

Till Death Do Us Part: Lived Experiences of HIV-Positive Married African American Women

Lorece V. Edwards, Shalon M. Irving, and Anita S. Hawkins
Morgan State University, Baltimore, Maryland, USA

HIV/AIDS disease continues to be an escalating health problem, particularly among women. However, African American women are among the leading demographic groups for HIV prevalence in the United States. The typical woman with HIV/AIDS is young, in her late twenties, economically challenged, and of childbearing age. Participants were recruited from an HIV/AIDS outpatient clinic to explore their perceptions of social support, life experiences and marriage. Data were collected through tape-recorded interviews using a semi-structured guide and journaling. Participants reported that most of their time was spent providing care for their husbands who were HIV-positive. Very often their health and well-being were compromised by providing care to others. Participants reported a lack of social support and challenges managing their self-care. Key Words: Marriage, HIV/AIDS Medication Adherence, Perceived Social Support, Qualitative Study, African-American Women.

The HIV/AIDS epidemic continues to take its toll throughout the U.S., particularly within the African American community (Centers for Disease Control and Prevention [CDC], 2008b). A prime example of the HIV/AIDS devastation would be the nation's capital, Washington D.C. It is now estimated that three percent of all residents in the District of Columbia are living with HIV/AIDS; the highest burden of disease is found among African American males at a rate of 6.5% (District of Columbia, Department of Health, 2008). Moreover, the estimates of HIV prevalence among African Americans are strikingly similar to, and in some cases exceed, population-based estimates of HIV seroprevalence among adults, ages 15-49 years, reported by several countries in sub-Saharan Africa, Asia, and the Caribbean (UNAIDS & World Health Organization [WHO], 2007). At the end of 2006, there were approximately 1.1 million people living with HIV infection in the United States, of which 46% were African American (CDC, 2008b).

Recent U.S. incidence data show that the rate of HIV infection is seven times higher among African Americans than it is among Whites (Hall et al., 2008). HIV/AIDS have hit the African American community the hardest and longest. Although African Americans only accounted for about 13% of the U.S. population in 2006, they accounted for 46% of new infections that year alone (Sutton et al., 2009). African American men and women bear the disproportionate burden of new HIV/AIDS cases.

Despite advances in prevention and treatment of HIV/AIDS, women continue to suffer from this disease at increasingly alarming rates (Armistead, Morse, Forehand, Morse, & Clark, 1999). In the U.S. in 2006, African American women had an incidence rate that was 15 times higher than that of White women and nearly four times higher than that of Hispanic women (CDC, 2008a).

African American women continue to be disproportionately affected by the HIV and AIDS epidemic over time and across circumstances. This disparity has been observed throughout the course of the U.S. epidemic (Hader, Smith, Moore, & Holmberg, 2001). Recent data suggest that African American women represent a disproportionate number (65%) of the total number of women currently living with HIV/AIDS (The Henry J. Kaiser Family Foundation, 2009). In general, women between the ages of 18-44 years constitute the fastest growing group of people infected with HIV/AIDS in the United States (O'Leary & Wingood, 2000).

There is a growing concern about morbidity and mortality associated with HIV/AIDS among African American women across the life span. El-Sadr Mayer, and Hodder (2010) note that more than a quarter of new HIV infections in the United States occur in predominantly Black or Hispanic women. However, one in 30 African American women is estimated to be diagnosed with HIV in their lifetime (Sutton et al., 2009) which is commonly transmitted through heterosexual behavior. Although only 12% of the women in the U.S. are African Americans, 67% of the U.S. women diagnosed with AIDS in 2004 were African American (CDC, 2005). The estimated rates continue to be alarming. Recent research proffers that HIV was the third leading cause of death for African American women between 25 and 34 years of age (National Alliance of State and Territorial AIDS Directors, 2008).

The lives of HIV-positive African American women are complex and unique. HIV/AIDS forces women to incorporate their diagnosis, treatment, and psychosocial factors into their day-to-day life responsibilities as well as experiences. As such, women are often the gatekeepers of care in a family. HIV/AIDS has significantly increased the burden of care for many women. Lack of social support combined with HIV/AIDS has turned the care burden for HIV-positive women into a crisis with far reaching health, economic and social consequences. It is critical to understand the influence of social support on marriage and its relations to medication adherence for married HIV-positive African American women. The current study takes a phenomenological approach to explore the lived experiences of married HIV-positive African American women. Data derived from journaling and semi-structured interviews delve into the women's perceptions and actual experiences with social support, the role of marriage in their social support systems, and the possible impact these experiences may have had on their HIV medication adherence.

Social Support and Health

Over the past three decades, the importance of social relationships for physical and emotional health and well-being has been well established (Berkman & Syme, 1979; Cohen & Wills, 1985). Scholars have suggested that humans have an innate need to form and maintain social bonds and that these social relationships, when positive, have health benefits (Crocker & Canevello, 2008). Social support, defined by House, Umberson, and Landis (1988) as the "positive, potentially health promoting or stress-buffering, aspects of [a] relationship" is associated with lower likelihood of mortality (House et al.) and decreased incidence of morbidity (Berkman & Syme).

House, Umberson and Landis (1988) identified two additional processes by which social relationships may affect individuals, separate from social support. *Relational*

demands or conflict “refers to the negative or conflictive aspects of relationships that may be deleterious to health,” while “*social regulation or control* refers to the controlling or regulating quality of social relationships which, depending on the behaviors controlled or regulated, may be either health promoting or health damaging” (p. 302). This triad of processes helps to elucidate the role of social relations in affecting health—however; much of the extant research has focused on social support.

Most studies have demonstrated a significant relationship between social support and health—either as a buffer of stressful life events or as a direct predictor of physical and mental health outcomes (Berkman & Syme, 1979; House et al., 1988; McCoy et al., 2009; McDowell & Serovich, 2007; Vyavaharkar et al., 2009). House and colleagues (1988) suggest that the buffering effect of social support is most evident in the presence of social stressors. Likewise, Uchino (2009) highlights the importance of understanding the context of received support since it is provided in response to specific stressful situations or experiences. Interestingly, scholars posit that the perception of social support may be more important than the actual receipt of social support (Crocker & Canevello, 2008; McDowell & Serovich; Uchino). In a recent study, Edwards (2006) found that women who perceived social support from family and friends had better medication adherence to their Highly Active Antiretroviral Therapy (HAART) than those who did not.

