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Medication Adherence Among African American Women Who Have Been HIV Positive for 10 or More Years

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Abstract

Although new HIV infections in African American women have decreased, this population still constitutes the over half of all new HIV infections in women. Risk-reduction interventions and advancements in antiretroviral therapies have helped HIV-positive persons live longer. However, there are lags in care linkages and retention. Medication adherence is an important aspect of enhancing quality of and prolonging lives of persons living with HIV/AIDS. While studies have explored barriers and facilitators to medication adherence, gaps in the literature related to adherence for high-risk populations remain. By using narrative inquiry and the Health Belief Model, this exploratory study sought to gain insight on facilitators of and barriers to medication adherence among African American women who have been HIV positive for 10 or more years. The women discussed personal experiences and cues to action that help them remain adherent. Additional studies testing interventions designed specifically for long-term survivors may be advantageous within public health.

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Introduction

The Centers for Disease Control and Prevention (CDC) reported nearly 1.1 million people in the United States are infected with HIV (CDC, 2018a). Of populations hit hardest by the HIV epidemic, African Americans face the greatest burden of disease. While African Americans comprise only 12% of the U.S. population, nearly 44% of all new HIV infections are in this demographic. Although new HIV infections in African American women have decreased by 20% between 2011 and 2016, this population still constitutes 61% of all new HIV infections in women compared with 19% of White women and 16% of Hispanic women (CDC, 2018b). In addition, African American women comprise 59% of all women living with HIV. As public health efforts have made great strides to reduce new infections in African American women, it is imperative to ensure women living with HIV are linked to care and provided with opportunities to live a quality life. With adequate linkages to care and appropriate treatment, many people living with HIV/AIDS (PLWHA) achieve viral suppression, experience fewer opportunistic infections, and are less likely to become resistant to HIV medications (NAM, 2015). The CDC (2014) estimated that life expectancy can increase by nearly 40 years for persons successfully linked to care and taking antiretroviral therapy (ART) as prescribed. However, even with evidence demonstrating the importance of ART, only 40% of PLWHA are linked to care. Therefore, this study seeks to add to the body of research exploring medication adherence and is a part of a larger research project that sought to understand the experiences of African American women who are HIV positive (Cherry et al., 2018). Within the frame of narrative inquiry and the Health Belief Model (HBM), this study used a subset of the data to explore barriers to and facilitators of medication adherence among African American women from Georgia and South Carolina who have lived with HIV for 10 or more years ($N = 7$).

Background

Research focusing on PLWHA has been ongoing for nearly three decades to improve health outcomes for this population. Lather and Smithies (1997) conducted one of the first qualitative studies to understand the experiences of HIV-positive women in 1997. By visiting a series of support groups, the authors sought to explore the experiences of the participants (*N* = 26). The results provided insight to what participants' lives were like during the early years of the epidemic. Since that time, a plethora of research has focused on medication adherence in PLWHA.

Findings from several studies have highlighted the importance of incorporating religion and spirituality in public health initiatives designed for African Americans in general, and African American women specifically (Bourjolly & Hirschman, 2001). Parsons et al. (2006) conducted a cross-sectional study to examine associations between religious beliefs and medication adherence. The authors found while being in medical care was associated with patient satisfaction and a belief that HIV is not a sin, gaps between diagnosis and start of medical treatment were significantly associated with injectable drug use (IDU) and a stronger belief that HIV was a punishment from God.

Bandura (1989) defined self-efficacy as "people's beliefs that they can exert control over their motivation and behavior and over their social environment" (p. 128). Johnson et al. (2006) conducted a multisite, cross-sectional study to determine the association between self-efficacy, patient-provider relationships, and ART. The researchers concluded that self-efficacy related to medication adherence mediated the relationship between positive patient-provider relationships and ART adherence. Holstad et al. (2016) used baseline data from the Keeping Healthy and Active with Risk Reduction and Adherence (KHARMA) trial to examine key traits of women who exhibited different levels of ART, as well as HIV-related risk behaviors. The authors found participants who were considered high adherers had greater levels of adherence self-efficacy.

