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Am I My Mother's Keeper? Children as Unexpected Sources of Social Support Among African American Women Living With HIV-AIDS

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Abstract

HIV-AIDS continues to be an escalating health problem, particularly among women. In the United States, African American women are among the leading demographic groups for HIV prevalence. African American women represent 65% of the total women living with HIV-AIDS. The typical woman with HIV-AIDS is young, in her 20s, economically challenged, and of childbearing age. Adherence to HIV therapies is critical if patients are to achieve and maintain virologic suppression. Adherence is especially significant for women, who are often the gatekeepers of care for the family. Scholars have long recognized the importance of social support for general health and well-being. This study explores unexpected sources of social support among women living with HIV-AIDS and how social support networks may affect medication adherence, health, and well-being. Young children were identified as social actors of care.

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Despite aggressive public health efforts to curb the epidemic, it is estimated that more 560,000 new cases of HIV infection occur annually in the United States (Hall et al., 2008). The HIV-AIDS epidemic continues to remain a major public health concern in the United States, especially among communities of color. Of importance, HIV-AIDS diagnoses are greatest among African American women and exceed those of every other racial-ethnic group of women and men (Morris, Kurth, Hamilton, Moody, & Wakefield, 2009). Despite advances in prevention and treatment, women continue to suffer from HIV-AIDS at increasingly alarming rates (Armistead, Morse, Forehand, Morse, & Clark, 1999). For females (adults and youth), the rate for African American females (60.6) was nearly 20 times as high as that of white females (3.3) and nearly 4 times as high as that of Hispanic and Latina females (16.0) (Centers for Disease Control and Prevention, 2010).

Since the beginning of the epidemic, HIV has been associated with considerable mental stress and psychiatric morbidity among African American women (Prachakul, Grant, & Keltner, 2007). African American women represent a unique population with special needs owing to distinct stressors and contextual circumstances (Ball, Tannenbaum, Armistead, & Maguen, 2002). Low-income HIV-positive women who live in the inner city encounter stressors from their environment that are commensurate with poverty, low socioeconomic status (SES), racism, drug abuse, mental illness, (Hudson, Lee, Miramontes, & Portillo, 2001), and intimate partner violence (Outwater, Neema, & Campbell, 2005).

The lives of HIV-positive African American women are complex and unique and very often challenging. The transformation of HIV disease from an acute deadly illness to a manageable chronic disease has brought additional psychological stressors for women living with HIV-AIDS (Vyavaharkar, et al., 2011). Living with HIV-AIDS forces women to incorporate their diagnosis, treatment, and psychosocial factors into their daily lives. As such, being the gatekeepers of care for the entire family can become very challenging and demanding when attempting to maintain and manage their own health status and well-being.

Given the increasing impact of HIV-AIDS, it is imperative to identify factors that may influence the quality of life (Vyavaharkar, Moneyham, Murdaugh, & Tavakoli, 2011). It is critical to understand the impact of social support and its relationship to chronic disease management and health outcomes for

women living with HIV-AIDS. The current study takes a phenomenological approach to explore the life experiences of HIV-positive African American women and social support. Data derived from journaling and semistructured interviews delve into the women's perceptions of social support, unexpected sources of social support, and the impact these experiences had on their HIV medication adherence and practices. Additionally, their reflections of life living with HIV-AIDS were also captured.

Related Literature Review and Theoretical Perspective

General Social Support

Scholars have long recognized the importance of social support for general well-being and health (Berkman, 1984; Berkman & Syme, 1979; Cohen & Wills, 1985; Uchino, 2009). Although the biopsychosocial process by which social support affects health has not been fully explicated (House, Umberson, & Landis, 1988; Uchino, 2009), the extant literature supports an association between social support and a decreased incidence of morbidity (Berkman & Syme, 1979) and lower likelihood of mortality (House et al., 1988).

However, with relative consistency, scholars suggest that individuals are better able to cope with ordinary and extraordinary life stressors in the presence of social support (House et al., 1988; Schaefer, Coyne, & Lazarus, 1981). Social support can be defined as "a person's perception of the supportive value of social interactions" (Schaefer et al., 1981, p. 382). Interestingly, scholars posit that the perception of support may be more important than the actual receipt of social support (Crocker & Canevello, 2008; McDowell & Serovich, 2007; Uchino, 2009). According to the stress-buffering hypothesis, individuals with the highest levels of stress may receive the greatest benefit from supportive social relationships (Dorsey, Klein, & Forehand, 1999; House et al., 1988).

