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Perspectives of Middle-Aged African American Women in the Deep South on Antiretroviral Therapy Adherence

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Abstract

Despite evidence of stabilization in some areas of the US, HIV infection in Black women is not declining in the *Deep South*. Using a phenomenological approach to qualitative inquiry, we investigated women's experiences influencing their adherence to HAART in an urban setting. Inclusion criteria specified Black women who had been aware of their HIV status for at least two years and were engaged in HIV outpatient care. Twelve single face-to-face confidential in-depth semi-structured interviews were conducted from a sample of pre-dominantly middle-aged women retained in care at an HIV clinic in Atlanta, Georgia. Data was analyzed by two independent reviewers and three themes emerged from the group of women's accounts of their experiences. First, sentinel events led to changes in perspective and motivated women to adhere to HAART. Second, recognition that one had the personal strength necessary to cope with HIV fostered adherence. Finally, relationships with healthcare providers especially trust issues surrounding this

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relationship, impacted adherence both positively and negatively. These findings suggest that HAART adherence is a complex issue among middle-aged urban Black women with HIV in the Deep South. Providers caring for this patient population should recognize that sentinel events, personal strength, and positive healthcare relationships are opportunities to improve adherence.

Keywords

HIV; HAART; adherence; Black women; South

Introduction

HIV/AIDS continues to be at epidemic levels, particularly in Black women with low education (Simard, Fransua, Naishadham, & Jemal, 2012) and those living in high prevalence zip codes (Hodder et al., 2013). Among the 11,200 new infections in the US population in 2009, a disproportionate 57% were Black females (Centers for Disease Control and Prevention [CDC], 2011). In 2006, HIV infection was the third leading cause of death for Black females aged 35-44 ([CDC], 2010).

After the introduction of highly active anti-retroviral therapy (HAART) in 1996, persons with HIV have increased life expectancy and quality of life (Antiretroviral Therapy Cohort Collaboration, 2008). Despite this, women are less likely than men to be adherent to greater than 95% (Paterson et al., 2000) anti-retroviral therapy (Puskas et al., 2011). Factors negatively impacting adherence in women include personal and relationship issues (Ubbiali et al., 2008; Knowlton et al., 2011; Sayles, Wong, & Cunningham, 2006), as well as depression (Cook et al., 2006), perception of body fat changes (Plankey et al., 2009), heavy drinking (Jones et al., 2010), and drug use (Meade, Conn, Skalski, & Safren, 2011; Knowlton et al., 2010).

Black women in the South face additional cultural barriers including lack of trust in health care providers (Bogart & Thorburn, 2005) and perception of inferior quality of HIV services in rural areas (M. V. Vyavaharkar, Moneyham, & Corwin, 2008). The *Deep South* includes six states; Alabama, Georgia, Louisiana, Mississippi, North Carolina, and South Carolina, all of which were among the fifteen US states reporting the highest AIDS death rates per 100,000 US standard population in 2009 (Kaiser Family Foundation: State Health Facts, 2009). Aggressive efforts to care for patients with HIV/AIDS in this region are in process (Sutton et al., 2009), yet disparities in morbidity and mortality remain.

Over the past decade, research has contributed to improved methods for linking this population to care (Aziz & Smith, 2011). Yet, much of the available data on Black women in this region is from rural areas (M. Vyavaharkar, Moneyham, Murdaugh, & Tavakoli, 2012). Using qualitative inquiry, we investigated factors that influence adherence to HAART in Black women in the urban Deep South.

Methods

Our study focused on Black women with the likelihood of being offered HAART therapy. To be eligible, participants had to be aware of their HIV status for at least two years and meet the following inclusion criteria (a) have had at least two HIV primary care appointments at a local infectious disease clinic (b) reside in the state of Georgia, (c) be 18 years of age or older, (d) be biologically a woman, (e) self-identify as Black, (f) speak fluent English, and (g) have lived in the southeastern United States for at least 10 years.

A list of women was generated from the women's clinic providers' schedules at the local infectious disease clinic. Eligible participants were contacted by telephone and mail and invited to participate. A trained research interviewer obtained informed consent and conducted face-to-face 45-60 minute semi-structured digitally recorded interviews which were composed predominantly of verbal, open-ended questions with, as necessary, unstructured verbal probes for clarification and further detail (Creswell, 2007). Questions were directed to include experiences with racism, sexism, prior or current substance abuse, criminal activity, romantic relationships, experiences with the health care system, and HAART. Participants were asked to complete a short survey on demographics and health information at the end of the session. The most recent CD4 count and viral load were obtained from the EMR. All data were de-identified and randomly assigned a unique numeric identifier and a pseudonym. The protocol was approved by Emory University Institutional Review Board and the Grady Research Oversight Committee.

Two researchers independently reviewed and analyzed the transcribed interviews searching for commentaries which offered insight into how participants interpreted their lives. These were collapsed into themes or codes that were managed using Nvivo® software version 9 (QSR International Pty Ltd, Victoria, Australia). The code structure was developed using an integrated (inductive and deductive) approach (Bradley, Curry, & Devers, 2007). There was over 90% intercoder agreement.