Rintamaki et al. (2006) presented an example of how stigma may impact the health outcomes of PLWHA. In a mixed methods study, significant findings were that persons with stigma concerns were 2.5 times more likely to misinterpret their CD4 count and 3 times less adherent, and concerns about HIV disclosure were the only statistically significant, independent predictor of medication adherence when multivariate analysis was conducted.

Vyavaharkar et al. (2007) explored the relationship between social support and medication adherence for women, as well as sociodemographic factors and coping mechanisms related to ART. The authors concluded satisfaction with social support, along with coping focused on managing HIV, were the best positive predictors of medication adherence. In a randomized controlled trial (RCT) conducted by Lehavot et al. (2011), findings indicated age was more strongly associated with medication adherence (older participants were more adherent) than race. Medication-specific support moderated the association between alcohol and other drug use (AOD) and medication adherence; therefore, the association between AOD and medication adherence was only significant when medication-specific support was added to the analysis model.

In 2009, HIV/AIDS adherence researcher Seth Kalichman published *Denying AIDS: Conspiracy Theories, Pseudoscience, and Human Tragedy*. As described by Kalichman, these views include a wide range of perspectives, including denying HIV exists, debunking linkages between HIV and AIDS, and conspiracy theories about pharmaceutical companies and the effectiveness of ART. As highlighted by Kalichman, beliefs related to AIDS denialism may affect medication adherence and have the potential to influence other PLWHA as they contemplate seeking care and taking medication. Following *Denying AIDS*, Kalichman et al. (2010) published a follow-up article on AIDS denialism. The researchers found that AIDS denialism beliefs were common among one in five participants. Participants who believed there is still a debate about if HIV causes AIDS were less adherent had higher viral loads and experienced increased HIV symptoms.

While some of the aforementioned studies have included African American women in the sample, there is also a plethora of research examining barriers to and facilitators of medication adherence exclusively among this population. Social support has been found to be a significant factor in medication adherence among HIV-positive, African American women. Edwards (2006) found social support as a facilitator of medication adherence, while stigma, among a few other variables, was identified as barriers. Likewise, Edwards et al. (2012) identified social support as a facilitator to medication adherence and stigma related to HIV disclosure status as a barrier to medication adherence. Amutah-Onukagha et al. (2018) determined that managing comorbidities, lack of social support, and fluctuations in mood (depression, stress, etc.) were barriers to medication adherence. The presence of social support, positive relationships with clinicians, and access to health education were facilitators of medication adherence. According to a study by Geter et al. (2018), African American women reported lack of social support, poor quality of HIV services, and stigma as barriers to medication adherence. Facilitators included feelings of reliance, positive relationships with care providers, and adequately addressing mental health. Sangaramoorthy et al. (2017) found financial obligations and managing comorbidities as major barriers to medication adherence. In addition, a unique aspect of Sangaramoorthy et al.'s (2017) findings that are relevant to this study is the authors reported adherence increased with age because of the women's acceptance of their condition, hopefulness, and resilience. Finally, Dalmida et al. (2012) found that spirituality and social support were positively associated with medication adherence for this population.

Research using a variety of methodologies has sought to investigate medication adherence specifically among African American women living with

HIV/AIDS. However, a recent analysis conducted by Kegler et al. (2019) found no studies published in a popular public health journal used a narrative approach to conducting public health research. Similarly, few studies have used a narrative approach to explore medication adherence in African American women who have lived with the virus for 10 or more years.

Research Design

This study is a part of a larger research project that sought to understand the experiences of African American women who are HIV positive (Cherry et al., 2018). Within the frame of a narrative inquiry approach, specifically narrative interviews, a subset of the data were used to explore barriers to and facilitators of medication adherence among African American women from Georgia and South Carolina who have lived with HIV for 10 or more years ($N = 7$). This methodology positioned the study in a framework of research design seeking to know and understand versus predict and alter (Czarniawska, 2004; Kramp, 2004). Our lives can then be understood as stories presented or constructed in ways to help us understand and make meaning of our experience. For this study, narrative research positioned the researchers to focus on the lived experiences of the participants as told in story form and detailing a series of events related to their HIV infection and medication adherence. Polkinghorne (1988) described interviews as a basic source of data for descriptive, narrative research. In keeping with these methodologists, we used a repeat-interview structure.

