and emotional support families need to assist older women with HIV self-management.

As demonstrated in our study, concerned family members can become an additional burden on women, if they are not educated about HIV. Our recommendation to involve family members in the HIV self-management of older women is in direct support of findings^{10–11, 35, 43, 45} that suggest that enlisting family members as allies in the fight against chronic illness is an effective intervention. All of these strategies could be facilitated with the use of a patient navigator program.⁴⁶ Under this model, trained personnel including medical, behavioral and/or lay professionals assist chronically ill patients to overcome barriers to care, including a lack of social support and illness stigma.

Limitations

Although findings from this study may provide important insight into the social support needs of African American women aged 50 and above, this study 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.²⁹ Given that the study participants are members of a longitudinal study where they are queried bi-annually about their health and health-seeking behaviors, they may think about their social support needs more than women who are not members of a longitudinal study. Furthermore, WIHS itself may serve as a model of positive formal support, thus creating a unique experience for its study participants that may not be generalizable to non-WIHS participants.

In addition, participants of this study may only represent a portion of the target population in terms of motivation, HIV/AIDS status, and overall health. Therefore, a selection bias maybe present. Furthermore, nine of the 23 participants reported ever having AIDS and one participant was newly diagnosed with HIV. This is important to note because variations in HIV/AIDS status could influence women's perceptions regarding their social support needs and the social relationships that are the most important to fulfill these needs. For all of the above reasons, these findings may not be generalizable to all older African American women living with HIV.

Conclusion

Health care providers should be aware of how much their older African American patients may value the extra emotional support that they receive from formal sources. This emotional support becomes important in laying a foundation for women to pay attention to their own

emotional and physical wellbeing in order to support themselves. With increased knowledge of women's daily life struggles with HIV and how those struggles may change over the life course, providers could enhance their treatment plans and conversations with older HIV positive African American women patients to support women who look forward to full lives ahead from their perspective at midlife.

Social support programs that help to facilitate self-efficacy and self-acceptance are key to helping chronically ill patients engage in illness self-management,^{38, 41} especially older HIV-positive African American women who may need additional emotional support to combat the negative health effects produced by multiple, intersecting statuses.^{19, 20} The success that participants in this study reported in managing their HIV⁸ is encouraging, and much can be learned from these women to create social support interventions that could help older HIV-positive African American women age well with HIV.

Acknowledgments

Data in this manuscript were collected by the Women's Interagency HIV Study (WIHS). The contents of this publication are solely the responsibility of the authors and do not represent the official views of the National Institutes of Health (NIH). WIHS (Principal Investigators): UAB-MS WIHS (Michael Saag, Mirjam-Colette Kempf, and Deborah Konkle-Parker), U01-AI-103401; Atlanta WIHS (Ighowwerha Oforokun and Gina Wingood), U01-AI-103408; Bronx WIHS (Kathryn Anastos), U01-AI-035004; Brooklyn WIHS (Howard Minkoff and Deborah Gustafson), U01-AI-031834; Chicago WIHS (Mardge Cohen), U01-AI-034993; Metropolitan Washington WIHS (Mary Young), U01-AI-034994; Miami WIHS (Margaret Fischl and Lisa Metsch), U01-AI-103397; UNC WIHS (Adaora Adimora), U01-AI-103390; Connie Wofsy Women's HIV Study, Northern California (Ruth Greenblatt, Bradley Aouizerat, and Phyllis Tien), U01-AI-034989; WIHS Data Management and Analysis Center (Stephen Gange and Elizabeth Golub), U01-AI-042590; Southern California WIHS (Alexandra Levine and Marek Nowicki), U01-HD-032632 (WIHS I - WIHS IV). The WIHS is funded primarily by the National Institute of Allergy and Infectious Diseases (NIAID), with additional co-funding from the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), the National Cancer Institute (NCI), the National Institute on Drug Abuse (NIDA), and the National Institute on Mental Health (NIMH). Targeted supplemental funding for specific projects is also provided by the National Institute of Dental and Craniofacial Research (NIDCR), the National Institute on Alcohol Abuse and Alcoholism (NIAAA), the National Institute on Deafness and other Communication Disorders (NIDCD), and the NIH Office of Research on Women's Health. WIHS data collection is also supported by UL1-TR000004 (UCSF CTSA) and UL1-TR000454 (Atlanta CTSA).