Results

One hundred eleven black women were initially identified and seventy-eight were eligible. Twenty five women agreed to meet with the interviewer, however, eleven did not show. Fourteen women enrolled and completed the interview process from January 2012 through May 2012. Two were excluded due to 1) identification of the primary investigator as the primary care physician and 2) participant repeatedly not following instructions during the interview process.

Demographic characteristics of our sample are included in Table 1. Most resided in the greater Atlanta area. The mean age was 46 and eight of the women were over 45. The mean CD4 count was 489 cells/uL and 10 out of the 12 participants had an undetectable viral load (HIV-1 RNA < 50 copies/ml). Women cited several side effects which occurred while taking the medicine such as drowsiness, diarrhea, vivid dreams, and achy bones. Ideas of not feeling “normal” while taking HAART, being in denial about having HIV, and concomitant use of drugs or alcohol emerged as factors that made it difficult for them to adhere. Review and analysis of the interview transcripts revealed three major themes (Table 2) with respect to events and conditions that influenced HAART adherence.

First, sentinel events experienced by the participants or in one case, a loved one, such as near death from opportunistic infection and very low T cell counts, motivated six of the twelve women in this cohort to adhere to HAART. Following recovery, women further cited wanting to avoid future illness and staying alive for themselves or their loved ones as reasons for sustained adherence. Second, participants recognized their personal inner vitality to cope with HIV could be coupled with healthy day-to-day choices including taking HAART, getting plenty of rest, avoiding stress, and eating properly to help them live healthy lives. Furthermore, women mentioned their relationship with their primary care provider as positively influencing adherence. Many described the local HIV treatment center as a sanctuary where they were comfortable getting care because all levels of providers were knowledgeable and respectful. Lastly, negative interactions with hospital staff also influenced adherence. In two situations, women were motivated to adhere to avoid negative

experiences with inpatient healthcare providers whom they would encounter if they got sick and required hospitalization.

Discussion

In our study, we found that HAART adherence was a complex issue among a sample of predominantly middle-aged urban Black women with HIV in the *Deep South*.

The impact of sentinel events on adherence to antiretroviral therapy was prominent and suggests a crucial period for intervention. The experience of illness prompting consideration of individual mortality was a leading factor in motivation to adhere. Prior research suggests that women with lower CD4 counts (who are therefore less healthy) are actually more adherent to 90% HAART therapy (Ortego et al., 2012). Factors other than near death experiences which may contribute to stronger adherence in women at lower CD4 counts include increased HAART toxicity (Nguyen et al., 2002) such as peripheral neuropathy, fatigue, or weight loss (Kempf et al., 2009), and differences in rates of dysthymia (Turner & Fleishman, 2006). Additional investigation is needed to elucidate methods to facilitate early adherence among women who have yet to experience HIV-related symptoms at higher CD4 counts.

In this sample, personal strength contributed to an ability to cope with HIV, including taking HAART at times while concurrently suffering from emotional stress or experiencing side effects. This may be partly explained by adherence self-efficacy (Bandura, 1986), as prior evidence has demonstrated that higher levels of self-efficacy equate to better adherence and higher CD4 counts (Johnson et al., 2007), yet we have not found reports of personal strength being related to adherence. Further inquiry is needed to explore the culturally significant values, skills, or assets that are imparted by inner strength.

Finally, early and sustained adherence involves establishment of sound relationships with health care providers, including avoidance of negative interactions which impair the formation of relationships with new providers (Kochen et al., 1991) and lead to further disengagement (Malcolm, Ng, Rosen, & Stone, 2003). Our study paradoxically revealed that multiple negative inpatient experiences actually promoted adherence in order for a few select women to avoid hospitalization. As such, is important to recognize that women require a comprehensive network of emotional and physical support as they move along a trajectory of “dying from” to “living with” HIV (Watkins-Hayes, Pittman-Gay, & Beaman, 2012).

Limitations of our study included a low sample size and low response to recruitment attempts, as well as little participation from women less than forty years of age. Perspectives from non-adherent women were minimally represented and are needed.

Conclusion

HAART adherence among middle-aged Black women in the Southeastern United States is a complex issue impacted by both personal and relationship issues. In the era of HAART, it is vital to develop innovative approaches that target population subgroups to improve adherence to life-saving antiretroviral medications.

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Statement of Relevance

Data from Black women with HIV in the urban *Deep South* is limited with respect to HAART adherence. This qualitative study examines the psychological and socio-medical aspects influencing adherence to antiretroviral medications in the greater Atlanta area, adding valuable perspective from a growing population affected by HIV.