Instrument Development

In conjunction with narrative inquiry, the HBM (Bandura, 1989; Hayden, 2013; Hochbaum et al., 1952), served as a theoretical framework and guided data generation, as well as data analysis. The main constructs of the HBM include perceived seriousness, susceptibility, benefits, and barriers (Bandura, 1989; Hochbaum et al., 1952). In recent years, additional constructs have been added: cues to action or motivation and self-efficacy (Hayden, 2013). HBM posits that health behavior is a complex intermingling of a number of elements, including demographic factors and personal beliefs. Over time, the HBM has provided a useful theoretical framework for investigating determinants of a range of behaviors that impact one's health (Orji et al., 2012). While HBM is commonly used in public health to plan health promotion interventions, it is also useful to assess health beliefs and decisions absent of intervention development. The researchers used the HBM to explore (a) what experiences shaped participants' perceived susceptibility, severity, and threat of living with HIV, and not taking medication(s); (b) what participants described as the benefits of remaining adherent to medication; (c) what participants described as barriers to medication adherence; and (d) what were the cues to action or motivation to take medication as prescribed?

Recruitment and Study Protocol

The first author contacted three potential participants she knew from working and volunteering at a local AIDS Service Organization (ASO) to provide an overview of the study and inform them of a time commitment of 3 to 5 hours, along with a US$25 gift card for each completed interview (total compensation of US$75). The women were asked to refer at least one other person until seven participants were recruited, which yielded two additional participants. Two women were referred by Public Health practitioners in South Carolina after the first author called former colleagues to explain the study and ask for referrals. All participants who were contacted expressed an interest in participating in the study. No additional recruitment efforts took place. Following recruitment, we called participants to complete a brief, prescreen questionnaire to provide demographic data, schedule a first interview, and select a pseudonym to be used during the interviews. With the exception of one participant who requested interviews be conducted at her office, all interviews took place in a participant's home and were digitally recorded. Prior to a participant's first interview, we obtained consent using a consent form approved by the University of Georgia's Institutional Review Board. Eligibility for this study included women who self-identified as African American, were HIV positive, and were taking ART medication. Each participant completed three interviews (see Supplementary Appendix A) to establish rapport between the researcher and participant and enhance data triangulation (Roulston, 2010), establish validity (Seidman, 2013), and fill in missing gaps (Knox & Burkard, 2009). Interviews were designed on the work on the Seidman (2013). The first interview was the focused life history interview and allowed participants to discuss their family histories and events leading up to being diagnosed with HIV. The second interview was the detailed lived experience and provided the participant with an opportunity to discuss specific events related to medication adherence. The third interview aimed to reflect on the meaning and built on the previous interviews and encouraged the participants to contextualize their understanding and the meaning of their experiences, as well as living with HIV. Interviews were conducted 3 days apart. According to Stake (2006), the spacing between the interviews helps expand statements given by the participant, while allowing the participant a reasonable length of time to reflect on what was previously

Table 1. Participant Characteristics.

Name	Age	Marital status	Prior substance use	No. of years HIV positive	Mode of infection	No. of years medication adherent
Amy	59	Divorced	Yes	23	Sex with male partner	16
Felicia	48	Single	No	15	Sex with male partner	15
Josalin	61	Divorced	No	27	Sex with male partner	19
Madeline	66	Separated	Yes	22	Prostitution	16
Rochelle	53	Divorced	No	18	Sex with male partner	18
Shelly	52	Long-term partner	Yes	18	Sex with male partner	18
Taliah	23	Single	No	23	Perinatal	18

shared, and to elaborate during the next interview. All interviews were audio recorded and transcribed before the next interview took place. The first interview ranged in length from 24 to 108 minutes, with an average of 1 hour. Follow-up interviews lasted an average of 20 minutes. Participant ages ranged from 23 to 66 years old ($M = 51.7$), were HIV positive an average of 21 years, and only one participant was with a long-term partner. Three of the women had a history of substance abuse and six of seven participants contracted HIV via unprotected sex. The women had been taking HIV medication for an average of 17 years (Table 1).