The fact that “family” is often reported as a source of both stress and support (Edwards, 2006; Wohl et al., 2010) demonstrates the need to better understand the context and content of social relationships. Given the importance of reciprocity in social relationships, the ability of one’s partner to provide social support is paramount (House et al., 1988; Pasch & Bradbury, 1998). The failure to receive social support from a partner may also be more detrimental for women living with HIV/AIDS, particularly when providing support to their partner means that they are unable to dedicate the time to taking care of themselves and their own health needs (Edwards).

For women living with HIV, the gender differential of giving but failing to receive social support may be more pronounced (Edwards, 2006). Participation in health-promoting behaviors such as adhering to a medical regimen has been associated with the presence of perceived and received social support (Edwards; McCoy et al., 2009; Uchino, 2009; Rivero-Mendez, Dawson-Rose, & Solis-Baez, 2010). One of the mechanisms by which social support affects behavior is through social regulation which creates norms that encourage behaviors such as medication adherence (House et al., 1988). When this happens within the context of a marriage it may increase the positive role of marriage as a form of social support among women with HIV.

Health Benefits of Marriage

The central relationship for most adults is the institution of marriage. However, there is something transformative about marriage (Karasu, 2007). Research suggests that marriage itself is beneficial and offers so called “protective effects.” Wilcox, Doherty, Glenn, and Waite(2005) also states that marriage itself, and particularly good marriages, are protective physically, financially, and psychologically and the longer one stays married, the more benefits accrue. Those who marry possess certain characteristics that are different from those who do not marry (Karasu, 2007). Holt-Lunstad, Birmingham,

and Jones (2008) further note that being married has been reliably associated with health benefits including lower morbidity and mortality. Overall, marriage is purported to offer protection through processes that include economic well-being, healthier lifestyles, lower stress, and social support (Coyne et al., 2001; Umberson, 1992).

In a study of HIV-positive patients, McCoy and colleagues (2009) found that married respondents reported higher levels of social support in several domains including emotional support and positive social interactions. For most adults, marriage plays a central role in their lives even compared to other social relationships (Holt-Lunstad et al., 2008). Married men and women may be at a health advantage relative to their unmarried counterparts, for a number of reasons. First, marriage is viewed as a primary source of social support, and marriage may protect against the well-documented risks associated with social isolation (Berkman & Glass, 2000). Second, positive spousal influence and involvement may encourage health-promoting behaviors and deter health-compromising behaviors and attitudes (Umberson, 1992). Finally, it is suggested that married persons, particularly women, may be at a health advantage relative to their unmarried counterparts, through increased socioeconomic resources (Johnson, Backlund, Sorlie, & Loveless, 2000). However, other findings strongly suggest that marital status and health have generally been less consistent for women than for men (Ross, Mirowsky, & Goldstein, 1990). Of importance, House et al., (1988) suggest that women are more effective providers of support than are men, with attendant psychological costs to women. However, in the presence of distress and dysfunction, marriage may actually have a deleterious effect on health.

Despite the fact that married people, on average, enjoy better mental and physical health than the unmarried, marriage's protective effects are notably stronger for men than women (Berkman & Breslow, 1983; Litwak & Messeri, 1989). The processes by which marriage promotes health and well-being for men compared to women is very different. In general, marriage seems to lead to greater reductions in mortality in men than women (Robles & Kiecolt-Glaser, 2003) and marriage may be better for men's mental health than women's (Bebbington & Tansella, 1989).

Previous research clearly suggests that being married exerts a health-protective effect for men (Litwak & Messeri, 1989; Ross et al., 1990). Although, several lines of research supports the idea that marital status has positive health benefits and promotes health-enhancing behaviors. It is clear that marital status affords greater protection from mortality for men compared to women (50% higher among women, 250% higher among men; Litwak & Messeri). Therefore, even among married women there may be an additional benefit to having female friends and supportive network members over and above her intimate partner (House et al., 1988; Wohl et al., 2010). The purpose of this study was to explore, from African American HIV-positive married women's own perceptions, social support, lived experiences, and the role of marriage.

Methods

This study was part of a larger project conducted by the first author (Edwards, 2006). The purpose of the larger study was to explore the relationship between perceived social support and HIV medication adherence among a cohort of African American women residing in an urban setting. In an effort to contribute to the literature on married

women with HIV infection, the purpose of the current study was to explore and describe HIV-positive African American married women's perspectives regarding their life experiences, perceptions of social support, and role of marriage and HIV/AIDS medication adherence. The data were derived from journaling and semi-structured interviews.

Data collection was completed at the Johns Hopkins Medical Institutions with the approval by the hospital's Committee on Human Research Subjects and the Institutional Review Board at Morgan State University.

Participants

A purposeful sample of five participants were recruited between April 4, 2003 and May 9, 2003 from the outpatient clinic through physician networks and posted flyers. Inclusion criteria for this study were: ages 20-49 years, African American female, receiving HIV care at the clinic, mentally and physically healthy, and taking antiretroviral therapy (ARV). The age group was selected based on a report from the Maryland State AIDS Administration (2001) that stated the majority of HIV cases (87%) and AIDS cases (86%) in Baltimore, Maryland, are between the ages of 20 and 49 years.

The five eligible participants (married women) ranged in age from 29 to 49 years. All participants were African American women. The majority of the participants had children. Educational levels for this population varied. The majority had less than a high school education (n=3), one completed high school, and one completed college. Women's annual income ranged from \$4,999.00 to \$11,000.00. Most were unemployed at the time of the study.

Women in the study had been diagnosed with HIV for four or more years. Participants' viral loads ranged from undetectable to more than 50,000 copies/ml. In terms of HIV transmission, more than half reported contracting the virus via heterosexual contact. Three of the participants contracted HIV from their infected husbands after the marriage and two married HIV-infected partners. None of the participants reported active substance use within the past six months.