The relationship between social support and health may be of particular importance for women living with HIV, as the role of social support may help to significantly offset the stressors of living with a chronic disease diagnosis (Dorsey et al., 1999). Unfortunately, Dorsey and colleagues (1999) found that HIV-infected women actually report lower levels of support from friends and family compared to their noninfected counterparts. This may be attributable to the fact that chronic stressors, such as a chronic highly stigmatized illness, may overtax a social network and result in a reduction of support (Lincoln, Chatters, & Taylor, 2005).

Social Support and HIV-AIDS

Social support is a key factor in buffering the effect of stressors, thus minimizing adverse outcomes of stressful situations (Hudson et al., 2001). Although social-support processes of middle-class populations have been extensively studied, less empirical research has been conducted with poor populations (Mickelson & Demmings, 2009), particularly, women. Berkman and Syme (1979) clearly articulated that lack of social support has been associated with physical illness, psychological distress, and mortality in a variety of populations. Social support has been associated with positive emotional and health outcomes for people living with HIV-AIDS. An HIV-positive woman's social support network may promote healthy behaviors and help reduce delay in seeking care (Williams, Shahryarine, Andrews, & Alcabes, 1997) as well as provide protective factors within the disease process that affects the psychological adaptation to living with a chronic disease.

Social support has been found to be a critical factor in coping with HIV (Rodgers, 1995). In a study of HIV-positive African American mothers, Hough, Brumitt, Templin, Salzt, and Mood (2003) found that effective coping was positively related to their social support system. This study revealed that mothers with adequate social support were more likely to use effective coping strategies and to exhibit decreased mood disturbances. Furthermore, results from this examination pointed to the importance of social support as a buffer against the deleterious effects of HIV-related stress and coping.

According to Hough, Magnan, Templin, and Gadelrab (2005), the data clearly indicate that quality of social support influences coping, psychological well-being, and health-related outcomes in persons with a chronic illness, including HIV-AIDS. Despite the tendency toward secrecy among HIV-positive individuals, the beneficial effect of social support on psychological distress has been demonstrated consistently among samples of gay men (Leserman, Perkins, & Evans, 1992) and HIV-positive women (Clark et al., 1995). Clark et al. (1995) reported that HIV-positive women who were less depressed were more likely to have a confidante. An examination of social support among racially underrepresented women reported that HIV-positive women received less emotional social support than a sociodemographically similar group of uninfected women (Klein et al., 2000).

Types and Sources of Social Support

Scholars have posited the existence of at least three distinct domains of support. Emotional support, tangible support (including direct aid or services),

and informational support are three often-cited forms of support (Berkman, 1984; Schaefer et al., 1981; Uchino, 2009). It is possible that the type of social support that is most beneficial may depend on the stressor that the individual is facing; therefore, support that is not responsive to a given stressor is unlikely to be beneficial (Jacobson, 1986). Jacobson (1986) suggests that the type of support that is necessary or most beneficial may differ depending on timing, specifically, "one type of support takes the place of another" (p. 252). Whereas during a crisis, emotional support may be most helpful, it is cognitive or informational support that is most helpful during transitional states. And during deficit states in which people must readjust to life after "chronically excessive demands," material or instrumental support is most helpful (Jacobson, 1986). In the early stages of illness, for example, after an HIV diagnosis, emotional support may be beneficial. This is consistent with, and appropriate to, the task of coping with the emotional arousal associated with such a crisis state (Jacobson, 1986, p. 255).

Dorsey et al. (1999) note that of the various types of social support, instrumental and informational may be of greatest import for HIV-infected mothers—especially as it relates to maintaining their ability to effectively parent. Of the various sources of social support, marriage is assumed to be a fundamental source of social support, so much so that married people are expected to experience lower mortality rates than their unmarried counterparts (Berkman, 1984). However, although marriage is cited as an important source of support in much of the literature, there is also literature to suggest that women are the primary providers of social support (House et al., 1988) and that this "female-centered" support system is of critical importance for women living with HIV (Wohl et al., 2010). In a study exploring HIV and marriage, Edwards, Irving, and Hawkins (2011) found that HIV-positive married women were faced with a set of unique challenges and reported less satisfaction with their social support system. Although less frequently studied, children may provide a source of support as well.

Children as Sources of Social Support: The Role of Parentification

In families affected by HIV and other sources of stress, children often take on leadership roles that were once designated for the parent. The process of *parentification* refers to the early and premature assumption of parental roles and adult responsibilities in children or adolescents before they are emotionally or developmentally prepared for such roles (Broszormenyi-Nagy & Spark, 1973; Jurkovic, 1997). Parentification can take on many forms,

including emotional care provided to the mother, instrumental care, responsibility for siblings and other household or family members, and responsibility for family negotiation with the larger neighborhood and community (Keigher, Zabler, Robinson, Fernandez, & Stevens, 2005).

Parentification and children as sources of social support for parents with HIV have received little study (Broszormenyi-Nagy & Spark, 1973; Minuchin, 1974). What is known is that in families experiencing various stressors (e.g., single parenting, substance dependence, marital dysfunction, divorce, illnesses, imprisonment), the likelihood of parentification is increased (Tompkins, 2007). Existing research on social class and social support has consistently demonstrated that social support varies by SES, such that lower-SES individuals report less social support from family and friends than higher-SES individuals (Mickelson & Demmings, 2009). Additionally, low-income women are not able to rely on their traditional social ties of adult family and friends, because they lack the resources to aid them, given their similar life situations (Mickelson & Demmings, 2009). As a result of this deficit, low-income women may substitute their minor children in place of these traditional adult social ties (Mickelson & Demmings, 2009).

Research differs on whether children who function as sources of social support are positively or negatively affected by the role reversal. Previous discussion in this area (Broszormenyi-Nagy & Spark, 1973) has raised the issue of children functioning as sources of social support and the negative impact it has on children (loss of childhood; neglect of developmental tasks, such as identity formation and autonomy). However, competing research has highlighted the positive impact of the role reversal for children.

Some of the potential benefits to children are increased self-esteem, a greater sense of altruism, improved sense of taking responsibility, and increased competence. The degree to which children serve as caregivers, the duration of the caregiving, and the acknowledgement of the social support are constructs that would benefit from further inquiry and analysis (Groce, 1995; Jurkovic, 1997; Jurkovic, Thirkield, & Morrell, 2001).

Another aspect of the parentification of children with maternal HIV infection is the concept that HIV as a chronic illness is different from other chronic illnesses. Specifically, the treatment of HIV involves complex and time-intensive medication regimens that extend the life of the parent but also have severe side effects that may hinder the role functioning of the parent. Furthermore, stigma and issues of disclosure may preclude the parent from forming a complete network of social support and cause the parent to lean and depend on the child for longer periods of time (Tompkins, 2007).

Tompkins (2007) conducted a study with a group of children whose parents had HIV and compared them with a group of children whose parents did not have HIV. Higher rates of parentification were expected in those families affected by maternal HIV infection. Furthermore, the author hypothesized that the difference would be seen even after controlling for potential confounding factors, such as maternal drug use, marital status, and number of children in the home. In the results of the study, parentification was not associated with maladaptive parenting or child outcomes, particularly among families affected by maternal HIV (Tompkins, 2007). Contrary to expectation and to previous research examining parentification in a sample of parents with AIDS, the findings suggested a salutary relationship between parentification and child adjustment (Stein, Rotherram-Borus, & Lester, 2007). Mothers who reported that their children engaged in more parental role behaviors had children who reported lower levels of depressive symptoms and higher social competence (Tompkins, 2007).

As previously stated, the body of research on the parentification of children with HIV-positive mothers is scant. Thus, future research in this area is warranted. Without a longitudinal perspective, it is unknown whether findings that suggest a favorable relationship will remain positive or whether performance of adult roles over time will interfere with the achievement of long-term developmental goals for the children in these families.

With regard to African Americans, previous research has reported that there is no reference to parentification in the African American family literature (Anderson, 1999). Work by Keigher et al. (2005) stated that children in immigrant and racially underrepresented families, where interdependence is considered to be a strength, parentification may not be considered deviant or non-normative behavior (Keigher et al., 2005). Thus, additional research in the area of parentification, HIV-AIDS, and African American families could undoubtedly influence policy and programmatic initiatives in underserved communities around the country.

Theoretical Perspective

The theoretical framework used in this study was the health belief model (HBM). The HBM has been one of the most widely used conceptual frameworks in health behavior research to explain both change and maintenance of health-related behaviors (Glanz, Rimer, & Viswanath, 2008). The HBM contains several concepts that predict why people will take action. The HBM constructs include susceptibility, seriousness, benefits and barriers to a

behavior, self-efficacy, and cues to action. In applying the framework to the research at hand, minor children as unexpected sources of social support provided cues to action for medication adherence and compliance, thereby influencing perceived benefits of social support, caring, and commitment.