Data Analysis

The first author conducted, audio recorded, transcribed verbatim, and analyzed all interviews. The researcher used MAXQDA, a type of Qualitative Data Analysis Software (QDAS), for multiple rounds of coding (refer to Supplementary Appendix B). A code book was created and initial codes were added with definitions based on the constructs of the HBM. Additional codes and definitions were added as data analysis continued and reviewed by the second author. Once all interviews were coded, the first and second authors reviewed the code book and transcripts to group codes into categories, as well as consolidate or eliminate excessive codes not used frequently. The researchers used MAXQDA and other visual aids to create code maps and continue organizing the codes. After codes and categories were solidified, the first author added supporting quotes throughout to tell the participants' stories as they related to medication adherence. This process allowed the project to remain closely aligned with the HBM as the major constructs guided code organization and narrative research as participant's stories were used to explore the nuances and detail their experiences and related beliefs about medication adherence (Josselson, 2011). The first author consistently met with the other members of the research team to review findings and achieve researcher triangulation. As a reflexivity practice, the first author maintained a researcher journal to log interactions with participants, changes in the interview schedule, post interview reflections, and questions about coding or data analysis. Finally, to include member checking in the data analysis process, the preliminary findings were shared with all participants to verify what was recorded and confirm they were comfortable with the transcriptions as presented. No participant objected to and requested the removal of any interview data.

Results

This study explored how African American women who have been HIV positive for 10 or more years described barriers to and facilitators of medication adherence. Figure 1 uses the format of the HBM, while illustrating the key findings of this research in two of the three overarching constructs of the model: beliefs and action. The women described experiences and personal beliefs related to sickness, death of loved ones, gaining knowledge to about HIV, and being tired of taking their medication. The participant's beliefs were associated with cues to action for the health behavior of this study—medication adherence.

Beliefs

The women spoke about their medication adherence-related beliefs and experiences. Their discussions were integral to understanding how these beliefs and experiences were associated with their medication adherence. Five of seven women had near-death experiences and these experiences shaped their perspectives about the perceived severity of not taking their HIV medication, perceived susceptibility of other AIDS-related complications, and the threat of HIV related to health. All the women talked about the perceived benefits of taking their medication, including being able to read and interpret their HIV labs to monitor T cells and viral loads. The participants identified pill fatigue or being tired or taking their ART as the most common barrier.

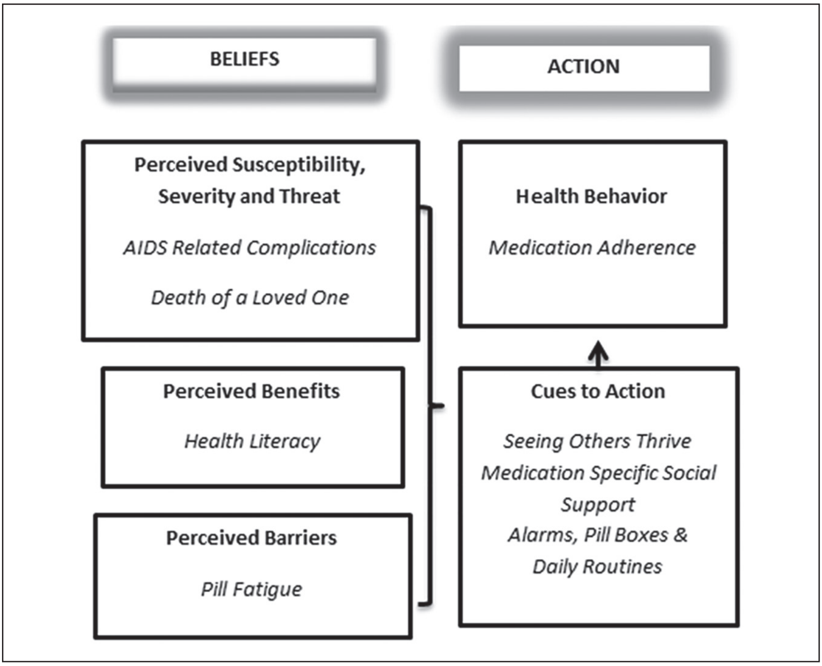

Figure 1. Beliefs and cues to action associated with medication adherence.