References

1. Scandlyn J. When AIDS became a chronic disease. *West J Med.* 2000 Feb; 172(2):130–133. <http://dx.doi.org/10.1136/ewjm.172.2.130> PMID:10693378 PMCID:PMC1070775. [PubMed: 10693378]
2. Nixon SA, Hanass-Hancock J, Whiteside A, et al. The increasing chronicity of HIV in sub-Saharan Africa: re-thinking "HIV as a long-wave event" in the era of widespread access to ART. *Global Health.* 2011 Oct 20;7:41. <http://dx.doi.org/10.1186/1744-8603-7-41> PMID:22014075 PMCID:PMC3206821. [PubMed: 22014075]
3. Centers for Disease Control and Prevention (CDC). HIV among people aged 50 and over. Atlanta, GA: CDC; 2016. Available at: <http://www.cdc.gov/hiv/risk/age/olderamericans/#footnotes>
4. Kirk JB, Goetz M. Human immunodeficiency virus in an aging population, a complication of success. *J Am Geriatr Soc.* 2009 Nov; 57(11):2129–2138. Epub 2009 Sep 28. <http://dx.doi.org/10.1111/j.1532-5415.2009.02494.x> PMID:19793157. [PubMed: 19793157]
5. Centers for Disease Control and Prevention (CDC). Diagnoses of HIV infection among adults aged 50 years and older in the United States and dependent areas, 2007–2010. Atlanta, GA: CDC; 2013. Available at: http://www.cdc.gov/hiv/pdf/statistics_2010_HIV_Surveillance_Report_vol_18_no_3.pdf
6. U.S. Census Bureau. Population estimates. Washington, DC: U.S. Census Bureau; 2010. Available at: <https://www.census.gov/popest/data/historical/2000s/index.html>

7. Centers for Disease Control and Prevention (CDC). HIV among women: fact facts. Atlanta, GA: CDC; 2016. Available at: <http://www.cdc.gov/hiv/risk/gender/women/facts/index.html>
8. Warren-Jeanpiere L, Dillaway H, Hamilton P, et al. Taking it one day at a time: African American women aging with HIV and co-morbidities. *AIDS Patient Care STDS*. 2014 Jul; 28(7):372–380. Epub 2014 Jun 16. <http://dx.doi.org/10.1089/apc.2014.0024> PMID:24933093 PMCID:PMC4074760. [PubMed: 24933093]
9. Gallant M. The influence of social support on chronic illness self-management: a review and directions for research. *Health Educ Behav*. 2003 Apr; 30(2):170–195. <http://dx.doi.org/10.1177/1090198102251030> PMID:12693522. [PubMed: 12693522]
10. Warren-Findlow J, Prohaska TR. Families, social support, and self-care among older African-American women with chronic illness. *Am J Health Promot*. 2008 May-Jun;22(5):342–349. <http://dx.doi.org/10.4278/ajhp.22.5.342> PMID:18517095. [PubMed: 18517095]
11. McDoom MM, Bokhour B, Sullivan M, et al. How older Black women perceive the effects of stigma and social support on engagement in HIV care. *AIDS Patient Care STDS*. 2015 Feb; 29(2): 95–101. Epub 2014 Dec 11. <http://dx.doi.org/10.1089/apc.2014.0184> PMID:25494607. [PubMed: 25494607]
12. Heaney, C., Israel, B. Social networks and social support. In: Glanz, K.Lewis, F., Rimer, B., editors. *Health behavior and health education: theory, research, and practice*. 2nd. San Francisco, CA: Jossey-Bass; 1997.
