

MID-LIFE AFRICAN-AMERICAN WOMEN WITH TYPE 2 DIABETES: INFLUENCE ON WORK AND THE MULTICAREGIVER ROLE

Purpose: Few studies have examined the multicaregiver role, including the work role, of African-American women and the influence of that role on diabetes self-management and the ability to cope with type 2 diabetes. Therefore, the purpose of this study was to explore the perceptions of work and the multicaregiver role of a group of such women to more clearly identify the influence of these factors on diabetic self-management and personal coping.

Methods: Focus group methodology was used to collect data from 12 mid-life African-American women. After data inspection, the research team extracted themes related to work and the multicaregiver role. Identification of relationships among and between themes helped delineate explanations of data and refine questions for future research.

Findings: Focus group analysis of participant responses elicited 4 themes. *Family as core* represented the participant's role as leader of her household. *Work as survival* defined the stresses of work and the physical and psychosocial responses to not working due to the social and economic costs of diabetes. Participants also identified pressures of balancing work and family responsibilities due to diabetes, a theme of *impaired role function*. The final theme, *inner-strengthening*, defined participants' methods of self-preservation through introspection and spiritual behaviors.

Conclusions: Despite their identification of physical and psychosocial struggles with diabetes, participants did not think of diabetes as a life-long illness because it affected their ability to remain at "the head of the table," to continue engaging in paid work outside the home, and to provide for their families. Historical, social, political, and economic factors supported the themes of the study and provide a foundation for further research and health-care delivery system changes focused on improving the lives of these women and their families, who are facing the challenges of chronic illness. (*Ethn Dis.* 2002;12:555-566)

Key Words: African-American Women, Working Women, Diabetes Mellitus—Type 2, Life Change Events, Role Concept

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INTRODUCTION

Type 2 diabetes is considered epidemic among African Americans in the United States. African Americans are twice as likely to have diabetes as compared to European Americans.¹ This problem is particularly evident among women and increases with age for this group. African-American women exhibit an even greater prevalence of diabetes when compared to African-American men, with 25% of African-American women over age 55 having diabetes.^{1,2}

African Americans with diabetes also experience higher rates of complications from their disease than do European Americans. For example, African Americans are more likely to experience hypertension,³ retinopathy,⁴ and end-stage renal disease¹ compared to European Americans who have diabetes. However, significant educational, attitudinal, and socioeconomic barriers hinder efforts to improve care among African-American women and to prevent life-threatening complications.⁵ These barriers cause more perceived diabetic care burden for African Americans than for other minorities because of the high rate of complications among this group and because African Americans perceive the self-care regimen required to control their disease as being more complex than do other ethnic groups.^{2,6} To that end, research has attempted to identify factors within

the social network of individuals with diabetes that contribute to their effective self-care and efforts to prevent complications and early death from the disease.⁷⁻⁹

One component of the social network for many African-American women with diabetes is work, paid activity occurring outside the home. The environment of a patient's life includes the effects of a social network of interactions between the patient, family members, and healthcare providers.¹⁰ African-American women's interactions with co-workers also fit into this social network definition. More than 60% of African-American women are in the paid workforce, and many of these women work to economically survive and to care for dependent children as single mothers.^{11,12} Almost 26% of these women work as clerical staff¹³ or as service or retail personnel.¹⁴⁻¹⁸ These jobs reflect working-class positions as defined by the US government¹⁹ and involve work that is often tedious and physically demanding, and that lacks benefits such as health insurance, paid vacation time, and social support services generally believed to facilitate individual and family health.¹⁹⁻²¹ Frequently working-class African-American women receive lower pay than do their European-American counterparts in similar jobs, a factor that influences access to services that promote the health of African-American families.²²

An additional component of the social environment of African-American women with diabetes is a multicaregiver role, defined as serving directly or indirectly as a provider of instrumental and emotional support to others in one's social network. Despite the historical

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African-American women exhibit an even greater prevalence of diabetes when compared to African-American men, with 25% of African-American women over age 55 having diabetes.^{1,2}

value placed on this role by many African-American women, competing roles inherent in the multicaregiver role affect these women's ability to effectively manage their diabetes.^{9,23,24} These competing roles include providing service as a worker outside the home, as a parent, a partner, and a community member. Few studies have examined the multicaregiver role of mid-life African-American women and the influence of that role on diabetes self-management and ability to cope with diabetes. Therefore, the purpose of this study was to explore African-American women's perceptions of their social network of work and the multicaregiver role to more clearly iden-

tify the influence of these factors on their diabetic self-management and personal coping.