Perceived Severity, Susceptibility, and Threat

The women's perceptions about their diagnosis and not taking HIV medication, as well as their perceived susceptibility or threat of becoming ill, highlighted facilitators of medication adherence. For five of seven participants, having personal experience of almost dying shaped how they viewed the severity of having HIV, as well as what they perceived would happen if they did not take their medication. For Mary and Taliah, the memory of loved ones dying from HIV was a constant reminder of the importance of medication adherence.

AIDS-related complications. The women shared a range of experiences related to their diagnosis and integration to HIV treatment. For Josalin, Amy, Shelly, and Madeline, their recollection of a time when they nearly died due to HIV-related complications served as a moment of awakening and encouraged adherence through the years. Josalin had no intention of starting HIV medications and delayed treatment for nearly 10 years. She shared,

> It was ‘98 and I was in the hospital for about 2 months and they didn’t know what was wrong and I was dying. I got down to like 98 pounds, had lost a lot of my hair and so they sent me home to die. I found out that I had MAC [Microbacterial Avian Complex]. That’s the only reason I started taking medications.

Josalin viewed her encounter with Mycobacterium avium complex (MAC) as a final call to begin HIV medication. Unlike Josalin, three of the women were battling drug addiction and an HIV diagnosis, further complicating their initial start of a treatment regimen. Amy stated,

> I went and stayed with my daughter up until I went in treatment. Her husband was more or less my drug dealer so I didn’t get out on the streets and hustle. I had my dope right at home. Then it took a toll on me that’s when I started getting sick. [My doctor] got in touch with my daughter and told her if she didn’t get me up to the hospital within a few days I didn’t have but a month to live because my T-Cells were just that low.

After Amy went to see her care provider, she was told she had an uphill battle in front of her:

> [The nurse] said we don’t have the medicine to help you with this, we’re going to have to put you in another clinic because at that time all they had me on was AZT. She said that wasn’t enough because [my] T-Cells at the time was just one.

Like Amy, Madeline kept using drugs after her diagnosis and did not agree to seek treatment until she thought she was close to death:

> But then one day I had taken all I could take—I was really sick. I couldn’t do it anymore. My body was breaking down. My HIV was expanding because I wasn’t taking care of it. I was like 90 pounds over there.

Shelly’s experience mirrors that of Amy and Madeline related to battling drug addiction, but her HIV diagnosis and AIDS-related complications happened concurrently:

> I called my sister and my sister came and got me and I went to the hospital and they admitted me because I had PCP/pneumonia. They ran test—that’s when they said I had AIDS. And I almost died. I think I had about 50 T-Cells. I was like 62 pounds and I was jet black—like the pocket book [points to black purse].

The women vividly recounted their experiences with nonadherence and substance use as indicators of the effect of not taking medications as prescribed. These experiences shaped their perception of the severity of HIV and served as a reminder of what could happen if they were nonadherent. The death of loved ones provided a parallel reminder for participants of the outcome of not taking medication.

Death of a loved one. For three of the participants, seeing others die was another reminder of the power of HIV and its effect on a body if they did not take medication as prescribed. Madeline recalled,

> I've lost quite a few [like] Ms. Allison. She was one of my best friends and she just slipped away. She got disgusted with taking the medicine and they told her she had diabetes. Then they told her—her liver was going bad. That was heavy for me so I said I'm not going to follow her. I'm going to take my medicine.

Taliah shared her experience with seeing a loved one die,

> So, after my mother died in 2011 that's when I was like well, you know I can live a long time if I just take care of myself because I saw she was drinking and drugging and not taking her medicine, so if I just do the opposite of what she did then maybe I can live longer so that's what I'm doing.

The women described these experiences as difficult and challenging events to watch unfold, but also motivators to take their medication. They also identified several perceived benefits to taking their HIV medication.