Table 1
Demographic and Clinical Characteristics of Study Participants, n = 11*

	Minimum	Maximum
Age of Participant	23	68
Year diagnosed with HIV	1986	2001
CD4 Count	114	1370
Viral Load	undetectable	19.49 log ₁₀
	Frequency	Percent
Education		
8 th grade or less	1	9.0
9 th – 11 th grade, no diploma	3	27.2
High School Graduate or GED completed	5	45.4
Some college credit but no degree	2	18.1
HAART History		
Diagnosis of HIV prior to 1996	6	54.5
Taking HAART at the time of interview	10	90.9
Marital Status		
Married	3	27.2
Widowed	1	9.0
Divorced	2	18.1
Never been married	5	45.4
Employment Status		
Working for pay at a job or business	3	27.2
Not working and not looking	8	72.7
Annual Personal Income		
\$0-7500	3	27.2
\$7500-10,000	5	45.4
\$10,000-20,000	5	45.4
Did cost delay or impair ability to get medications?		
No	9	81.8
Yes	2	18.1
Health Care Coverage		
Private Health Insurance	0	0.0
Medicare	5	45.4
Medicaid	7	63.6
State-sponsored health plan	1	9.0
AIDS Drug Assistance Program (ADAP)	2	18.1
History of Substance Abuse in the Past Year:		
Alcohol	3	27.2
Crack Cocaine	2	18.1
Marijuana	3	18.1
None	6	54.5

	Minimum	Maximum
History of Regular Substance Abuse:		
Alcohol	4	36.3
Crack Cocaine/Freebase	6	54.5
Marijuana/Hashish	3	27.2
Cocaine (by itself)	1	9.0
Heroin	1	9.0
Heroin and Cocaine (mixed together as speedball)	1	9.0
None	2	18.1

* One woman did not complete the demographic questionnaire.

Table 2
Themes derived from quotes on HAART adherence

Sentinel events lead to change in perspective and motivate women to adhere to HAART.

“So after he passed I really started thinking about I don't wanna die like that. I saw how he died. I saw what he went through, and only if he had of found out sooner, only if he could have known sooner. All of this stuff went through my mind and I figured – I just said, “I got to do something about it. I can do something about it [HIV]. So that's when I started going and taking care of myself.” *Keisha, 42 years old, husband died from complications of HIV*

“I was so high I jumped out of a window. And I died and they put the sheet over my head. And, on the way to the hospital or wherever they take dead people, my heart started beating back. So God – I have – I'm on a mission now for Him because He saved me for a reason. [My health is] very good. I take my medicine right.” *Mary, 51 years old, wants to become a counselor for others women with HIV*

“I couldn't believe it. It took me 10 years to believe it. Every time they told me, I stayed in [the local hospital] so much with pneumonia. Uh-huh, and I still couldn't believe it until the last time I went, they had to put them tubes in me, pump my lungs and stuff, that's when I know something was wrong with me. So zero T cell. I'm gonna die. So I didn't have a choice. So I took it [HAART medications].” *Jackie, 41 years old, diagnosed 2001, 3 children, nearly 25 grandchildren*

Personal strength is necessary for adherence to HAART therapy.

“But I'm a strong survivor, and I'm not going to let HIV kill me. I'm going to kill HIV. That's what I'm going to do. I'm going to outlive HIV. Before I die they're going to have a cure. That's my motivation. If you take your medication, keep your appointments, eat properly, and get rest you can overcome anything.” *Sherry, 37 years old, diagnosed 1996, suffered from depression*

“And I always have been a strong-minded person. And I said, well, if I keep my appointments and if I take my medicine like I'm supposed to, maybe I'll live a long time, you know? So I'm here 11 years later doing wonderful. The medicine doing what it supposed to do, but it's more who you are on the inside. You got to be strong. You got to fight this.” *Shanequa, 48 years old, married for over 20 years*

“I'm responsible for keeping me healthy. And the doctor by giving my measurement to me, you know, giving my medicine to me. I'm the responsible one to keep healthy by taking it. My health will be real good. As long as I stay on the medicine, I can see further in the future. And I think things will be good for me.” *Lenae, 44 years old, prior bout with Cryptococcal meningitis resulted in permanent blindness*

Relationships with healthcare providers impacts adherence both positively and negatively.

“I love the [local HIV clinic]. They support us. They show us so much love, never look down. They be a part of it pushing us when I'm tired. And that keeps me going 'cause they love us so much. That building kept me alive.” *Tasha, 46 years old, diagnosed 1989, studying medical assistance, intermittently on HAART for 13 years*

“I'm a long-term survivor. If I had not had good caregivers, I probably would not be here. We work together as a team. I always try to make sure I have good people on my team.” *LaShawn, 67 years old, diagnosed 1990, Type II Diabetic, local church has HIV support group*

“Them first 10 years at (a local hospital) were hell, but I stuck it out. But now that I take the medicine, I don't be sick. I might get nauseated. Sometimes might be real, real, dehydrated like I am now. But other than that, I try to take it every day so I won't have to go up there. And I ain't been up there in a long time.” *Jackie, 41 years old, diagnosed 2001, primary caregiver of mother with dementia*