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# *Self-Care Behaviors of African American Women Living With HIV: A Qualitative Perspective*

**Kimberly Adams Tufts, DNP, WHNP-BC, FAAN**  
**Judy Wessell, APRN, BC, AACRN, AAHIVMS**  
**Tanya Kearney, MPA**

*Significant numbers of African American (AA) women have been diagnosed with HIV over the past decade. HIV may be viewed as a chronic condition that can be actively managed through the use of self-care behaviors, yet little is known about how these women define self-care (SC) for themselves, and still less is known about what facilitates and hinders SC behaviors among these women. This article highlights the results of a qualitative research study undertaken with AA women living with HIV in a metropolitan city in the southeastern United States. The objective of this study was to systematically collect data about the SC experiences of these women. Focus group methodology was used. Content analysis of the data was conducted. Two primary domains emerged: do what the doctor says and living healthy. SC activities included seeking social support, managing disclosure, engaging in pampering, taking part in religious customs, and maintaining recovery.*

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**Key words:** African American women, HIV-infected, pampering, peer education, self-care, social support, spirituality

Significant numbers of African American (AA) women have been diagnosed with HIV over the past decade. Fortunately, a diagnosis of HIV is no longer a death sentence for many of these women but may be viewed as a chronic condition that can be actively

managed through self-care (SC) behaviors. Yet little is known about how AA women living with HIV define SC for themselves, and still less is known about what facilitates and hinders SC behaviors among these women. This article highlights the results of a qualitative research study undertaken with AA women living with HIV infection. The women in this study lived in a large metropolitan area in the southeastern United States, an area highly impacted by the HIV epidemic. The purpose of this study was to systematically collect data about the SC experiences of these women.

## **Background**

### **HIV and African American Women**

Of the 33 million people living with HIV (PLWH) globally in 2007, an estimated 50% were women (Avert International AIDS Charity, n.d.). In the United States, approximately 56,300 new cases of HIV occurred in 2006 (Hall et al., 2008). Of these new cases of HIV, some 30% occurred in women.

*Kimberly Adams Tufts, DNP, WHNP-BC, FAAN, is associate professor, Old Dominion University School of Nursing, Norfolk, Virginia. Judy Wessell, APRN, BC, AACRN, AAHIVMS, is a nurse practitioner, Eastern Virginia Medical School, Norfolk. Tanya Kearney, MPA, is Director, HIV/AIDS Resource Center, Eastern Virginia Medical School, Norfolk.*

Although substantial numbers of women contract HIV secondary to injection drug use (26%), more than 70% of women who contract HIV do so via heterosexual contact because of considerable exposure of mucosal tissue to seminal fluids (Centers for Disease Control and Prevention [CDC], 2008). Approximately 64% of newly infected women are AA women. AA women's vulnerabilities to HIV are linked to biological, behavioral, and psychosocial factors, and 74% of AA women who contract HIV reportedly do so via heterosexual contact (CDC, 2008). Thus, considerable numbers of AA women are living with HIV and are searching for ways to manage this condition.

### Self-Care Behaviors

Kaiser Family Foundation (2004) reported that deaths from HIV declined by 70% during the period from 1995 to 2002 because of the advent of highly effective combination antiretroviral therapy (ART) and evidenced-based treatment protocols (Louie, Hsu, Osmond, Katz, & Schwarcz, 2002), and HIV infection is now considered a chronic illness. Promotion of a better quality of life and decreasing potential comorbidities in persons living with chronic illnesses is a national public health priority (CDC, 2007). SC behaviors are increasingly emphasized in the management of chronic illnesses and have been linked to better health outcomes, improved quality of life, and decreased medical costs (Bower, Richards, & Lovell, 2001; Henry, Holzemer, Weaver, & Stotts, 1999; Jones et al., 2003; Stearns et al., 2000).

Traditionally, SC behaviors have included self-determined actions to manage illness, decisions to seek information, communication with health care professionals, and decisions to do nothing (Dean, 1981). SC is learned through interpersonal relationships and communications (Orem, 1995). SC is more than seeking advice from health care professionals and often includes tapping into social support from persons in one's own community of acquaintances (Chou, Holzemer, Portillo, & Slaughter, 2004). Barroso (1995) equated SC with "taking care of oneself," a focused set of actions that persons use to enhance their mental and physical health. Research focusing on the impact of SC behaviors

on health outcomes has been performed in a variety of populations with chronic conditions including diabetes (Lin et al., 2004), lupus erythematosus (Sohng, 2003), anxiety and depression (Richards et al., 2003), and asthma (Laird, Chamberlain, & Spicer, 1994). SC research has resulted in the identification of a range of SC behaviors including dietary changes, exercise, adherence to medical regimens, symptom management, and practicing spiritually based customs such as prayer (Anderson et al., 1995; Coleman et al., 2006). Cultural context is also important when defining SC. Becker, Gates, and Newsom (2004) interviewed 167 AA persons living with chronic illnesses. They reported that SC behaviors were culturally based and concluded that cultural influences on SC behaviors had been underemphasized in the literature. For the purposes of this study, SC behaviors are defined as the personal practices and activities that HIV-infected AA women use to achieve, maintain, or sustain their own health (Shambley-Ebron & Boyle, 2006).

A substantial body of literature has emerged that describes the SC behaviors of PLWH. Several mixed gender (male, female, and transgendered) descriptive studies exploring SC behaviors have been conducted with PLWH. Investigators have reported that PLWH use SC behaviors to manage a variety of HIV-related symptoms including depression, fatigue, nausea, peripheral neuropathy, and anxiety (Coleman et al., 2006; Eller et al., 2005; Kempainen et al., 2003; Nicholas et al., 2007; Siegel, Brown-Bradley, & Lekas, 2004). Kempainen et al. (2006) moved the science forward by measuring the effectiveness of SC behaviors for managing anxiety, asking participants to rate the effectiveness of various SC behaviors. The participants ( $N = 502$ ) in this multicountry (Norway, Taiwan, and United States) study rated prayer as the most effective SC behavior, followed by meditation and exercise. In a study assessing the association of gender with the use of prayer as an SC behavior, Coleman et al. (2006) concluded that AA women living with HIV used prayer more often to manage fatigue when compared with AA men living with HIV, whereas men more often used prayer to self-manage depression and nausea. Chou (2004) studied 352 PLWH (77% male) and reported that gender was a predictor of spiritually based SC behaviors and that race was the predominant predictor.

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