Perceived Benefits

Health literacy played a role in the women understanding the importance of their medication and its subsequent effect on their health. Over the course of the first 12 years following diagnoses, all the women participated in HIV-related education programs to increase their knowledge and, in some cases, prepare them to educate others. These programs were the primary way they learned about HIV and medication adherence. The knowledge helped them monitor their health progress. For the women, seeing positive changes in their HIV labs encouraged them to remain adherent.

Health literacy: Understanding T cells and viral loads. The women repeatedly expressed the importance of knowing and understanding their HIV labs as they relate to their T cells and viral loads. Seeing an increase in their T cells assured them of their medication working. Amy recalled how many T cells she had when first diagnosed and how much her numbers have improved over the years, “Because at this point I started out—like I said one, zero and then one and then seven and then back down so I have come a long way and now my T-Cells are 1258.” Felicia stated, “My T-Cells have gone up. I said I’m okay. I take good care of myself.” These sentiments were shared by Shelly, “My T-Cells have gone back up since they went down to that three something, now they’re 658 and they’re going up.”

An awareness of their viral loads and T cells was not enough to stop some of the women from taking drug holidays. These holidays were unplanned, varied in the length of time, and were infrequent for Taliah, but a part of a normal routine for Josalin. Taliah shared,

> The longest I went without my medicine was 6 months. That was around the time my mom passed and I was real depressed. I had to start over taking about 12 pills until my T-Cells got back where [they] were supposed to be.

Taliah was back on schedule with her medications after taking a drug holiday and Josalin was working to do the same,

> I did a long [drug] holiday this summer and my viral load did climb up and this is the first time I haven’t been undetectable. So I got right back on my meds and I’m not doing a holiday right now. I’m getting my body back in order.

Both women took time off from their medication and were aware of the impact of drug holidays. This helped keep Taliah adherent, but for Josalin other concerns, such as the perceived toxicity of the medication continued to impact her ongoing adherence levels. As the participant who had been living with HIV the longest, Josalin expressed worry about needing to preserve her organs and what she perceived would happen if she consistently adhered to her regimen as her doctor wanted her to. She continued to balance her medication regimen by including occasional drug holidays, monitoring her T cells, and taking her medication consistently when her T cells dropped or her viral load increased. Pill fatigue also remained a concern for all participants.

Perceived Barriers

Although the women were not asked directly to identify barriers to their medication adherence, they all discussed experiencing times when they were tired of taking HIV medication or pill fatigue. For some of the women, this experience was exacerbated by taking multiple pills for other comorbidities, such as diabetes and hepatitis. As the women remained hopeful of an HIV medication innovation eliminating the need to take pills daily, they described their approaches to managing pill fatigue.

Pill fatigue. All the women described times when they do not want to take medication and questioned how long they would have to take daily HIV medication. While most of the women were on a one pill a day regimen, Madeline's other health challenges kept her from being able to decrease the number of pills she took. Although her regimen served as a barrier to taking her medication, she found a way to manage this challenge:

> The medicine is not easy to take and sometimes some people take 7 or 8 medications and it's not easy, it's not easy to remember all the time. [But] I focus on living so if I want to live I do what I have to do.

In addition to beliefs about the toxicity of the medication, seeing others develop health complications from the medication encouraged Josalin to take regular drug holidays. At other times, she did not want to think about her diagnosis or the need to take medication:

> It's like a lot of times I took my [drug] holidays because I was going to Jamaica two months out of the year. I'm not trying to take any HIV medicine because when I get off that plane, HIV stays on that plane. And it works for me and that's what I was trying to explain to my doctor last week. I figured with 27 years up under my belt I should know a little bit of something.

For Josalin, HIV was not something she wanted to think about every day, but Madeline's regimen was a constant reminder of her diagnosis, as well as the existence of other comorbidities. Felicia, Amy, Shelly, and Taliah reported while they got tired of their daily regimens and looked forward to the day when there is a once-a-week pill regimen, a shot they could receive, or even a cure, they continued to take their medications. In many regards, the participants seemed to want an occasional break from the daily reminder of living with the virus.

Action

Participants talked about tangible and intangible resources they used to help them remain adherent. Although these resources changed through the years, each woman depended on their family or some other tool for support.

Cues to action. The women discussed multiple sources of motivation and support for remaining adherent. Shelly, Amy, Taliah, and Madeline talked about the benefits of having HIV medications delivered right to their door. This service was described by the participants as a major asset to reduce barriers to medications. Medication-specific social support from family members was the most frequently discussed category of social support. Having family members ask whether the women had taken their medication or remind them to take their medication was an important resource, particularly when the women first started their regimens. Six of the women identified alarms, pill boxes, and a daily routine as tangible ways to be adherent.

Seeing others thrive. Following their diagnoses, all the women engaged in HIV-related advocacy or education work and shared enthusiasm around meeting other women who were HIV positive. The women viewed meeting other HIV-positive women who were healthy and doing what they termed as *thriving* as an asset to their experiences. For them, thriving was more than merely surviving with HIV—it was living a healthy and full life despite HIV. When asked at what point Rochelle saw a shift in her response to her HIV diagnosis, she replied,

> When I was 12 years positive and I began to see some of the women who were thriving and surviving like what! I was like look at those women, they are beautiful—I can do this. And it was funny because we'll talk about medication, but my CD4 would never go above 600. When I disclosed my status, it went up. So that to me is when I really started living.

For the other participants, it was important to see women who were successful, active in their communities, and appeared to be happy despite their HIV diagnosis. Receiving social support was instrumental as well.

Medication-specific social support. Six of the participants identified tangible sources of support and encouragement to take their medication. The most commonly discussed type of support was medication-specific social support from family members. Felicia recalled,

> That reminds me when I first started taking medication my kids knew that I was taking medicine at 10 o'clock. And my youngest son shook me so hard he scared the heck out of me. Ma, ma, ma wake-up, wake-up. I said what the hell is going on? He said ma, it's 10 o'clock you have to take your medicine.

Felicia's son was a source of support for her during the earlier years of her diagnosis and Rochelle had a similar relationship with her family. Rochelle shared, "My sister was kind of my buddy and even a lot the family members who knew, like my mom or whoever would be like did you take your medicine?" Amy gained support from family to stay on track with her medications, "[My daughter] knows that I have to take my medicine and she makes sure I do." Madeline discussed a similar experience, while sharing why it was important for her church members to know she was HIV positive. She recalled, "Sometimes I go to church and I have to take my medicine with me, especially if we are having a long day. I don't want have to [sneak] and do it. Everybody knows." The participants also identified a few more resources they used to remain adherent.

Alarms, pill boxes, and daily routines. Family was the most frequently discussed source of medication specific social support, but many participants transitioned to other resources to maintain adherence. These tools included an alarm clock, pill boxes, and a fixed daily routine around when and how they took their medication. Amy stated, "[It] is just like clockwork: I get up after I wake up, make my bed, make my coffee and get my stuff set up to eat. And then I go and take my medicine . . ." Amy's routine helped keep her on track with taking her medication and maintain some consistency with her daily schedule. Madeline had a routine she maintained along with several reminder systems for taking her daily doses, as well as preparing for the next week:

> I get up at 9 o'clock every morning and I take those 8 pills. I just take all 8 of them and then about 3 or 4 o'clock I take that one—its magnesium. Then at night I take 2 liver pills. Yeah, I got it on my calendar, got it in my phone. I know when it's time to get in there. And then will I fill my box on Saturday nights I know if I have another week's supply or is it time for me to order again.

Having a set schedule, including identifying the best times to take their medication, kept the women adherent to their regimens.

Discussion

The findings described in the previous sections focused on identifying beliefs and cues to action related to medication adherence in African American women who were HIV positive for 10 or more years. By exploring participants' experiences of living with HIV, as well as adherence to their HIV regimens, the findings were then contextualized and re-presented in the constructs of the HBM.

Research related to barriers to medication adherence for PLWHA includes stigma (Rintamaki et al., 2006) and denial (Kalichman et al., 2010). The women in this study identified pill fatigue (Claborn et al., 2015), as well as concerns about the long-term effects of HIV medication and comorbidities, as additional barriers to adherence. The participants' experiences with barriers to medication adherence bring to the forefront challenges for long-term survivors, including concerns about the effect of taking HIV medications for prolonged periods and managing multiple medications for comorbidities. As PLWHA live longer, practitioners need to consider the importance of programs for survivors to provide education on the long-term effect of HIV medications and how PLWHA can manage multiple comorbidities, while remaining adherent to a HIV regimen (Effros et al., 2008; High et al., 2012; Slavin et al., 2011).

Public health interventions have tested the efficiency of cues to action or tools used to increase adherence (Kalichman et al., 2016; Pellowski et al., 2016) and the findings from this study highlight the importance of peer support in helping women remain adherent (Edwards, 2006; Marino et al., 2007; Vyavaharkar et al., 2007). Peer support programs designed specifically for long-term survivors is one area where additional exploration may be useful. Other cues to action for participants in our study included medication-specific social support, especially from family members who reminded the women to take their medication. This finding may warrant an increased emphasis on educational programs focusing on helping family members of PLWHA provide medication-specific support.

Since the discovery of the HIV/AIDS epidemic, communities worldwide have tested various ways of addressing the disease in hopes of slowing or completely halting its spread. In one of many efforts to address the spread of the disease in all communities, several states enacted legislation to "impose criminal penalties on people living with HIV who know their HIV status and who potentially expose others to HIV" (CDC, 2014). Like many other laws in the United States, individual states were left with discretionary power to decide how strict their HIV disclosure policies would be and what the parameters of the penalties would entail. Subsequently, 23 states enforce some sort of HIV criminalization law, 19 states required disclosure to sexual partners, and 12 required disclosure to needle-sharing partners.

Disclosure is an important part of leading a healthy life while living with HIV and research has also shown that those who disclose their status are more likely to access resources, develop positive support networks, and ultimately improve their quality of life. However, this process can also be a scary and life-altering event. Those who choose to disclose are often concerned about stigma, especially from family and friends, medical care providers, and employers. Women face an additional burden with the possibility of assault or abuse as a result of disclosure. Therefore, as additional research and resources are allocated for long-term survivors, stigma and disclosure remain central policy-oriented concerns especially when HIV criminalization laws are considered.

Medication adherence for persons living with HIV/AIDS is a complex phenomenon and has been the subject of public health research for nearly three decades. With more than 1.1 million people in the United States living with HIV, one in four women is HIV positive, and African American women comprise the majority of women living with the HIV (CDC, 2018b), timely linkages to care and medication adherence are important aspects to prolong the lives of PLWHA (NAM, 2015). The findings from this study emphasize the need for research specific to improving medication adherence among long-term survivors. Additional areas for future research could include a larger and more diverse sample of long-term survivors; an exploration of the impact of education programs for long-term survivors; pilot studies to test additional tools to assist with medication adherence resources among long-term survivors; an exploration of the relationships between mode of transmission, as well as duration of HIV infection, and medication adherence; and ongoing research on the impact of HIV criminalization laws, specific to long-term survivors and other vulnerable populations.

Limitations

While the researchers maintained a researcher journal, conducted member checking, and met regularly to review the code book and subsequent analysis, this study has several limitations. Some researchers have noted that the HBM does not adequately provide an explanation for beliefs or other determinants that account for an individual's actions and assumes that there is equal access to information regarding prevention and treatment of a disease (Orji et al., 2012). Beyond the women's experiences with HIV and related compilations, the authors did not explore individual beliefs or access to HIV-related medication that may be associated with medication adherence. The first author conducted and transcribed all interviews. While this process helped the researcher be intimately familiar with the data, there was not an observer to take notes during the interviews, a co-transcriber, or co-coder. The researchers worked together to review the code schemes and verify consistency of coding. However, we did not test for inter-coder reliability. Finally, with the exception of the youngest participant, the sample was homogeneous thereby limiting generalizability of the findings. According to Josselson (2011), narrative research does not seek to generalize, but to explore and can provide pilot data for further research. Therefore, we believe our study offers valuable insight to culture, health, and sexuality researchers seeking to gain knowledge of medication adherence among long-term survivors, particularly African American women.

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