METHODS

Study Population

Participants were 12 women between the ages of 35 and 55 years of age (defined as mid-life) who were patients at an ambulatory family practice clinic in an urban community in the southeastern United States. All women currently worked or had worked outside the home for pay in the recent past. The majority of women identified themselves as working-class employees, and all noted they held concurrent life roles (mother, partner, worker, community member) and had lived with diabetes for at least one year. Religious affiliation and activity was not directly collected for the study, although participants verbalized the importance of this activity in all focus groups. The average age of the participants was 49.3 years; 50% were divorced or separated; almost 60% had education beyond high school; and 58% had an annual income of \$25,000 or less. Due to the participants' choice of a range of annual income on the demographic data form, the mean income

and standard deviation of this variable could not be calculated to describe the sample (Table 1).

Procedures

A family nurse practitioner and research study assistant presented the study to women who met the focus criteria of the research during their regular clinic visits. Only women who agreed to participate in the study received a follow-up phone call by the research assistant and by one of the research team members, who provided information on placement and time of each focus group. The research team paid special attention to the busy lives of the interested women through flexible scheduling of focus group sessions. No one on the research team had worked with these women before the study. Data collection completed during focus groups did not provide evidence that any participants were related to one another nor did it allow for comparisons between the participants and women who chose not to be part of the study.

Design

Focus groups were used to identify opinions and attitudes of the sample on the multicaregiver role and its relevancy to diabetes self-management. The Afri-

Table 1. Description of the sample (N = 12)

Age	Marital Status	Job Role*	Annual Income	Education
35-44 years (5 women)	Single = 0 (0%) Divorced = 1 (20%) Separated = 1 (20%) Married = 3 (60%)	A = 4 (80%) B = 0 (0%) C = 1 (20%) D = 0 (0%)	Less than \$25,000 = 2 (40%) \$25,000-50,000 = 2 (40%) \$50,000+ = 1 (20%)	Less HS = 0 (0%) HS diploma = 1 (20%) HS+ = 4 (80%)
45-54 years (4 women)	Single = 1 (25%) Divorced = 1 (25%) Separated = 1 (25%) Married = 1 (25%)	A = 1 (25%) B = 1 (25%) C = 1 (25%) D = 1 (25%)	Less than \$25,000 = 3 (75%) \$25,000-50,000 = 1 (25%)	Less HS = 0 (0%) HS diploma = 1 (25%) HS+ = 3 (75%)
55-64 years (3 women)	Single = 0 (0%) Divorced = 2 (67%) Separated = 0 (0%) Married = 1 (33%)	A = 0 (0%) B = 0 (0%) C = 0 (0%) D = 3 (100%)	Less than \$25,000 = 2 (67%) \$25,000-50,000 = 1 (33%)	Less HS = 1 (33%) HS = 2 (67%) HS+ = 0 (0%)

* Job role = data entry/clerical (A); teacher assistant/bus driver (B); teacher (C); or retired (D).

† Education = less than high school (less HS); high school diploma (HS); or educated beyond high school (HS+).

can-American community has a strong oral tradition for responding to stressful life events,²⁵ and focus group methodology, as defined by one expert,²⁶ maintained this tradition for the study. This focus group methodology optimized the ability of participants to express in their own words the experience of being an African-American, mid-life woman with diabetes and multiple roles. Over the course of 6 weeks, 3 separate focus groups were held in a quiet classroom at the Family Practice Clinic. An African-American member of the research team with a history of conducting focus groups with African-American women moderated the sessions. A note taker and the study's principal investigator also attended each session. Each session began after traditional work hours for the participants (ie, 5:30 pm). The research team provided refreshments appropriate to a diet for persons with diabetes prior to and during each focus group. Audiotaping of the focus group sessions occurred based on prior informed consent of the participants. The moderator used a focus group guide and relevant probes to gain additional responses to the posed questions (Table 2). As participants responded to each question, their responses were placed on poster paper and displayed across the room. After the first focus group, the research team refined the initial questions to provide further insight into the multicaregiver role. All sessions lasted approximately 1.5 to 2 hours. The study was approved by the human safeguards committees at the authors' places of employment prior to implementation.

Throughout the study, efforts were made to address the trustworthiness, integrity, and validity of the research process as recommended by several qualitative research authors.²⁶⁻²⁷ These efforts included using focused group questions grounded in the literature on work and diabetes of African-American women; testing the questions with similar women as the participants; establishing rapport with the women through the con-

Table 2. Focus group guide

Multicaregiver role:

- How has diabetes affected your life as a woman? (probes: as a mother, as a partner in an important relationship)
- How does diabetes affect your family? (probes: affect your life as a working woman)
- How does your family respond to your diabetes? (probes: how does your family help or support you; if they help, who helps and how do they help; if your family doesn't help, why? What could they do to help you; how do you share your needs related to diabetes with your family?)

Life stress/Social support:

- What are the special stressors in your life? (probe: how do you deal with these stressors? What works and what does not work?)
- What are the needs of African-American women with diabetes? (probes: how do the following help these women [such as you] meet these needs: family, community, church/faith in God, healthcare personnel and healthcare system? Are there groups that provide support for women [such as you] who have diabetes?)
- If you don't have someone close to you to help you with your diabetes, what do you do?
- What does social support by others mean to you as a diabetic woman?
- If you could change one thing about your life as a diabetic woman, what would that be? (probe: what advice would you give an African-American woman with diabetes to more effectively manage her life and health?)
- How are the lives of diabetic African-American women different than the lives of diabetic women who are not African-American?