13. Williams SW, Dilworth-Anderson P. Systems of social support in families who care for dependent African American elders. *Gerontologist*. 2002 Apr; 42(2):224–236. <http://dx.doi.org/10.1093/geront/42.2.224> PMID:11914466. [PubMed: 11914466]
14. Becker G, Newsom E. Resilience in the face of serious illness among chronically ill African Americans in later life. *J Gerontol B Psychol Sci Soc Sci*. 2005 Jul; 60(4):S214–S223. <http://dx.doi.org/10.1093/geronb/60.4.S214> PMID:15980297. [PubMed: 15980297]
15. Wolfson CR, Barker JC, Mittness LS. Personalization of formal social relationships by the elderly. *Res Aging*. 1990 Mar; 12(1):94–112. <http://dx.doi.org/10.1177/0164027590121005> PMID: 2315556. [PubMed: 2315556]
16. Shippy RA, Karpiak SE. Perceptions of support among older adults with HIV. *Res Aging*. 2005 May; 27(3):290–306. <http://dx.doi.org/10.1177/0164027504273780>.
17. Schrimshaw EW, Siegel K. Perceived barriers to social support from family and friends among older adults with HIV/AIDS. *J Health Psychol*. 2003 Nov; 8(6):738–752. <http://dx.doi.org/10.1177/13591053030086007> PMID:14670207. [PubMed: 14670207]
18. Durvasula R. HIV/AIDS in older women: unique challenges, unmet needs. *Behav Med*. 2014; 40(3):85–98. <http://dx.doi.org/10.1080/08964289.2014.893983> PMID:25090361 PMCID:PMC4152459. [PubMed: 25090361]
19. Watkins-Hayes C. Intersectionality and the sociology of HIV/AIDS: past, present, and future research directions. *Annu Rev Sociol*. 2014 Jul;40:431–457. <http://dx.doi.org/10.1146/annurev-soc-071312-145621>.
20. Mullings, L., Schulz, AJ. Intersectionality and health: an introduction. In: Schulz, AJ., Mullings, L., editors. *Gender, race, class, & health: intersectional approaches*. San Francisco, CA: Jossey-Bass; 2006.
21. Loutfy M, Logie CH, Zhang Y, et al. Gender and ethnicity differences in HIV-related stigma experienced by people living with HIV in Ontario, Canada. *PLoS One*. 2012; 7(12):e48168. Epub 2012 Dec 27. <http://dx.doi.org/10.1371/journal.pone.0048168> PMID:23300514 PMCID:PMC3531426. [PubMed: 23300514]
22. Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Soc Sci Med*. 2003 Jul; 57(1):13–24. [http://dx.doi.org/10.1016/S0277-9536\(02\)00304-0](http://dx.doi.org/10.1016/S0277-9536(02)00304-0). [PubMed: 12753813]
23. Collins, PH. *Black sexual politics: African Americans, gender, and the new racism*. New York, NY: Routledge; 2004. <http://dx.doi.org/10.4324/9780203309506>
24. Williams Shanks, T., Leigh, W. Assets and Older African Americans. In: Morrow-Howell, N., Sherraden, MS., editors. *Financial capability and asset holding in later life: a life course perspective*. Oxford, UK: Oxford University Press; 2015.