Method

This study was part of a project conducted by the first author (Edwards, 2006). The purpose of the original project 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 HIV-AIDS and social support, the purpose of the current study was to explore unexpected sources of social support among women living with HIV-AIDS and how social support affects medication adherence. Additionally, the current study captures reflections of the life experiences among African American women living with HIV-AIDS. The data were derived from daily journal entries and semistructured interviews.

Data collection was completed at the Johns Hopkins Medical Institutions–Moore Clinic with the approval by the hospital's Committee on Human Research Subjects and the institutional review board at Morgan State University. The Moore Clinic at Johns Hopkins Hospital was the first HIV clinic in Maryland and the second-oldest clinic in the United States. The Moore Clinic has been a national leader in the treatment of HIV-AIDS.

Participants

A purposeful sample of 20 HIV-positive participants was recruited. From April 4, 2003, to June 9, 2003, a phenomenological study was conducted. We recruited participants from the outpatient clinic using physician networks and posted flyers. To participate, one had to be an African American woman 20 to 49 years old, have children and/or be a primary caregiver of a child, be receiving primary HIV care at the clinic, be mentally and physically healthy, and be taking highly active antiretroviral therapy (HAART). The age group was selected on the basis of a report from the Infectious Disease and Environmental Health Administration, formerly known as the Maryland State AIDS Administration. The report stated that the majority of HIV cases (87%) and AIDS cases (86%) in Baltimore, Maryland, at the time were among individuals between the ages of 20 and 49 years.

The 20 eligible participants ranged in age from 20 to 49 years. Educational levels for this population varied, with 70% of the sample having less than a

high school education. Among the sample, 30% of the participants had a history of substance abuse. The average annual household income was less than $11,000. Most of the participants were unemployed and had been diagnosed with HIV-AIDS a minimum of 4 years prior to participation. Participants' viral loads ranged from undetectable to more than 50,000 copies/ml. More than half reported contracting HIV through heterosexual contact.

Journaling

Qualitative data were collected through daily journal entries and semistructured interviews. After enrollment in the study, participants were introduced to the concept of journaling and given an exercise to break the ice. Journaling was chosen as a methodology because of its therapeutic process to enhance self-awareness and self-efficacy, build self-confidence and self-esteem, and track adherence patterns, perceptions of social support, and reflections of 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 and give them meaning."

According to social science researchers, journaling can be especially effective when writing about life changes, relationships, or chronic disease and illness (Pennebaker, 1997). Moreover, Pennebaker (1997) found that writing or talking about emotional topics has a beneficial influence not only on health but also on immune function, including T-helper cell growth.

The participants in this study were instructed to journal three times a week for a 2-week period and for a minimum of 10 min about their perceptions of social support and social ties, medication adherence, and reflections of their life experiences living with HIV-AIDS. They were reassured that they should not worry about grammar and spelling and that they should feel free to be creative in their communication by writing in any way that they wished (e.g., poems, lyrics, scripture, list, stories, quotes). This technique was used to increase the likelihood that participants would feel comfortable journaling as instructed.

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. An example of a typical question written in the journal included "Did your family/friends help you (or remind you) to take your HIV meds today?" In addition, the journals included baseline social support information and clearly defined areas where participants could share any other information and document reflection notes. The baseline section of the journal gathered demographic information (e.g., whom they lived with, access to telephone and/or transportation, whether they have a best friend, whether

family members or friends were aware of their HIV status, and whom they can turn to in an HIV-related medical crisis). Journals were coded by hand in their written form.

Interviews

Following the 2-week journal period, individual interviews were conducted with all participants. Written consent was obtained prior to the start of each interview. The semistructured interviews focused on social support, medication adherence, and reflections of life experiences living with HIV-AIDS. The length of the interviews ranged from 1 hr to 90 min and allowed those participants who were not comfortable journaling the opportunity to freely share about their social support system, social support networks, and life experiences living with HIV-AIDS. Participants were compensated $7.50 per journal entry and $10.00 for participating in the interview.

Coding and Analysis

We transcribed interviews verbatim and coded them to organize main themes using Atlas.ti (qualitative software). A phenomenological methodology incorporating Colaizzi's (1978) seven stages was used to analyze the data. Colaizzi delineates that as a phenomenologist, one must contact a phenomenon as people experience it (real word), proceeding along the lines of describing their experiences. Colaizzi's concept of data analysis includes (a) reading and rereading 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) using themes to develop as complete a picture as possible from 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, we also allowed for the emergence of subthemes. The analysis began with the guiding concepts for comparing the participants' experiences of social support and HIV-AIDS medication adherence practices. Interviews were initially coded for conceptual categories and then subjected to "focused coding" to identify subthemes supported by quotations. Two researchers coded the same data to clarify any differences in coding and to verify reliability (Miles & Huberman, 1994). Member checking was also initiated by

the authors and a graduate assistant to validate the accuracy of the data. This was accomplished by allowing the participants to critically analyze the findings and provide comments for accuracy. All journals were coded by hand in their written form. Individual interviews were professionally transcribed and coded using qualitative software Atlas.ti (Muhr, 1997). Additionally, memo writing for the transcribed interviews facilitated analysis and assisted in looking at the codes in new and unique ways (Denzin & Lincoln, 2000).

Results

The results of this study are presented on the basis of the three themes that were derived: life experiences of African American women living with HIV-AIDS, perceptions of social support and social ties related to medication adherence, and unexpected sources of social support. A detailed description of their experiences is captured in their own words. This study is a preliminary step in increasing our understanding of minor children as social actors for their parents living with chronic disease.

Life Experiences of African American Women Living With HIV-AIDS

HIV-AIDS continues to be a major public health problem for women residing in urban communities. The women participating in this study suggest that HIV-AIDS has not gone away, but in fact, it often hides in abusive relationships, the secrecy of the church, high-risk heterosexual relationships, and rape and sexual assault; and it is driven underground by lack of knowledge, discrimination, stigma, and fear. The transmission of HIV-AIDS among women has become an alarming crisis in the United States with enormous social consequences. Women living with HIV-AIDS are faced with challenges that are accompanied by the personal and social cost associated with this chronic disease. One participant eloquently reflected on her life experiences:

> After all of these years people still don't understand HIV. They think that you can catch it just by hugging somebody. I have been living with HIV for a long time and I am not comfortable sharing my status. I often feel alone because I am not comfortable telling people my status. First of all, people tell your business and talk about you behind your back. Sometimes more than one person in a family is living with HIV but it is kept a secret. You know, HIV is a disease that affects the whole family.

Another participant shared this view reflecting on her life experiences:

> It is so important to stay connected to your doctor. I hate taking medication so I really need to keep my appointments. I have doctors' appointments, support groups sometimes, and I take care of my eight year old grand-daughter. She is my sunshine. Between her and God, I make it from day to day. When I look back at my life, I should have been dead a long time ago but God spared my life for a reason. I have used drugs, been raped, and physically and emotionally abused by a boyfriend. HIV brought things full circle for me. It was my wake-up call and now I have to make sure that no one else misses the alarm. Life is more than what it makes you, it is what you make it. All I can say is HIV is preventable and people don't have to get HIV.

Perceptions of Social Support and Social Ties Related to Medication Adherence

Transformation of HIV disease from an acute deadly illness to a manageable chronic disease has brought additional psychological stress for persons living with HIV (Vyavaharkar, et al., 2011), particularly, women. Recent research has noted that a large part of the psychological stress associated with HIV-AIDS is stigma, discrimination (Vyavaharkar, et al., 2011), and in many cases, a lack of social support (Edwards, 2006). With the current and projected future impact of HIV disease among women of color, it is critical to understand the role of social support and its impact on the life experiences of women living with HIV and their medication adherence practices. Social support may be more of an important factor in women's adaption to HIV-AIDS and medication adherence than previously thought. A participant vividly describes the following:

> HIV/AIDS is a stressful disease. There are so many things to remember. I have to keep up with taking medicine, going to the doctor, eating right, and taking care of my family. There are just too many things to juggle. If I had someone to go to appointments with me that would be a help. Sometimes, I don't always understand what the doctor says and I accidentally confuse my medications. It would be nice to have someone to bounce that kind of stuff off. But, as I think about it, the people who really help are those you least expect. Women should really think about getting HIV. Don't be like me. Use a condom and value your

vagina. There are female condoms out there, if you can find them. No man is worth having HIV/AIDS. You will end up alone.