Data Collection

Journaling. Qualitative data were collected via journals and semi-structured interviews. Upon enrollment in the study, participants were introduced to the concept of journaling. Journaling was chosen as a methodology because of its therapeutic process to enhance self-awareness, build self-confidence/self-esteem, and track adherence progress, perceptions of social support and life experiences living with HIV/AIDS. Journaling was presented to the participants as, "Writing about events that are happening to you or around you, in a way that helps you put them in perspective."

According to researchers, journaling can be especially effective when writing about life changes, relationships, or illness (Pennebaker, 1997). Moreover, Pennebaker found that writing or talking about emotional topics has a beneficial influence on immune function, including t-helper cell growth. However, self-reports also suggest that writing about upsetting experiences, although painful in the days of writing, produces long-term

improvements in mood and indicators of well-being. All journals were pre-formatted with text and labels, which facilitated the journal entry process.

The participants were instructed to journal three times a week for a two-week period and for a minimum of ten minutes regarding HIV medication adherence, perceptions of social support and life experiences living with HIV/AIDS. They were reassured that they should not worry about grammar and spelling and they should feel free to write in any way that they wished (e.g., poems, songs, scripture, list, stories, & quotes). This technique was used to increase the likelihood that participants would feel comfortable journaling as instructed. In addition, participants were informed that at the end of the study they could keep the journal but that a copy would be made for the investigator.

All participants made their first journal entry upon enrollment into the study. This method was used to help make the participants feel relaxed with journaling and to “break the ice.” The journal questions included: Did anyone in your family help you (or remind you) to take your HIV meds today? Did a friend help you or remind you to take your HIV meds today? Did anyone or anything get in the way of you taking your HIV meds today? In addition, the journals included baseline social support information and clearly defined areas where participants could share any other information. The baseline information included: who they lived with, access to telephone and/or transportation, do they have a best friend, and are family members or friends aware of their HIV status, and who they can turn to in an HIV-related medical crisis. Journals were coded by hand in their written form.

Interviews. Following the two-week journal period, individual interviews were conducted with all participants. The semi-structured interviews focused on perceived social support, medication adherence, and life experiences living with HIV/AIDS. The length of the interviews ranged from one hour to ninety minutes. Interviewing allowed those participants who were not comfortable journaling the opportunity to freely talk about their experiences. Participants were compensated \$7.50 per journal entry, up to six entries, and \$10.00 for semi-structured interviews.

Coding/Analysis

Interviews were transcribed verbatim and coded to organize main themes. A phenomenological methodology incorporating Colaizzi’s (1978) seven steps was used to analyze the data. Colaizzi delineates that, as a phenomenologist, one must contact a phenomenon as people experience it, proceeding along the lines of describing their experiences. Colaizzi’s concept of data analysis includes: (a) reading and re-reading the data to gain a sense of the whole picture, (b) extraction of significant statements and phrases related to perceived social support and medication adherence, (c) drawing meanings from the phrases and statements, (d) clustering the meanings into themes, (e) utilizing themes to develop a complete picture as possible, descriptions of the experiences of perceived social support and medication adherence, (f) forming statements of identification from the descriptions, and (g) verifying the descriptions with study participants.

Although Colaizzi's (1978) process guided the analysis of the narrative data, this analysis is grounded in that the author also allowed for the emergence of sub-themes. The analysis began with the guiding concepts for comparing the participants' experiences of HIV/AIDS medication adherence and perceived social support. Interviews were initially coded for conceptual categories and then subjected to "focused coding" to identify sub-themes supported by quotations. Two researchers coded the same data to clarify any differences in coding and verify reliability (Miles & Huberman, 1994). All journals were coded by hand in their written form. Individual interviews were professionally transcribed and coded using *Atlas ti* (Muhr, 1997). Additionally, memo writing for the transcribed interviews facilitated analysis and assisted in looking at the codes in new ways (Denzin & Lincoln, 1998).

Results

Life Experience of African American Women Living with HIV/AIDS

HIV/AIDS continues to be an escalating health problem for women throughout the world and it permeates our urban neighborhoods. The women participating in this study suggest that HIV/AIDS has not gone away but it often hides in vacant and deplorable housing units, abusive and high-risk heterosexual relationships, and is fueled by discrimination, stigma, and fear. The transmission of HIV/AIDS among women has become the center of the HIV/AIDS epidemic in the U.S. Women are faced with many challenges that come with personal and social costs associated with this chronic disease. One participant eloquently captured this theme by stating:

After all of these years people still talk about HIV by making derogatory remarks. I often feel alone because I am not comfortable telling people my status. You are taking a chance when you disclose your HIV status. People are quick to judge you, let you down, and treat you different. I wish that the world was different about this disease. You know HIV is a disease that affects the whole family. We must begin to cope with this disease this as a family unit. And heal as a family.

Another participant shared this view regarding her life experiences:

HIV keeps me busy. This is a keep you busy and on your toes disease. I have doctors' appointments, support groups from time to time, and the care of my family. And, the one thing that gets me through all of this is my relationship with the higher power of my understanding. This disease is not easy. But the people say what does not kill you will only make you stronger. I believe in that and I will make it somehow in light of my challenges. My family comes first and if they make it I will make it too.

Despite improved public awareness and education about HIV, it remains a much stigmatized disease. Recent research suggest that stigma negatively impacts peoples' quality of life, self-image and behaviors, resulting in them not seeking HIV testing or

care and not disclosing their HIV status (Foster & Gaskins, 2009). Life experiences with stigma and discrimination are common among African American woman living with HIV/AIDS. One participant voiced this perception:

HIV has a dark side. I have been positive for seven years and I am still ashamed and embarrassed to say that I am HIV-positive. I have had so many painful experiences that are a result of my HIV status that I once stopped loving myself. I had no support from others and my doctor wasn't very friendly. It's hard to cope with being HIV-positive. I thought that I had supportive friends and special family members who cared, but I was wrong.