Work:

- Has diabetes changed your life as a worker outside the home? If so, how?
 - If you do not work outside the home, what do you do during most days?
 - Has diabetes affected what you do each day, or how you feel about your daily tasks?
-

sumption of snacks and engaging in informal conversation prior to the focus groups; listening carefully to participants' words and manner of responding; and seeking clarification of responses through respectful probing by the moderator. The study also involved an ex-

perienced focus group moderator who reflected participant ethnic and age background, and an additional research team member who had published information on focus groups for persons with diabetes. Integrity of the study was also addressed by assuring women through both oral explanation and written consent that their responses would be kept confidential; summarizing the content of each session at the end of each focus group, thus allowing participants to verify the accuracy of their comments; and using a systematic data collection and analysis process throughout the study.²⁶⁻²⁷

Analysis

Each focus group was audiotaped, and transcription of tapes occurred by a typist who did not attend the focus groups. To extract initial emerging themes, the transcribed texts were compared to specific notes taken by a research team member that detailed verbal and nonverbal comments of participants (triangulation of data sources²⁷). Each member of the research team independently evaluated both of these records from each focus group as soon as each was available (analyst triangulation²⁷) to verify and validate the analysis, as used in a similar study.^{9,26} The research team then met and reached 75%–80% agreement on the 8 to 10 different themes evolving from individual team member review. Continued team discussion allowed for further comparison and development of 4 primary themes related to work and the multicaregiver role. Consistent with thematic analysis, identification of relationships among and between themes also occurred to delineate explanations and define questions for future research.²⁷

RESULTS

Focus group analysis of the participant responses elicited the following themes: family as core; work as survival;

impaired role function; and inner-strengthening. *Family as core* represented the participant's function as matriarch and leader of the household. *Work as survival* included responses about the stress in daily work, defined more as a job than a career, and the stresses of not working due to the social and economic costs of diabetes. Tied to the pressures of work and family were the problems associated with *impaired role function*, or the ability to manage diabetes given competing responsibilities at work and home. *Inner-strengthening* involved preservation of one's self through introspection and spirituality. Through their connection to God and supportive others associated with the church, and by reinterpreting the meaning of their disease to themselves and others, these African-American women developed resilient skills that allowed them to cope with adverse life events. Further description of these themes follows.

Family as Core

Overall, these women appeared to prioritize family over work considerations in their daily lives. Other roles in life seemed secondary to serving as a mother or helper to family members. Work wages supported the essential needs of the family. One unmarried woman, who had a stroke at age 60, described her required role as a worker outside the home to enable her dependent siblings to stay together after their parents died. She spoke of "switching off" shift work with her younger sister so that one or the other could be at home with the younger children. Despite this sharing of caregiving, this participant believed she would always be the one to "lead the family."

Maintaining the lead role of the family (or "head of the table") remained important to the participants despite their fatigue and complications from lack of effective disease management. Two women noted the "burden" of maintaining this role while trying to manage their diabetes. One woman

knew her family depended on her leadership, but illness prevented her even from "helping herself." She acknowledged she did not know "how to let someone else be protector and provider of her family." The second woman, crying during the focus group meeting as she talked about 2 homeless grown sons who had recently come to live with her, resumed the protector and provider role after retirement by doing private duty nursing at night to pay for the treatment of one son's chest infection. She stated that she worried the entire time at work about her son's condition, as well as her ability to provide safe care to her patients at work.

Family came first, even when participants perceived that their children and husbands did not physically or emotionally support them. More than one woman accepted the role to care for children and spouse and, initially, these women stated that they expected little help from family members in return. Most women in the groups were reluctant to ask for their children's help; however several stated that when they had asked for help, they found their children willing to pay for expensive diabetes medications or to provide resources for their mother's basic living needs. Other women did not wish to become dependent on their children and allow them to "handle family affairs," a behavior which several participants noted occurs more often in European-American women (called "White" by participants) than in African-American women with diabetes. More than one participant noted that African-American women face more challenges to diabetes self-management than do "White" women because "African-American men do not take care of their wives," and many African-American women "serve as a wife and also a mother" to their husbands. By the end of 2 of the 3 focus groups, women agreed that African-American women must raise more "sensitive sons, husbands, and daughters" who are willing to share the "head of the household"

role in order to strengthen the African-American family. According to participants, this support would increase family understanding of the disease and decrease African-American women's perceptions that they "alone" handle a complex self-care regime involving diet modification, exercise, and stress management, lifestyle changes that lessen the severity of later disease complications.