Another participant shared this concern:

I get so tired of taking pills. Dealing with HIV and other illnesses is a pain in the you know what. A couple of years ago, I got up enough nerve to tell my sister that I was HIV-positive. She was upset but promised to be my anchor in the storm. So far, she has kept her word. She's like an alarm clock calling throughout the day to remind me to take my meds and to be sure to eat. I tell you, I couldn't do this alone. You really need support when living with HIV—somebody to connect with who will walk with you through the ups and downs. You know I found that people with no social support don't stay well, they seem to have more illnesses. You've got to find somebody you can count on.

Because HIV-AIDS is a clinical syndrome with progressive loss of physical function and recurrent symptoms of fatigue and breathlessness, the illness restricts women's social and daily activities and can give rise to feelings of emotional distress and impaired psychological well-being (Catz, Gore-Felton, & McClure, 2002). This participant shared a common concern felt by many others in the study:

Never in my life before have I experienced such loneliness and fear. Life is uncertain right now but somehow God will pull me through. Before my HIV diagnosis, I had lots of friends and social ties with friends and family. Now, things are different. Sometimes, I feel so tired and worn-out and the day-to-day activities are overwhelming. I pray for strength because I have to take care of the family and try to look out for myself. Things get very emotional at times and I begin to feel like I have no purpose or hope. Where is everybody? When I get depressed, I don't always take my medication—who cares anyway. My grandchildren keeps me going and they care for me in sincere ways.

Unexpected Sources of Social Support

There is a growing body of literature that examines the relationship between social support and HIV health-related processes and outcomes, particularly in such areas as medication adherence (Power et al., 2003; Simoni, Frick,

Lockhart, & Liebovitz, 2002), clinical outcomes (Bourgoyne, 2005; Gonzalez et al., 2004), and mental health outcomes (Ingram, Jones, Fass, Neidig, & Song, 1999; Stewart, Cianfrini, & Walker, 2005). Social support has been clearly associated with positive health outcomes for people living with HIV-AIDS (Rodgers, 1995).

As rates of HIV infection increase among women, it becomes more imperative to understand the impact of HIV-AIDS and sources of social support. Vyavaharkar et al. (2011) suggest that social support is an essential resource for effectively coping with HIV disease. Furthermore, prior research suggested that women rely more on social support compared with men in similar situations (Hurdle, 2001). Women in the present study experienced unexpected sources of social support related to HIV coping, care, and resilience. Here is what one participant shared:

> I am really trying to live with this disease. People have no idea what I go through almost every day. The adults in my home are clueless! They absolutely have no idea of the challenges that come with this disease. If it wasn't for my seven year old daughter, I don't know what I would do. She helps me out so much. She will fix me a sandwich so that I can take my medications with food. Everyday she'll ask, how do you feel today? That means so much to me. Can I do something to help you? I love you, mom. She watches over me like a little angel every day.

Another participant shared this view of unexpected social support:

> Sometimes, I am so tired, I can't even get off the sofa. I have three boys that I am raising by myself. My oldest is 11 years old and looks after the younger two. Sometimes he will fix something to eat for all of us. He thinks that he's the man of the house. My oldest son is a life saver. He is very confident in looking out for the family. Before he goes to bed at night, he'll bring me something to drink so that I can take my pills and make sure all the doors are locked. He tells my mother all the time, my mom is sick and I am going to care of her. I don't know what I am going to do with that boy. He really looks out for our family and has become a role model for his younger brothers. He is my support.

The improvements in HIV treatment and care have resulted in women living longer, including mothers, but with compromised health, reduced finances, decreased energy, increased isolation, and depleted resources

(Keigher et al., 2005). For this population, positive social support systems helped absorb the burden of living with HIV-AIDS. HIV-positive women find themselves in a whirlwind of emotional turbulence on a daily basis. The emotional struggles often felt by these women are consoled and nurtured by minor children. According to Mickelson and Demmings (2009), disadvantaged women turn to their minor children as a support network substitution. A mother of two shared the following:

> My 12 year old daughter is a bright girl and she has a bright future. She tells me to be strong and don't cry. Can you believe that? I am trying to get my life together and my daughter is the counselor. I don't want my child to carry the emotional cargo of this disease. I want her to have a better life and one free of HIV/AIDS. I want to be a good parent in spite of my illness.

This is the story of a young participant:

> I have been living with my cousin and her husband for the past year and both of them are HIV-positive. We don't talk about HIV and they never offer any kind of support or help. My little boy is 10 years old. He knows that I am sick with HIV but he doesn't understand what HIV is. I tell him that I have to take my medicine every day and he helps out by getting me something to drink, my pills, and checking on me from time to time. It's amazing, as soon as he comes into the house he will remind me to take my medication. You would think that my cousins would be more helpful and supportive but they are not. We could help each live better with HIV and support one another, but for right now, all I have is my son.

Many of the women in this study identified minor children as their significant source of social support. The minor children identified included biological children and/or grandchildren. Participants' voices echoed a deep concern for their children's well-being and their own health and quality of life living with HIV-AIDS. For this cohort of women, social support matters and draws a thin line between health and wellness and disease and disability. One mother shared a common unease:

> I struggle to take care of myself and my kids but living with HIV/AIDS is not easy. There is so much stigma and discrimination on top of being sick. This does not help anybody. I want to be able to take care of

myself and not have to depend on others, especially the little ones. I can only depend on my granddaughter to help me when she spends the night. She provides so much encouragement and love. I don't know what I would do without her. Between my faith and my little grand-daughter, I know that I will be okay.

Social support is critical for people infected and affected by HIV-AIDS. Attention must be given to minor children as a significant source of social support or an emerging caregiver population that may be easily overlooked. However, it is important, nonetheless, to recognize the roles of children as primary sources of social support. The participants reported that on average young children provided 5 to 8 hr weekly providing instrumental support (e.g., preparing meals, helping with siblings, offering their services). In terms of emotional support (expressions of love, caring, trust, and empathy), children were regularly engaged and attentive to the needs of their mothers.

The findings suggest a common thread among the themes highlighted in this exploration—survival. In spite of a lack of needed social support and resources, women met the hardships of life (e.g., discrimination, stigma, poverty). They never gave up on hope and were strongly encouraged by minor children. One participant stated, "Life isn't about how to survive the storm, but how to dance in the rain."

Discussion

The transformation of HIV disease from an acute illness to a chronic disease has brought additional stressors for persons living with HIV-AIDS (Vyavaharkarr et al., 2011), particularly, women, (Edwards et al., 2011). HIV-AIDS continues to be a major public health crisis with no abatement in sight in terms of its multiple personal, social, and health care ramifications (Beals, Wight, Aneshensel, Murphy, & Miller-Martinez, 2006). As such, it is extremely important to address the social factors that affect African American women living with HIV-AIDS and to explore women's perceptions of social support, social ties, and practices associated with HAART and health care use.

The voices of HIV-positive women in this study highlight the challenges that some women face when attempting to manage their health and daily demands. It is clear from these findings that to understand the many challenges that accompany an HIV diagnosis and medication adherence, one must give full consideration to the multiple sources of social influences and social factors that women attend to in restructuring their lives as parents as well as their adherence practices. Of importance, this is often combined with

the lack of needed support and resources to manage day-to-day tasks and the challenges of ongoing stressors. Minor children as unique and unexpected sources of social support are becoming more common among racially underrepresented women. Consistent with recent literature, racially underrepresented women often turn to their minor children for social support and resources (Mickelson & Demmings, 2009).

The women in this study stated that three decades into the HIV-AIDS epidemic, people still do not know or understand the modes of transmission of this disease. Many women stated that they were not comfortable sharing their HIV-AIDS status because of fear of stigma, discrimination, and the overall lack of education about HIV-AIDS that continues to plague the African American community. Women shared that feelings of stigma and discrimination occurred when they revealed their HIV status with family members and friends and identified HIV-AIDS as the family disease of the 21st century.

For many women who are HIV-positive, social isolation is not an uncommon phenomenon, because people continue to avoid physical contact with those who are HIV-positive. Few illnesses in modern times have been associated with the high levels of stigma resulting in social isolation that accompanies a diagnosis of HIV (Black & Miles, 2002). African American women have been found to report a fear of societal stigma related to HIV from a variety of sources, including family members, church congregants, health care professionals, and the broader community (Black & Miles, 2002).

According to Bassuk, Weinreb, and Buckner (1996), the people they wish to turn to for help and support—their family and friends—are usually dealing with similar issues. Although social support has been associated with positive health outcomes for people living with HIV-AIDS and is a critical factor in coping with HIV-AIDS (Rodgers, 1995), it is surprising how little we know about social support among disadvantaged and underserved populations (Mickelson & Demmings, 2009). As low-income women are often unable to turn to the most appropriate source of social support, many frequently have turn to their minor children.

The women in this study quickly recognized that minor children were their primary sources of social support. Although other adults may have been living in the home, it was neither unusual nor unique for women to rely on minor children to help them cope and effectively structure their lives living with a chronic disease. In many circumstances, for the children, this involved medication reminders, preparing small meals, supporting their mother's physical and emotional needs, and becoming the primary social actor of care. It is clear from the findings of the present study that children are assuming a high level of parental care.

As was found by Keigher et al. (2005), the first and most prominent care provided by children is emotional care. This includes listening to, supporting, and encouraging their mothers, whose emotional needs are magnified by living with HIV-AIDS. The mothers in the present study stated that their children keep them going. Children motivated and empowered their mothers not just to live but also to take care of themselves by keeping medical appointments, getting rest, eating properly, and taking their medication. Children became their primary reason for living and their motivation and fortitude of resilience.

As was found in prior research (Mickelson & Demmings, 2009), minor children were a source for social support. Women relied more on children because they were available and provided the required emotional and social support. The authors also stated that low-income women dealing with recent life events and stressed networks would rely on their minor children for support. In this investigation, the authors stated that women who relied more on their minor children for support would experience decrements in their health, possibly because of the awareness of the burden they are placing on their minor children. The investigators also suggest that greater stress among the mothers was related to greater reliance on minor children for support. Moreover, it was stated that minor children may experience decreased well-being the more they are relied on by their mothers. Role reversal, also known as parentification, can also have positive benefits for children.

Skovdal and Ogutu (2009) conducted a study examining the psychosocial well-being of young caregivers providing care and social support for their family members chronically ill from AIDS. Findings from this study revealed that children managed their caring responsibilities and coped despite adverse circumstances. Alongside the responsibilities, children showed great concern for the care and well-being of their sick parents. In this sample of young children, many of them were able to draw on the benefits of their challenging circumstances: survivorship and communal values. One participant from this particular study stated, "The duty of a child is to help parents. A child is called a helper."

Although certain cases of parentification may be detrimental to a child, this is not always the case. Findings from the present study support those exemplified by Skovdal and Ogutu (2009). The ability of caregiving children to identify and draw on the benefits of their roles as primary social actors has been previously noted as a strategy for psychological survival (Robson, Ansell, Huber, Gould, & van Blerk, 2006). Although premature assumptions of negative aspects of the parental role exist, according to the mothers in the present study, the social support provided by their children was beneficial

and helped them manage their HIV-AIDS disease and medication adherence and strengthened the values and bonds of the family. In essence, young children as social actors of care, social support, and resources represented cues to action for their mothers living with HIV-AIDS. Mothers were more likely to adhere to medication regimens and to keep medical appointments. However, they assumed that adult family members and/or close friends would satisfy these roles.

Another notable finding and perspective from the present study is the concept of resilience within the family unit. The HIV-AIDS epidemic has caused adverse psychosocial consequences leading to change in the function of the family and often disturbing the capacity and fortitude to respond to the needs of its members and nucleus. Resiliency is especially critical for those infected and affected by HIV-AIDS. Families develop unique patterns of resiliency and learn how to cope with challenges and meet individual needs in very extraordinary ways. In the present study, children were instrumental in the role of social support connectedness. These findings are consistent with Masten (2001) that suggested that despite serious threats to adaptation or development, resilience is common even among those with many serious risk factors for negative outcomes. Furthermore, early parentification of children may be protective and may provide them with greater resilience in the long run (Stein, Nyamathi, Ullman, & Bentler, 2007).

Strengths and Limitations

This study has acquired valuable information from a unique and often underrepresented population, but limitations of this study should be noted. First, the study is cross-sectional; hence causation cannot be inferred. Social support and HIV-AIDS medication adherence were assessed only at one point in time. Second, given the small sample size, findings cannot be generalized to others and apply only 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.

Although the limitations of this study cannot be ignored, 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 the effects of HIV-AIDS among the family unit, and against all odds, African American women have strong coping abilities and profound survival instincts. Additionally, parenting is a high priority for HIV-positive women (Faithful, 1997). Future

research may want to investigate the following: gender differences and parentification, and appropriate age for HIV-AIDS education among children affected by HIV-AIDS. Additionally, research is needed to investigate support for children of racially underrepresented women living with chronic disease and the psychosocial factors that may affect these children at the demise of their parent.

Implications for Research

The findings from this study could inform the design and implementation of an HIV-AIDS family intervention program. A family approach to enhancing social support and medication adherence involving husbands or significant others, family members, and close ties to increase their knowledge of HIV-AIDS and the benefits and need for social support could benefit those newly diagnosed with HIV-AIDS. 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.

Declaration of Conflicting Interests

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