In the past, HIV caregivers were disproportionately gay-identified men caring for gay-identified partners or friends (Bor, Du Plessis, & Russell, 2004; Turner, Catania, & Gagnon, 1994). However, as the case fatality rate for HIV dropped in the U.S., traditionally defined family members (e.g., mothers and wives) are increasingly being called upon to assist persons living with HIV (Beals, Wight, Aneshensel, Murphy, & Miller-Martinez, 2006). Several participants expressed the challenge of caring for others. Women verbalized the pathways of their upbringing and socialization as "taking care" of others before taking care of themselves. In many cases they failed to recognize and address their own needs being faced with HIV/AIDS. As stated by one participant:

I have a husband who is positive and other family members who need my help from time to time. In the midst of my day, I will remember that I have to do things for myself. I spend most of my time caring for other family members who are sick and my husband who is HIV-positive. I sometimes don't get a chance to deal with my own physical and emotional needs and the requirements of this disease. I could really use more help and support. I am often very tired and don't have much energy. If I had somebody to look out for me the way that I look out for others, I would really be okay.

Marriage and HIV

HIV infection presents many challenging life circumstances for individuals. Managing HIV may be facilitated by social support and this support may be instrumental (e.g., providing transportation or money) or emotional support (e.g., providing positive feedback or giving advice; McDowel & Serovich, 2007). However, married women in this investigation were faced with a different set of challenges and reported less satisfaction with their social support system (emotional & instrumental support), particularly social support and assistance from their husbands. Married women reported spending an absorbent amount of their time caregiving for their HIV-positive husbands. For these women, much time was spent addressing the medical needs, emotional support, and psychological needs of their HIV/AIDS infected husbands as well as meeting the requirements of daily life. More than often presented with a dichotomy, married women

jeopardized their own health and well-being and self-care to provide the day-to-day care and support of their husbands. The voice of one woman shared this view:

I spend most of my time taking care of my husband. He does not follow the doctor's order and refuses to take the meds like he's supposed to and I have to take him to the doctors sometimes. Plus, he doesn't want anybody to know that the both of us are living with the virus. So I can't get support from the family cause I'm forbidden to tell. He doesn't even want me to say anything to our adult children. When I am not at work, I am taking care of him. And, when I am at work, I call home to make sure he has taken his medication. To tell you the truth, most of the time I forget to take my meds because I am trying to help him. When I get sick I am on my own. My husband doesn't help me because he don't know how and he is pretty much focusing on himself. If I had more support I could take my meds better. I know that they are keeping me alive. It's so true, HIV is a lonely person's disease. I don't have any kind of help or support. I want to do better with taking the meds and I want my husband to do better too, but it's hard for me when I have to take care of him. Helping out my husband gets in the way of my own adherence. However, if he was emotionally supportive or would just understand what I'm going through we could do better together. I do my best to care for my family and to work. Sometimes, I don't take my medication at work because somebody is always around. Sometimes I don't feel like going to work because I am tired. I just do the best I can.

Another participant had this to say:

My husband depends on me for everything. We try to take our medications at the same time but it doesn't always work out. You see, I have to look out for my mother too. She is sick and can't do much for herself. I want her to come live with us but my husband refuses. So by the time I run over to her house and come back home, I am wiped out. I ask myself throughout the day, did you take your medicine. And, then I call my husband and ask him. He'll say, I've been waiting for you to call me about that instead of just taking the damn pills. I should be mad at him for infecting me but instead I am his personal alarm clock. I have very little social support in this relationship. I provide all the support and don't get any. They should have a support group for couples so that we can learn to be supportive. Why do women have to do everything? I just might die helping everybody else.

The relationship between spousal support and marital well-being has been extensively documented in the literature. Marriage is known as a social institution in which expectations and norms are established within the union that often leads to a template of behavior. The participants reported that it was often very challenging to keep up with their own HIV/AIDS medication regimens. However, having the responsibility

for themselves and the expectations of their husbands transformed their self care and well-being to a new level. For example, one participant noted:

My husband is my best friend in many ways. We like to do some of the same things (play cards, and video games, go dancing) and we have been friends for a long time. Therefore, he expects me to help him with these medications. On a daily basis, I cook the meals, wash clothes, and keep the house clean. I wish that he would take control over his own health. I have enough to do. But the good thing is that I have one good girl friend that I can talk to about everything. She is trustworthy and supportive. I don't have to worry about my business getting out. I just need some help with getting my husband to be on top of his health.

Another participant echoed these thoughts:

For real, I used to get upset and depressed about having HIV and not having the social support and help from my husband and some of my close family ties. I really expected more support from my husband because he is living with the virus too. But I am over it now. I know that I can live a quality life with the virus. I have hooked up with a couple of women who are HIV-positive and we support each other. We pray together, go to the store together, and help each other. Sometimes my husband acts like he is jealous because of my relationships. He doesn't want anybody to know his status and that's on him. At one time, I had hit rock bottom living with this disease, but now, I am taking care of me. I know that I can do all things through Christ who strengthens me.

In contrast to the previously described life experiences of married women living with HIV/AIDS and social support, one participant reported that her husband was an important source of support and that his immediate family was supportive as well. In times of crisis the couple could count on each other and their social system. The participant explained:

I did not know that I was HIV-positive until my husband got sick. When I learned of my status I was terrified. My husband felt so bad about the situation that he vowed that we would get through this together. Both one of us was working and all we had was each other and our love. So we decided to tell certain family members and to try and form a support network in case we needed somebody. So we just take care of each other. My husband is a different kind of man. He respects me and cares about our relationship. He is not self absorbed or only thinking of himself. One time he walked along the way to the clinic to get my meds because we did not have money for a cab. If both of us are having a bad time we can count on his sister. She will help us out by cooking enough food to last a while. HIV is a not a disease to have and live alone. We have to start talking about this disease and helping others. It's not fair for people to

treat someone bad because they have HIV. We have to take responsibility and talk to our children, family, and neighbors to end the spread of this disease. Every time we fail to tell another somebody else may become infected. I feel bad for women who don't have the support of their husband. If two people together have this disease. They have to help each other out if they are going to make. You can't do HIV by yourself and live with quality.

Discussion

New HIV infections and HIV/AIDS-related deaths disproportionately affect African American women (Hader et al., 2001; Lee & Fleming, 2001) despite advances in HIV treatment and declines in HIV infections among other risk groups (Rose et al., 2008). HIV/AIDS continues to be a major public health crisis with no abatement in sight in terms of its multiple personal, social and healthcare ramifications (Beals et al., 2006). As such, it is extremely important to address the social issues and factors that affect African American women living with HIV/AIDS and examine the links between social structure and systems as well as health-promoting activities and behaviors.

The present study explored from the perceptions of married HIV-positive women, their life experiences (daily living requirements), perceptions of social support, and role of marriage in HIV/AIDS medication adherence. This study provides a rich elaboration of the phenomenon of the life experiences of married HIV-positive African American women using the words of the participants.

The voices of HIV-positive women in this study highlight the challenges of marriage and family care that some women face when attempting to adhere to antiretroviral therapy (ART). It is clear from these findings that in order to understand the many challenges that accompany HIV medication adherence, one must give full consideration to the multiple sources of social influences, including marital relationships that women attend to, in structuring their adherence practices. Of importance, this is often combined with the lack of needed support to manage the day-to-day responsibilities and the challenges of ongoing stress. Based on some of the accounts from the participants, HIV-positive married women often experience a social death due to caregiving, secrecy, and social isolation.

The women in this study became the providers of care for their HIV-positive husbands. In many circumstances this involved reminding them to take their medications, accompanying them to medical appointments, supporting their physical and emotional needs, and helping them manage the full range of their HIV/AIDS care and treatment. In the delivery of care to their husbands and sometimes other family members, there came a price and social cost, which included poor medication adherence, compromised health care and a lack of social support and/ or social isolation (Mosack & Petroll, 2009). It is clear from these findings that there are potential family barriers to HIV/AIDS medication adherence and an enormous caregiving burden for married women living with HIV/AIDS. Not to mention that individuals living with HIV/AIDS are often confronted with racism, stigma, and isolation that often impacts adherence practices.

As was found by other researchers (Maneesriwongul et al., 2004), the framework for care providers who take on the responsibility of caring for people living with

HIV/AIDS commonly includes providing physical care, assisting with activities of daily living, cooking, giving medicine, giving emotional support and sometimes bathing. Providing care often comes with health and social consequences for the caregiver, particularly women. Vithayachockitikhun (2006) proffers that caregiver burden is a multidimensional phenomenon that reflects the physical, psycho-emotional, social and financial consequences of caring for an ill/sick family member. Married HIV-positive women providing care to others frequently jeopardize their own health and well-being. In general, living with HIV/AIDS presents a number of unique challenges in order to maintain any quality of health (Folkman, Chesney, Cooke, Boccellari, & Collette, 1994) despite the burden or stress of providing care for others as well as the requirements of day-to-day living coupled with self-care.

LeBlanc, London, and Aneshensel (1997) investigated the adverse impact of caregiving on the physical health of informal AIDS caregivers. Findings from their study revealed that symptoms of poor physical health are markedly present among AIDS caregivers and are significantly associated with care-related stressors and demands. Women in the current study did not voice concerns regarding their physical health, other than being tired. However, they clearly stated that caring for their husbands was often stressful and demanding. Furthermore, participants posit that there were not any signs of reciprocity within the relationship in terms of instrumental and/or emotional support. And, on occasion there was marital strain due to the expectations and demands of their husbands that had a direct impact on their ability to maintain HIV/AIDS medication adherence and form needed external support systems.

This pattern of findings was consistent with other research that suggests that marriage may be better for men's mental health than women (Frude, 1990; Sogaard, Kritz-Silverstein, & Wingard, 1994) and that marriage protective effects are notably stronger for men than women (Litwak & Messeri, 1989). Furthermore, women caregivers tend to fare worse than men, reporting higher levels of symptoms tied to depression and anxiety and lower levels of subjective well-being, life satisfaction, and physical health (McGuire, Anderson, Talley, & Crews, 2007).

Another notable finding and perspective from the current study is lack of social support in times of need and crisis. A significant body of research suggests that social support plays a key role in managing stress associated with having HIV, resulting in better psychological outcomes among person living with HIV/AIDS (Vyavaharkar et al., 2009). Social support provided by informal caregivers (i.e., friends, partners, parents, or significant others) has been found to improve medication adherence among HIV-positive people (Mosack & Petroll, 2009). Moreover, in addition to providing emotional support, informal caregivers can contribute to successful adherence practices, medication reminders, and setting up medical appointments. These findings are consistent with the current study. However, in most cases, only the HIV-positive husbands were reaping the benefits of the support provided by their HIV-positive wives. Participants in the current study revealed that they provided social support to their husbands and others but seldom were they on the receiving end. HIV/AIDS is often referred to as a "social disease" but what are the social consequences for African American women living with HIV/AIDS, particularly married women who cannot afford to be without a support system? Women in this study felt alone and were dissatisfied and unhappy because they did not receive support from their husbands. The participants firmly believed in the institution of

marriage and many of the practical implications for example, through sickness and health, and till death do us part.

According to the literature, there is generally a positive impact of marriage on health and other related attitudes (Stein, Nyamathi, Ullman, & Bentler, 2007). It has been suggested that marriage regulates conduct and encourages healthy behaviors (Anson, 1989; Umberson, 1987, 1992). Furthermore, research suggests that morbidity and mortality are reliably lower for those who are married (Kiecolt-Glaser & Newton, 2001). Despite the advances in research on marriage and health, less is known about the impact of marriage, health and social support among African American married HIV-positive couples.

The present study highlights that HIV-positive married women who are the primary caregivers for their HIV-positive husbands often compromised their own health and well-being, thereby, jeopardizing the necessary adherence for HIV/AIDS infection. These women lack social support which is a major buffer for stress and is also strongly associated with both physical health benefits and mental health benefits (Larzelere & Jones, 2008). These findings suggest that it may be helpful for women at the time of diagnosis for their healthcare professionals to conduct a thorough assessment of the availability of social support so that women without adequate support (including married women) can be immediately linked to supportive services.

In keeping with the findings of other researchers (Catz, Kelly, Bogart, Benotsch, & McAuliffe, 2000; Gonzalez, Pendo, & Antoni, 2004; Murphy, Marelich, Hoffman, & Steers, 2004), the women in the present study indicated that social support is significantly associated with HIV medication adherence. Women who felt supported, cared for and reassured were more likely to be adherent. Participants expressed the need for emotional and instrumental support from their husbands and family, and perceptions of social support were more important than actual support in some cases. Women adamantly voiced, "Just knowing that someone is there to help you out, if need be, is a big relief. Just knowing that you don't have to do it alone and feel isolated helps you cope."

While this study has acquired valuable information from a unique and often understudied population, limitations of this study should be noted. First, the study is cross-sectional; hence causation cannot be inferred. HIV/AIDS medication adherence and perceived social support were assessed at one point in time. Second, due to the small sample, findings cannot be generalized to others and only apply to a similar population. Third, the study required a level of participation that may be difficult for the participants given the nature of disclosing one's HIV/AIDS status (stigma and discrimination). Fourth, journaling was self-selecting lending itself to potential bias because women were not selected randomly.

While this study has several limitations, we believe that the strengths of the study far outweigh the limitations noted here. The results demonstrate that, in spite of this complex picture and against all odds, African American women have strong coping abilities and profound survival instincts. Future research could be conducted to investigate the effects of marriage and social support among couples living with HIV/AIDS (co-habituating couples as well). We believe that these limitations are outweighed by the study's strength, however. Most importantly, this study explores and describes medication adherence, perceptions of social support, and the profound life experiences among a segment of the population (African American women) that

represent a disproportionate number (65%) of the total number of women currently living with HIV/AIDS in the United States.

The findings from this study could inform the design and implementation of antiretroviral therapy (ARV) programming for women, especially for women who do not have social support in their daily lives and who also provide primary care to others. Furthermore, social support programs could be adapted to include innovative ways to enhance adherence, especially among couples. Couple sessions may be an effective way to increase sexual decision-making as well as identifying the different types of social support to empower the relationship.

Additionally, intervention programs may be designed to introduce a family approach to enhancing medication adherence involving husbands/significant others to increase their knowledge of HIV/AIDS and the benefits and need for social support. Family approach models could highlight the family as a valuable source for health promotion, social support, and care for those living with a chronic disease. Furthermore, healthcare professionals may improve their care and services to HIV-positive individuals and their families by conducting a thorough assessment of the levels of social support of their patients and assist the family in identifying the appropriate sources social support within the unit and provide the needed resources.

References

- Anson, O. (1989). Marital status and women's health re-visited: The importance of a proximate adult. *Journal of Marriage and the Family*, *51*, 185–194.
- Armistead, L., Morse, E., Forehand, R., Morse, P., & Clark, L. (1999). African American women and self disclosure of HIV infection: Rates, predictors, and relationship to depressive symptomatology. *AIDS and Behavior*, *3*, 195-204. doi: 10.1023/A:1025400410099
- Beals, K. P., Wight, R. G., Aneshensel, C. S., Murphy, D. A., & Miller-Martinez, D. (2006). The role of family caregivers in HIV medication adherence. *AIDS care*, *18*(6), 589–596.
- Bebbington, P., & Tansella, M. (1989). Gender, marital status and treated affective disorders in South Verona: A case register study. *Journal of Affective Disorders*, *17*(1), 83–91.
- Berkman, L. F., & Breslow, L. (1983). *Health and ways of living: The Alameda county study*. New York, NY: Oxford Press.
- Berkman, L. F., & Glass, T. (2000). Social integration, social networks, social support, and health. In L. F. Berkman & I. Kawachi (Eds.), *Social epidemiology* (pp. 137-173). New York, NY: Oxford.
- Berkman, L. F., & Syme, S. L. (1979). Social networks, host resistance, and mortality: A nine- year follow up study of Alameda county residents. *American Journal of Epidemiology*, *109*(2), 186-204.
- Bor, R., Du Plessis, P., & Russell, M. (2004). The impact of disclosure on the index patients' self-defined family. *Journal of Family Therapy*, *26*, 167–192. doi: 10.1111/j.1467-6427.2004.00277.x

- Catz, S. L., Kelly, J. A., Bogart, L.M., Benotsch, E. G., & McAuliffe, T. L. (2000). Patterns, correlates, and barriers to medication adherence among persons prescribed new treatments for HIV disease. *Health Psychology, 19*(2), 124-133.
- Centers for Disease Control and Prevention (CDC) (2005). *HIV/AIDS surveillance report*. Vol. 17. Rev ed. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (2007) Retrieved from <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2005report/pdf/2005surveillancereport.pdf>
- Centers for Disease Control and Prevention (CDC). (2008a). HIV Prevalence Estimates United States, 2006. *MMWR, 57*(39), 1073-1076. Retrieved from <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5739a2.htm>
- Centers for Disease Control and Prevention (CDC). (2008b). *MMWR analysis provides new details on HIV incidence in the U.S. populations*. Retrieved from <http://www.cdc.gov/hiv/topics/surveillance/resources/factsheets/pdf/mmwr-incidence.pdf>
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98*(2), 310-357.
- Colaizzi, P. (1978). Psychological research as the phenomenologist views it. In R. S. Valle & M. King (Eds.), *Existential phenomenological alternatives for psychology* (pp. 48-71). New York, NY: Oxford University Press.
- Coyne, J. C., Rohrbaugh, M. J., Shoham, V., Sonnega, J. S., Nicklas, J. M., & Cranford, J. A. (2001). Prognostic importance of marital quality for survival of congestive heart failure. *American Journal of Cardiology, 88*(5), 526-529.
- Crocker, J., & Canevello, A. (2008). Creating and undermining social support in communal relationships: The role of compassionate and self-image goals. *Journal of Personality and Social Psychology, 95*(3), 555-575.
- Denzin, N., & Lincoln, Y. (1998). *Collecting and interpreting qualitative materials*. Thousand Oaks, CA: Sage.
- District of Columbia, Department of Health. (2008). *District of Columbia HIV/AIDS epidemiology update*. Retrieved from http://doh.dc.gov/doh/lib/doh/pdf/dc_hiv-aids_2008_updatereport.pdf.
- Edwards, L. V. (2006). Perceived social support and HIV/AIDS medication adherence among African American women. *Qualitative Health Research, 16*, 679-691. doi: 10.1177/1049732305281597
- El-Sadr, W. M., Mayer., K. H., & Hodder, S. L. (2010). AIDS in America – Forgotten but not gone. *The New England Journal of Medicine, 362*, 967-970. doi: 10.1056/NEJMp1000069
- Folkman, S., Chesney, M. A., Cooke, M., Boccillari, A. & Collette, L. (1994). Caregiver burden in HIV-positive and HIV-negative partners of men with AIDS. *Journal of Consulting and Clinical Psychology, 62*(4), 746-756.
- Foster, P. P., & Gaskins, S. W. (2009). Older African Americans' management of HIV/AIDS stigma. *AIDS Care, 21*(10), 1306-1312.
- Frude, N. (1990). *Understanding family problems: A psychological approach*. London: Wiley.

- Gonzalez, F., Pendo, F., & Antoni, M. (2004). Social support, positive states of mind, and HIV treatment adherence in men and women living with HIV/AIDS. *Health Psychology, 23*(4), 413-418.
- Hader, S. L., Smith, D. K., Moore, J. S., & Holmberg, S. D. (2001). HIV infection in women in the United States: Status at the millennium. *Journal of the American Medical Association, 285*(9), 1186–1192.
- Hall, H. I., Song, R., Rhodes, P., Prejean, J., An, Q., Lee, L. M.,... Janssen, R. S. (2008). Estimation of HIV incidence in the United States. *Journal of the American Medical Association, 300*(5), 520-529.
- Holt-Lunstad, J., Birmingham, W., & Jones. B. Q. (2008). Is there something unique about marriage? The relative impact of marital status, relationship quality, and network social support on ambulatory blood pressure and mental health. *Annals of Behavior Medicine, 35*(2), 239–244.
- House, J. S., Umberson, D., & Landis, K. R. (1988). Structures and processes of social support. *Annual Review of Sociology, 14*, 293-318. doi: 10.1146/annurev.so.14.080188.001453
- Johnson, N. J., Backlund, E., Sorlie, P. D., & Loveless, C. A. (2000). Marital status and mortality: The national longitudinal mortality study. *Annals of Epidemiology, 10*(4), 224–238.
- Karasu, S. R. (2007). The institution of marriage: Terminable or interminable? *American Journal of Psychotherapy, 61*(1), 1–16.
- Kiecolt-Glaser, J. K., & Newton, T. L. (2001). Marriage and health: His and hers. *Psychological Bulletin, 127*(4), 472–503.
- Larzelere, M. M., & Jones, G. N. (2008). Stress and health. *Primary Care: Clinics in Office Practice, 35*, 839-856. doi: 10.1016/j.pop.2008.07.011
- LeBlanc, A. J., London, A. S., & Aneshensel, C. S. (1997). The physical costs of AIDS caregiving. *Social Science and Medicine, 45*(6), 915–923.
- Lee, L. M., & Fleming, P. L. (2001). Trends in human immunodeficiency virus diagnosis among women in the United States, 1994 – 1998. *Journal of American Women's Association, 56*(3), 94-99.
- Litwak, E., & Messeri, P. (1989). Organizational theory, social supports, and mortality rates: A theoretical convergence. *American Sociology Review, 54*, 49–66.
- Maneesriwongul, W., Panutat, S., Putwatana, P., Srirapo-ngam, Y., Ounprasertpong, L., & Williams, A. B. (2004). Educational needs of family caregivers of persons living with HIV/AIDS in Thailand. *Journal of the Association of Nurses in AIDS Care, 15*(3), 27-36.
- Maryland States AIDS Administration. (2001). *The Maryland 2001 HIV/AIDS annual report*. Baltimore, MD: Department of Health & Mental Hygiene.
- McCoy, S. I., Strauss, R. P, MacDonald, P. D. M., Leone, P. A., Eron, J. J., & Miller, W. C. (2009). Social support and delays seeking care after HIV diagnosis, North Carolina, 2000-2006. *AIDS Care, 21*(9), 1148-1156.
- McDowell, T. L., & Serovich, J. M. (2007). The effects of perceived and actual social support on the mental health of HIV-positive persons. *AIDS Care, 19*, 1223-1229. doi: 10.1080/09540120701402830

- McGuire, L. C., Anderson, L. A., Talley, R. C., & Crews, J. E. (2007). Supportive care needs of Americans: A major issue for women as both recipients and providers. *Journal of Women's Health, 16*(6), 784–789.
- Miles, M., & Huberman, M. (1994). *Qualitative data analysis*. Thousand Oaks, CA: Sage.
- Mosack, K. E., & Petroll, A. (2009). Patients' perspectives on informal caregiver involvement in HIV health care appointments. *AIDS Patient Care and STDs, 23*(12), 1043–1051.
- Muhr, T. (1997). *Atlas.ti* (Version 4.1) [Computer software]. Berlin, Germany: Scientific Software Development.
- Murphy, D. A., Marelich, W. D., Hoffman, D., & Steers, W. N. (2004). Predictors of antiretroviral adherence. *AIDS Care, 16*(4), 471–484.
- National Alliance of State and Territorial AIDS Directors. (2008). *African American Women – Issue Brief 1*. Washington, DC: National Alliance of State and Territorial Directors.
- O'Leary, A., & Wingood, M. (2000). Interventions for sexually active heterosexual women. In R. J. DiClemente (Ed.), *Handbook of HIV prevention* (pp. 179–200). New York, NY: Kluwer Academic Press.
- Pasch, L. A., & Bradbury, T. N. (1998). Social support, conflict, and the development of marital dysfunction. *Journal of Consulting and Clinical Psychology, 66*(2), 219–230.
- Pennebaker, J. W. (1997). Writing about emotional experiences as a therapeutic process. *Psychological Science, 8*(3), 162–169.
- Rivero-Mendez, M., Dawson-Rose, C. S., & Solis-Baez, S. S. (2010). A qualitative study of providers' perception of adherence of women living with HIV/AIDS in Puerto Rico. *The Qualitative Report, 15*(2), 232–251. Retrieved from <http://www.nova.edu/ssss/QR/QR15-2/rivero-mendez.pdf>
- Robles, T. F., & Kiecolt-Glaser, J. K. (2003). The physiology of marriage: Pathways to health. *Physiology Behavior, 79*(3), 409–416.
- Rose, M. A., Sharpe, T. T., Ralieggh, K., Reid, L., Foley, M., & Cleveland, J. (2008). An HIV/AIDS crisis among African American women: A summary for prevention and care in the 21st century. *Journal of Women's Health, 17*(3), 321–324.
- Ross, C. E., Mirowsky, J., & Goldstein, K. (1990). The impact of the family on health: The decade in review. *Journal of Marriage and the Family, 52*(4), 1059–1078.
- Sogaard, A. J., Kritz-Silverstein, D., & Wingard, D. L., (1994). Finnmark heart study: employment status and parenthood as predictors of psychological health in women, 20–49 years. *International Journal of Epidemiology, 23*, 82–90.
- Stein, J. A., Nyamathi, A., Ullman, J. B., Bentler, P. M. (2007). Impact of marriage on HIV/AIDS risk behaviors among impoverished, at-risk couples: A multilevel latent variable approach. *AIDS and Behavior, 11*(1), 87–98.
- Sutton, M. Y., Jones, R. L., Wolitski, R. J., Cleveland, J. C., Dean, H. D., & Fenton, K. A. (2009). A review of the centers for disease control and prevention's response to the HIV/AIDS crisis among blacks in the United States, 1981–2009. *American Journal of Public Health, 99*(S2), S351–S359.
- The Henry J. Kaiser Family Foundation. (2009). *HIV/AIDS policy fact sheet: The HIV/AIDS epidemic in the United States*. Washington, DC: The Henry J. Kaiser

- Family Foundation. Retrieved from <http://www.kff.org/hiv/aids/upload/3029-10.pdf>
- Turner, H. A., Catania, J. A., & Gagnon, J. (1994). The prevalence of informal caregiving to persons with AIDS in the United States: Caregiver characteristics and their implications. *Social Sciences and Medicine*, *38*(11), 1543–1552.
- Uchino, B. N. (2009). Understanding the links between social support and physical health: A life-span perspective with emphasis on the separability of perceived and received support. *Perspectives on Psychological Science* *4*, 236-255. doi:10.1111/j.1745-6924.2009.01122.x
- Umberson, D. (1987). Family status and health behaviors: Social control as a dimension of social integration. *Journal of Health and Social Behavior*, *28*(3), 306–319.
- Umberson, D. (1992). Gender, marital status, and the social control of health behavior. *Social Science and Medicine*, *34*(8), 907–917.
- UNAIDS & World Health Organization (WHO). (2007, December). *AIDS epidemic update*. Geneva, Switzerland: Joint United Nations Programme on HIV/AIDS (UNAIDS) and WHO.
- Vithayachockitikhun, N. (2006). Family caregiving of persons living with HIV/AIDS in Thailand: Caregiver burden, an outcome measure. *International Journal of Nursing Practice*, *12*(3), 123-128.
- Vyavaharkar, M., Moneyham, L., Corwin, S., Saunders, R., Annang, L., & Tavakoli, A. (2009). Relationship between stigma, social support, and depression in HIV-infected African American women living in the rural southeastern United States. *Journal of the Association of Nurses in AIDS Care*, *21*(2), 144-152.
- Wilcox, W. B., Doherty, W., Glenn, N., & Waite, L. (2005). *Why Marriage Matters: Twenty-Six Conclusions from the Social Sciences* (2nd ed.). New York, NY: Institute for American Values.
- Wohl, A. R., Galvan, F. H., Myers, H. F., Garland, W., George, S., Witt, M., ... Carpio, F. (2010). Social support, stress, and social network characteristics among HIV-positive Latino and African American women and men who have sex with men. *AIDS and Behavior*, *14*(5), 1149-1158.

Author Note

Lorece V. Edwards, DrPH, MHS is the Director of Community Practice & Outreach/Assistant Professor in the Department of Behavioral Health Sciences in the School of Community Health and Policy at Morgan State University, Baltimore, MD. Her research interests include HIV/AIDS prevention, service-learning/community engagement, social epidemiology, and women's health. Additionally, Dr. Edwards was recently appointed to the Baltimore City Council HIV/AIDS Commission. Correspondence regarding this article can be addressed to: Dr. Lorece V. Edwards at E-mail: LoreceEdwards@aol.com; and Phone number: 410-207-0629.

Shalon M. Irving, PhD, MPH, CHES is a W.K. Kellogg Health Scholar at the School of Health and Policy at Morgan State University. Dr. Irving believes in the necessity of creating positive health and behavioral trajectories. She is particularly dedicated to using her research skills in applied settings and has recently begun exploring

the utility of community-based participatory research in addressing the health concerns of marginalized groups. Her specific area of interest is the reduction of HIV related risk behavior and improved sexual health among urban adolescents. Correspondence to the second author can be addressed to: Dr. Shalon M. Irving at E-mail: DrShalonIrving@gmail.com

Anita Smith Hawkins, PhD, MHS is an Assistant Professor in the School of Community Health and Policy, Department of Health Policy and Management at Morgan State University, Baltimore MD. She is actively involved in building community-research collaboratives and has served as the research partner for several community initiated projects addressing violence, HIV/AIDS, substance abuse and health care access and utilization. Correspondence to the third author can be addressed to: Dr. Anita S. Hawkins at E-mail: Anita.Hawkins@Morgan.edu

The first author wishes to acknowledge Jean R. Anderson, MD, Patricia Paluzzi, DrPH, Rena Boss-Victoria, DrPH, and all of the women at the Johns Hopkins HIV Women's Health Program. A poster presentation of these findings will be presented at the American Public Health Association's 138th Annual Meeting and Expo - November 6 - 10, 2010 in Denver, Colorado.

Copyright 2011: Lorece V. Edwards, Shalon M. Irving, Anita S. Hawkins, and Nova Southeastern University

Article Citation

Edwards, L. V., Irving, S. M., & Hawkins, A. S. (2011). Till death do us part: Live experiences of HIV-positive married African American women. *The Qualitative Report, 16*(5), 1361-1379. Retrieved from <http://www.nova.edu/ssss/QR/QR16-5/edwards.pdf>