Work as Survival

Although these women prioritized family needs over work, they believed they had "no choice" except to work outside the home in order to meet their family's financial needs. Half of the women in this study worked because they were the predominant breadwinners in their family. Eighty percent of the women worked or had worked as bus drivers, administrative assistants, teacher's aides, and secretaries/clerical personnel, jobs offering limited personal control and little money. Several women described their feelings related to workplace discrimination and the little personal power they feel they have due to their gender, race, and sometimes their chronic illness. When asked by the group facilitator whether work was a job or a career, several women noted work was a job—an activity completed because they "had to." Despite negative job environments perceived to increase personal stress, these women worked to enable themselves and their families to afford housing, food, transportation, expensive diabetes medication, and immediate healthcare treatment. Generally, women in the focus groups had limited economic resources with more than half of the sample having an annual family income of less than \$25,000. Despite this income level, these women were the sole providers for their families, ranging in size from 2 to 5 members. Placing their family's needs above their own, many women noted they could not spend their limited funds on perceived expensive diet, exercise, or stress management changes, although they agreed these might help control their diabetes.

Several women described their response to working outside the home as obligatory and unpleasurable, but stated that as head of the household, "you do what you don't want to do in order to keep things in place, to keep the family alive." These women emphasized, "you have no choice" [but to work]. The presence of diabetes contributed to the unpleasantness of their work because, for many women in the group, the illness "slowed them down," and they perceived themselves to be less efficient at work compared to their productivity before their illness. For these women, work was now done "out of necessity, not out of joy" (as it seemed to have been before diabetes).

On the other hand, one third of the women perceived a "need to work" for reasons beyond financial survival. They worked outside the home because "it was the right thing to do." For these women, work was more than just a job. Many noted they liked socializing with women co-workers and appreciated the opportunity work gave them to feel competent as an African-American woman. Others were committed to their communities, worked to improve those settings, and demonstrated a strong cultural work ethic. One woman, a bus driver of mentally handicapped children, spoke of going to administration to report a lack of attention to handicapped student issues that she believed were a result of discrimination against these children. She, like many women, valued the idea of working beyond the home, even though physical concerns limited more active participation with co-workers.

The 4 retired participants also reflected on the "need to work." Three of the 4 retired participants had worked as clerks or service personnel in the recent past, but had retired due to age or illness. Although employed participants noted that work was stressful, the absence of work was "devastating" for these retired women. They identified "loneliness" as an emotion because they

no longer had access to valued social connections with women like themselves. Loss of this role also led to fewer financial resources to cover diabetes care costs, including more expensive medications and frequent changes in these due to side-effects. The retired women also lacked partners who could help with the social and financial costs of not working. One woman noted that her monthly medications cost 3 times her monthly check from Social Security, but when she requested financial help from Social Services, she was told she made too much money. According to these women, Medicaid assistance for living expenses and for chronic illness management is too limited, hampering their access to healthcare services and needed information to manage their diabetes. One woman noted her frustration with the system saying, "I'm dirt poor and living in a tent up by the stop sign!" During the focus group meetings, several women indicated that they did not fully understand their illness insurance coverage or recent changes that slowed payment of their Social Security, Medicare, and/or Medicaid benefits. This unanticipated lack of economic and social assistance caused them to become more dependent on their children, leading to a perceived loss of the valuable "head of the household" role.

Several retired women expressed disbelief that the governmental Social Security system would not provide for their basic living needs after all their years of "paying into the system" while they were working. One woman, a retired licensed vocational nurse, shouted her belief that the government had misled her in allocating her retirement income:

". . . when you're on Social Security, you can't work . . . you can't get paid what you make . . . after 35 years of working, they decided to give me \$87 a month . . . if they had given me that money they took out for Social Security for 35 years, I wouldn't have had to worry about it . . . I'm just asking them to give

me what I put in there. No social service either."

Impaired Role Function

Many women defined their diabetes as "restrictive" because it limited their abilities to perform their multicaregiver role, a set of valued job functions that support the African-American family and community. Perceived barriers included symptoms of fatigue, neuromuscular weakness, vision problems, body weakness, dizziness, and anxiety related to the experience of diabetes. Participants also identified limited finances and the time required to manage their chronic disease as barriers. Based on these perceptions, many women rated their overall health as "fair" or "poor." Although participants knew the importance of daily checking their blood sugars before eating breakfast each day, many stated they lacked energy and time to complete testing before "bolting" out the door for work. Several women stated that fatigue affected their ability to efficiently function at work and to complete needed household daily tasks, and that they sometimes ignored their symptoms of glucose imbalance in order to complete their assigned work.

Participants identified an average of *six* daily roles that defined their multicaregiver role (mother, partner, worker, family chauffeur, cook, and community/church member). According to the participants, functioning in these various roles detracts from the time required to manage their disease. For the 7 study women without partners, daily demands related to the multicaregiver role were perceived as more complex, because there was no significant other to handle some of the "load." The role of cook was complicated for the majority of women who continued to cook traditional African-American foods based on their family's requests and who identified eating with family socialization. Women noted that they felt "isolated" from their families if they occasionally followed a diet for persons with diabe-

tes, a situation that did not support their desire to be perceived as the family matriarch. Neuropathy related to diabetes "restricted" the mothering role for some women as well. One stated she could not participate in outdoor activities with her family because she had limited sensation in her feet. Another described a drive home during which she needed her son's help to safely maneuver the steering wheel and accelerator of her car when her feet "failed her."

Women varied in their responses to questions about establishing routines for managing work and their diabetes. One woman had a strict morning routine for testing her blood sugar, engaged in daily exercise to control her disease, and had food at work or in her purse in case she had symptoms of low blood sugar. Disease management became part of her accepted daily schedule. Other women, less effective in disease management, perceived their disease to be quite disruptive. These women experienced delays in getting to work and felt "sleepy and tired" during the day, both of which affected their ability to be productive workers.

In all focus groups, women identified significant concerns about developing complications of diabetes that would affect their abilities to continue supporting their families. Although several mentioned ignoring symptoms of diabetes prior to their diagnosis, many had close relatives who had limb amputations due to poor diabetic management. One woman jokingly stated that in her family, "once we get to age 30, we figure everyone's gonna get high blood pressure or have sugar, maybe both." Although many of the participants used oral hypoglycemic agents, several had a history of insulin use and continued to be "very scared" about this method of blood sugar control. Rather than viewing insulin therapy as a way to control their blood sugar, they saw it as a sign of worsening diabetes and, thus, potential amputation, outcomes that would block their performance of the valued multicaregiver role.

Inner-Strengthening

Connecting with God and Those Associated with the Church

Participants coped with their challenging lives by having a strong religious connection to their church and bonds with supportive females (Black female kinship) within that structure. Many women spoke of the "uplifting" experience of church member phone calls to "check on" a participant after a physician visit. Visits by church members, intercessory prayer, weekly prayer meetings, and connections to other African-American women who were "good friends" helped focus group women cope with the multicaregiver role, diabetes, and their lives as African-American women. Many women noted they "trusted in the Lord," "talked to God," or read the Bible to "get through" when their lives became unmanageable.

The church represented a place where these women felt successful, safe, understood, part of a social network, and less burdened from the overload of their lives and perceived workplace biases. With many women expressing concern about diabetic healthcare access despite Medicare and/or Medicaid coverage, the church provided a "community that understood their needs as diabetics." The world views provided by the women when speaking about their informal church work vs their formal work experiences were vastly different. It was clear that their ability to cope with adversity, such as that related to chronic illness management, low paid employment, and the subtle forms of discrimination they often faced, came from the strength they gained from working with, being connected to, and receiving guidance from their churches. Women noted that this strong spiritual connection differentiated them from "White" women with diabetes who "do not rely on God to get them through this, maybe because diabetes is more of a crisis event for African-American women because only they can do it [complete the multicaregiver role]."

During the focus group meetings, several women cried and expressed sadness about "losing one of their long-term anchors in life" because work and fatigue prevented them from actively participating in their church.

Sharing Selectively

Self-protection also involved selective discussion of their diabetes with trusted others in order to maintain the valued multicaregiver role. In contrast to the physical and emotional support given by church members, the majority of participants did not freely discuss their disease with co-workers. These women supported such behavior by noting they had either experienced co-workers trying to control their jobs or had seen co-workers express an overbearing concern for a person with a chronic illness because they perceived the person's ability to perform the job competently was impaired. For many of these women, failing to mention their diabetes and not complaining about it allowed them more freedom and better mental attitude to meet their work goals. Disclosure of one's diabetes led to being judged by others, an outcome one previously quiet woman in the focus group mentioned toward the end of the group:

"Don't discuss your health with anybody so you can't be judged . . . My mother was thin and sickly looking with her diabetes, people would say, 'you probably don't feel good, do you?' After 5 or 6 people do that, you don't feel good."

Several women noted that they did not tell non-diabetic coworkers about their diabetes because they believed one had to have diabetes in order to fully understand it. In conversations with the focus group women, they recognized that even *they* did not understand as much as they needed in order to effectively handle their disease, so how could others without the disease understand this challenge to African-American women's lives?

Likewise, some participants stated they chose to share only essential infor-

mation about their lives and diabetes when seeking health care, a behavior they believed to be more common among African-American women, who “keep things bottled up inside” to protect themselves than do “White” women. Many participants noted that during healthcare visits, their physician or nurse focused only on the participant’s blood sugar value and not the life factors that could be addressed to improve one’s diabetic management. Although much has been written about dual discrimination in the workplace based on one’s identity as an African-American and as a female,²⁸ participants stated that diabetes produces a third level of discrimination for them when seeking health care. A retired woman spoke emotionally about the night she was diagnosed with diabetes and her perceptions of discrimination/lack of understanding by the healthcare system related to interactive factors of race, gender, and disease. Her story seemed particularly poignant because, although she had worked for a number of years as a licensed vocational nurse, most of her co-workers and a supervisor friend failed to support her when she was wrongly accused of alcohol abuse, often mimicked by symptoms of high blood sugar. As she told her story, she occasionally stopped to gain control over her anger about this situation that had occurred 15 years ago.

The majority of the women remained quiet during the storytelling of the more vocal participants, who seemed relieved to share their experiences of perceived discrimination in the healthcare system. These women believed that they, as African-American women, had less access to healthcare services and received less understandable information as compared to “White” women with diabetes. Several other women, encouraged by these more vocal women, stated that they had “few rights as African-American women” and that the current medical community “disrespected” them by not understanding how their cultural needs were compli-

cated by their diabetes. However, one woman disagreed, noting that “you do have rights” and encouraged others to “exert themselves” to change the healthcare system to improve the care of African-American women.

Not Claiming Diabetes

An additional self-protective behavior used by the participants included “not claiming their diabetes.” These women expressed a strong desire to remain at the “head of the table” in their families despite the existence of diabetes. Many women made it clear during the focus group sessions that they were not diabetic African-American women but “African-American women with diabetes.” These women refused to identify themselves as “sick,” which they stated many “White” women do. Several participants continued this “not claiming” behavior by noting their dislike of the phrase “chronic disease.”

“I hate the word chronic, sometimes I’m tired but chronic is such a (group response) DEVASTATING word; this is not my disease. You don’t own it! It’s a mental thing, you can keep it in control if you change things.”

At first, this statement of “not claiming” had a tone similar to denial. But it was clear that most of these women were not denying their disease because they sometimes had successfully implemented diabetic routines that were evidenced by their ability to work outside the home and provide care to others. The term “claiming” appeared to relate to their spirituality or religiosity. Because they believed that God would take care of their diabetes, they felt that they had to possess faith that God would make them healthy. This possession of strong faith was translated by these women into not accepting, or “claiming” the disease. Thus, they were determined not to show they were “sick.” Doing this would be a sign of weakness and lack of faith. They believed that God would make them well if they exhibit strength, a belief they identified more in African-American women than in their Cauca-

sian counterparts. Strength was the ability to complete multiple roles and responsibilities, without asking for help or complaining or acknowledging weaknesses, such as diabetes.

DISCUSSION

The themes of this study (family as core; work as survival; impaired role function; and, inner-strengthening) can be interpreted relative to the historical, social, political, health, and economic factors that influence these 12 women’s lives. Consideration must also be given to the factors of class, ethnicity, and gender, all of which affect access to care and the general quality of life of African-American women.²⁸⁻²⁹ An understanding of these factors, operating individually and cohesively, provides a foundation for supporting healthcare practice, research, and policy approaches that may improve the overall health of these women and their families, who vicariously face the challenges of this disease.

Consistent with Black feminist thought,²⁹ the women of this study prioritized their family’s needs over other daily needs. This perspective defines an African-American woman’s self-identity as based on her relationships with others and the welfare of her community. According to several authors, these women often face a conflict between responsibility to self and responsibility to others, and this conflict inherently influences a woman’s self-management of chronic illness.^{9,30} Compared to European-American women (“White” women from the perspective of the participants), African-American women have a long history of combining paid work and family roles, of surviving as unmarried mothers, and in performing a multicaregiver role to allow family survival.³¹ However, participants in this study, affected by the constraints of a chronic illness and the demands of these multiple roles, perceived themselves to be less able to reflect the

Afrocentric perspective: to be independent, strong, and self-reliant.²⁹

With the family as priority, many participants worked, despite unsatisfactory job conditions, to meet the basic survival needs of the family and, occasionally, their own emotional needs. More than half the women in the study were of single "heads of household," functioning at an economic status close to the poverty level.³² Seven of the 12 focus group members (58%) reported annual incomes between \$10,000 and \$24,999, and focus group conversations indicated that several women supported themselves and two to five dependents each on incomes of less than \$20,000 per year (close to the currently defined level of poverty in the United States). Although no specific question on health insurance coverage was asked in this study, participants, like many working-class women earning low wages, noted their personal difficulty in accessing needed health care due to cost and/or a lack of coverage for diabetes self-management. Although cultural behaviors influence the use of preventative and disease-specific care,³³ a lack of affordable/comprehensive insurance and sufficient work income prevents and limits healthcare access and use by African-American family members.³⁴ Thus, the intersection of class, ethnicity, and gender creates significant obstacles for African-American families seeking quality health care for prevention and active treatment of an illness such as diabetes.

The retired women of this study depended on Social Security benefits accrued during their work years and on Medicare to cover healthcare bills. For these women, and others dependent on Medicaid for health care, healthcare coverage problems arose due to an incomplete understanding of these social programs. Several women did not know that Social Security often fails to cover some prescription drugs and recommended diabetic protocols³⁵ and that Medicaid and Medicare contracts often narrowly define fundable prescriptive

drugs and preventative services.³⁴ Thus, many of the participants ended up paying "out-of-pocket" for new and expensive diabetic drugs and treatments to control their disease. Women noted that other suggested changes in their lives (diet, exercise, stress management, etc) for diabetes control were either too complicated to use due to work or family issues, or unavailable due to one's limited income. The lack of financial and insurance resources to pay for these lifestyle changes and lack of culturally relevant interventions to meet the needs of these women, limits African-American women's ability to focus on needed care and, ultimately, contributes to the development of diabetes complications.

The women of this study clearly did not wish to have diabetes as a life-long disease because it affected their ability to maintain their valued role of "sitting at the head of the table" of their family. Women acknowledged symptoms related to diabetes (an "illness") but did not acknowledge having a "disease" (a medical diagnosis by their physician), a distinction in definition that one author has made between illness and disease.³⁶ Not "claiming" this disease meant these women would not assume the "sick" role or respond to symptoms, but would continue life activities until symptoms limited their abilities to perform the multicaregiver role.

Despite the fact that the majority of the women knew diet changes could improve their symptoms of diabetes, many believed that diet modification would restrict their ability to complete the multicaregiver role, including work outside the home. As with many cultures, food and drink are central to the social lives of African Americans, and diet changes require women to prepare and eat different (and sometimes more expensive) foods, often at times apart from family. These changes affect African-American women's desire to meet their valued social role as family provider and to encourage family cohesion during meal times. Thus, an approach to effective

management of diabetes must take into account an individual's social responsibilities, resources, and personal priorities in order to understand the reasons for a person's noncompliance with recommendations made for their disease management.

Several women in the focus groups mentioned that symptoms of their diabetes and side effects from their diabetic medications affected their ability to safely work. Symptoms included fatigue, weakness, mental fuzziness, forgetfulness, nausea, diarrhea, and headache. Many women indicated that they initially ignored their "subtle" symptoms of the disease despite a strong family history of diabetes. Various authors^{6,37} have confirmed that African Americans may ignore mild symptoms or seek traditional healthcare system advice only after disease management options have been exhausted. This delay initiates the development of disease complications, negatively influencing the abilities of African-American women to complete the multicaregiver role.³⁷ Other authors note that a sense of present time and an external locus of control ("God will take care of this") may be factors in African-Americans' delay in seeking treatment and in modifying diet and exercise patterns, thereby worsening their disease.³⁸⁻³⁹

As a primary method of coping with their diabetes, women consistently referred to an overwhelming sense of belonging, community, and positive social network provided by being connected to their church and its members. This is consistent with literature identifying the historical role of the African-American church in fostering positive role models, encouraging ethnic pride, supporting coping strategies among its members, and promoting social change, thus creating a better quality of life for African Americans.³⁹⁻⁴⁰ Additionally, the church has supported African-American women's mental health by validating their life experiences for personal growth, providing preventive health services, and by

supporting women's rights to define the church's role in strengthening the African-American community.^{30,31,33,39-41} Furthermore, church support increases patient compliance with a medical regimen⁴² and acceptance of lifestyle changes such as altered diet, exercise, and blood sugar monitoring in mid-life African-American hypertensives⁴³ and/or diabetics.⁴⁴ Church involvement served as a source of strength and determination for each focus group woman who viewed diabetes in perspective and as only one part of her life.

In contrast to support by the church and its members, the majority of focus group women perceived little consistent social support from their co-workers or their families. Working participants felt that their workplaces supported their economic needs for survival, but failed to focus on their lifestyle needs related to their diabetes. Similar to the findings of another study,⁴⁵ several women stated that they would not discuss their diagnosis of diabetes with co-workers because they believed this would increase discrimination at work and besides, "what could these women do?" None of the participants mentioned a supportive co-worker when asked about mechanisms and persons used to cope with the stress of having diabetes. Most participants did not perceive social support from their children, which was conceptualized as "doing what was needed."⁴⁶ This absence of "doing" seemed particularly important to most of the women who lived alone and interacted infrequently with family members for physical and financial needs. A solitary existence, perceived by these women as unsupportive of African-American family values of the extended family and family matriarch, may increase the incidence and severity of chronic illness, including diabetes.^{9,37,47}

Most participants also identified a lack of healthcare system support for their diabetes. In particular, the retired women passionately argued for a more sensitive system, one addressing social

service and economic resources for diabetes management. Several women reported delaying or failing to continue health care due to concerns about culturally insensitive healthcare practices and limited resources for covering medication costs for their illness. These concerns supported findings of previous studies that have isolated multiple barriers to healthcare use among diverse populations, including racism, economic constraints, and differences in perceptions/expectations for preventative care and disease management among healthcare providers and consumers with diabetes.^{6,47-48} Perceived poorer quality care may also relate to healthcare providers lacking understanding/acceptance of patient life conditions, health-illness beliefs, previous negative care experiences, or to providers offering less-than-usual information on disease management when interacting with poorer clients.⁴⁹⁻⁵⁰

IMPLICATIONS FOR PRACTICE

Of the 60 women approached for the study, only 12 chose to participate over the 6-week time period. This small sample number, and the fact that these women reflected values and behaviors of a localized part of the country, must be considered when interpreting the applicability of the study to practice. Those who chose to be part of the study, however, remarked about the helpfulness of the group discussion in connecting them to similar women, in understanding their disease as part of their lives, and in finding direction for their future. Therefore, these women's information-rich feedback provides insight into the lives of mid-life African-American women with diabetes to direct practice, research, and healthcare policy changes.

Although a variety of individuals play a role in improving the lives of these women, **healthcare providers** appear to have a primary role in collabor-

ating with these women and their families in diabetic management. These professionals and ancillary personnel must use active listening skills and knowledge of African-American cultural values and behaviors (ie, the multicaregiver role, value of family) to implement quality care for these women. Ancillary personnel, lay representatives of the African-American community employed in a clinic or office, can facilitate this knowledge by sensitizing the healthcare team to the needs and healthcare issues of diabetic African-American women. During care, providers must encourage each woman to choose options for controlling her disease based on her individual circumstances and her own definition of diabetes. Healthcare providers must provide verbal reinforcement ("I'm so proud of you") to women and their families who choose to implement lifestyle changes, including the delegation of household tasks to other family members, that support more effective self-management of diabetes. Each healthcare visit should focus on supporting and teaching women and their families about diabetes while allowing for discussions on unique cultural factors and behaviors that influence management of symptoms, diabetes control, and prevention of complications. Based on the importance of the multicaregiver role, the social context (ie, family, quality of the marital relationship, work outside the home, and church) must be fully considered to design relevant interventions to manage mid-life events of African-American working women. Some women may express needs for information on nutrition, self-management, family issues, or for financial/social service/insurance information; healthcare providers need to provide this information, or refer women to appropriate personnel for culturally sensitive care and followup to address women's concerns. Other women may perceive limited support from family or co-workers, prompting healthcare providers to offer free and convenient group sessions for

During care, providers must encourage each woman to choose options for controlling her disease based on her individual circumstances and her own definition of diabetes.

diabetic women aimed at increasing women's insight into their disease and generating personal empowerment through information-sharing with similar women.

Healthcare providers and ancillary personnel must also practice their skills and knowledge about African-American women beyond their offices and clinics by consulting with workplace managers to improve both the physical and emotional setting for women with diabetes. Providers can offer free services focused on screening and treatment for illness within workplaces. Working with church leadership, providers can also demonstrate commitment to African-American women's issues and spirituality by providing care within the church community through health fairs, educational sessions, and social service referrals known to improve the life of those affected by diabetes.

Much potential exists for researchers in the area of working-class African-American women with diabetes who serve as multicaregivers. Although previous authors have examined mid-life working women,^{18,51-56} their focus has often been on non-diabetic women and occasionally on women engaged in non working-class roles. Based on the work of one researcher group focused on working-class women,^{18,53,55-57} researchers must successfully differentiate interactive factors such as ethnicity, SES level, education, work experience, and the experience of chronic illness (diabetes)

to design successful interventions focused on improving African-American women's health. Additional work must be done to more clearly define work as a blend of both public (paid, outside the home) and private (unpaid, inside the home or community) dimensions. This interactive concept of public and private work (the multicaregiver role), often not valued by our society, allows one to acknowledge the financial and societal gains created by ethnic women's commitment to a marketplace economy, as well as to social harmony and family and community health.⁵⁷ Further research must also focus on effective healthcare system changes that address the needs of diabetic African-American women who prioritize a "duty" to multiple roles despite a unequal burden of care that causes stress, overload, and may compromise their health.⁵⁸

This study also addresses the role of healthcare policymakers and the healthcare system in implementing culturally sensitive, comprehensive, and well-articulated care models to more effectively care for African-American women. Strategies should focus on improving healthcare access and creating a collaborative, long-term relationship between healthcare providers and women to manage both acute and chronic symptoms of the illness. Such interactions can empower these women and their families with knowledge and skills, thus producing a feeling of greater personal control over the illness process. Present concerns about the efficiency of managed care and large numbers of uninsured individuals (frequently members of minority groups) mandate that current healthcare policymakers exert their political power. Policymakers should work with other "players" (employers, insurance companies, financiers, etc) that determine support for healthy workplace environments, reimbursement for physical and psychosocial care, and inclusion of consumer information to define relevant and quality care. Policy development must focus on meeting

the principle of social justice: that each person has a right to quality health care despite economic status, cultural/ethnic background, or disease status. Particularly for minority groups such as African-American women, health inherently depends on socioeconomic status, a result of interactive and historical social, political, racial, and economic factors (including workplace choice) that affect the lifestyle and self-identity of these people.⁴⁹ Current healthcare policy must acknowledge the role of these factors in determining access, use, and evaluation of healthcare systems if these systems are to improve and to support better health for African-American women and for the larger society.

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