25. Colbert AM, Kim KH, Sereika SM, et al. An examination of the relationships among gender, health status, social support, and HIV-related stigma. *J Assoc Nurses AIDS Care*. 2010 Jul-Aug; 21(4):302–313. Epub 2010 Jan 29. <http://dx.doi.org/10.1016/j.jana.2009.11.004> PMID:20116295 PMCID:PMC2889012. [PubMed: 20116295]
26. Kim H. Older women's health and its impact on wealth. *J Women Aging*. 2006; 18(1):75–91. http://dx.doi.org/10.1300/J074v18n01_06 PMID:16635951.
27. Kitzinger, J. Focus groups. In: Pope, C., Mays, N., editors. *Qualitative research in health care*. 3rd. Oxford, UK: Malden - Blackwell Publishing; 2006. <http://dx.doi.org/10.1002/9780470750841.ch3>
28. Krueger, RA., Casey, MA. *Focus groups: a practical guide for applied research*. Thousand Oaks: Sage Publications; 2009.
29. Bacon MC, von Wyl V, Alden C, et al. The Women's Interagency HIV Study: an observational cohort brings clinical sciences to the bench. *Clin Diagn Lab Immunol*. 2005 Sep; 12(9):1013–1019. <http://dx.doi.org/10.1128/cdli.12.9.1013-1019.2005>. [PubMed: 16148165]
30. Patton, MQ. *Qualitative research & evaluation methods: integrating theory and practice*. 4th. Thousand Oaks, CA: Sage Publications; 2015.
31. Pope, C., Ziebland, S., Mays, N. Analysing qualitative data. In: Pope, C., Mays, N., editors. *Qualitative research in health care*. 3rd. Oxford, UK: Malden - Blackwell Publishing; 2006. <http://dx.doi.org/10.1002/9780470750841.ch7><http://dx.doi.org/10.1002/9780470750841>
32. NVivo qualitative data analysis Software; QSR International Pty Ltd. Version 10. 2012.
33. Strauss, A., Corbin, J. *Grounded theory in practice*. Thousand Oaks: Sage Publications; 1997.
34. Vance D. Relationship between duration of HIV disease and diagnostic history. *Psychol Rep*. 2006 Apr; 98(2):536–540. <http://dx.doi.org/10.2466/pr0.98.2.536-540> PMID:16796111. [PubMed: 16796111]
35. George S, Garth B, Wohl A, Galvan F. Sources and types of social support that influence engagement in HIV care among Latinos and African Americans. *J Health Care Poor Underserved*. 2009 Nov; 20(4):1012–1035. <http://dx.doi.org/10.1353/hpu.0.0210> PMID:20168014 PMCID:PMC3110696. [PubMed: 20168014]
36. van Houtum L, Rijken M, Heijmans M, et al. Self-management support needs of patients with chronic illness: do needs for support differ according to the course of illness? *Patient Educ Couns*. 2013 Dec; 93(3):626–632. Epub 2013 Aug 29. <http://dx.doi.org/10.1016/j.pec.2013.08.021> PMID: 24029582. [PubMed: 24029582]
37. Charmaz K. Loss of self: a fundamental form of suffering in the chronically ill. *Sociol Health Illn*. 1983 Jul; 5(2):168–195. <http://dx.doi.org/10.1111/1467-9566.ep10491512> PMID:10261981. [PubMed: 10261981]
38. Gallant MP, Spitz G, Grove JG. Chronic illness self-care and the lives of older adults: a synthetic review across four ethnic groups. *J Cross Cult Gerontol*. 2010 Mar; 25:21–43. <http://dx.doi.org/10.1007/s10823-010-9112-z> PMID:20177963 PMCID:PMC2929526. [PubMed: 20177963]
39. Hsia AW, Castle A, Wing JJ, et al. Understanding reasons for delay in seeking acute stroke care in an underserved urban population. *Stroke*. 2011 Jun; 42(6):1697–1701. Epub 2011 May 5. <http://dx.doi.org/10.1161/STROKEAHA.110.604736> PMID:21546471 PMCID:PMC3130551. [PubMed: 21546471]
40. Emler C. "You're awfully old to have this disease": experiences of stigma and ageism in adults 50 years and older living with HIV/AIDS. *Gerontologist*. 2006 Dec; 46(6):781–790. <http://dx.doi.org/10.1093/geront/46.6.781> PMID:17169933. [PubMed: 17169933]
41. Poindexter C, Shippey RA. Networks of older New Yorkers with HIV: fragility, resilience, and transformation. *AIDS Patient Care STDs*. 2008 Sep; 22(9):723–733. <http://dx.doi.org/10.1089/apc.2007.0260> PMID:18754703. [PubMed: 18754703]
42. Bardach SH, Tarasenko YN, Schoenberg NE. The role of social support in multiple morbidity: self-management among rural residents. *J Health Care Poor Underserved*. 2011 Aug; 22(3):756–771. <http://dx.doi.org/10.1353/hpu.2011.0083> PMID:21841277 PMCID:PMC3624890. [PubMed: 21841277]
43. Cagle C, Appel S, Skelly A, et al. Mid-life African-American women with type 2 diabetes: influence on work and the multicultural caregiver role. *Ethn Dis*. 2002 Fall; 12(4):555–566. PMID: 12477143. [PubMed: 12477143]

44. Ball S. Increased longevity in HIV: caring for older HIV-infected adults. *Care Manag J*. 2014; 15(2):76–82. <http://dx.doi.org/10.1891/1521-0987.15.2.76> PMID:25118513. [PubMed: 25118513]
45. Smith Fawzi M, Eustache E, Oswald C, et al. Psychosocial support intervention for HIV-affected families in Haiti: implications for programs and policies for orphans and vulnerable children. *Soc Sci Med*. 2012 May; 74(10):1494–1503. Epub 2012 Mar 6. <http://dx.doi.org/10.1016/j.socscimed.2012.01.022> PMID:22444459. [PubMed: 22444459]
46. Kelly E, Ivers N, Zawi R, et al. Patient navigators for people with chronic disease: protocol for a systematic review and meta-analysis. *Syst Rev*. 2015 Mar 14.4:28. <http://dx.doi.org/10.1186/s13643-015-0019-1> PMID:25874724 PMCID:PMC4375835. [PubMed: 25874724]

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript