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# PERCEPTIONS AND BELIEFS ABOUT TYPE 2 DIABETES AMONG NON-DIABETIC BLACK WOMEN

*Mary Shaw-Perry, Ph.D., CHES*

## I. ABSTRACT

Racial and ethnic disparities have existed in America since the birth of the nation. A vital part of working toward the elimination of racial and ethnic health disparities lies in understanding the *lived experiences* of those deemed high risk for preventable diseases such as type 2 diabetes. Few studies have explored the perceptions and beliefs that non-diabetic African American women have about type 2 diabetes and secondary complications that result from this chronic disease. The purpose of this formative research study was to involve African American women in focus group discussions to elicit their perceptions and beliefs about diabetes and to generate ideas for developing diabetes education, risk reduction, and screening programs tailored to African American women.

The study population consisted of low- and middle-income African American women with no personal history of diabetes that resided in two urban, northeast Texas counties. Twenty-eight African American women between the ages of 25 and 65 were recruited through the assistance of two churches, a beauty salon, and a public health clinic. Participants' perceptions reflected knowledge of the severity of complications resulting from untreated diabetes, but a lacked an understanding as to why these complications occur. Participants lacked knowledge about (a) signs/symptoms of diabetes, (b) how to access screening for the disease, and (c) reported being uncomfortable asking physicians questions about diabetes and requesting written information and tests for the disease.

These findings suggest that efforts to eliminate disparities in health and health care must begin with health promotion and policy reforms that will improve education outreach and engage communities in the design and implementation of health education programs, the organization and delivery of preventative care services, and the evaluation of all health services.

**KEY WORDS:** minority health, type 2 diabetes, African-American women

## II. INTRODUCTION AND BACKGROUND

Concerns regarding racial and ethnic disparities in health have dominated recent discourse among health professionals; however, health disparities have been a long and disturbing reality for people of color in the United States. For example, the prevalence of diagnosed diabetes in African Americans has tripled during the past 30 years. According to the National Medical Expenditure Survey 1992 (Peyrot & Rubin, 1992), more than \$100 billion is spent annually in the U. S. to care for people with diabetes. In 1998, 1.5 million out of 35 million African Americans had been diagnosed with diabetes. This is almost four times the number of African Americans known to have diabetes in 1968 (National Institute of Diabetes and Digestive and Kidney Diseases [NIDDKD], 1999). Braithwaite & Taylor (2001) reported that diabetes is the third leading cause of death in African Americans. According to the American Diabetes Association, diabetes is the fifth deadliest disease in the United, affecting 2.7 million or 11.4% African Americans aged 20 years or older (American Diabetes Association [ADA], 2005b).

Persistent health disparities are well-documented among minorities and women of color. One in four African American women over the age of 55 has diabetes, nearly twice the rate of white women (National Women's Health Information Center [NWHIC], 2000; McNabb et. al., 1997). Non-insulin-dependent diabetes mellitus (NIDDM), or type 2 diabetes, and the severity of complications that develop secondary to the disease represent a major health problem that contributes to the health disparities existing between African American women and other groups (U.S. Department of Health & Human Services, 2000). There are several risk factors associated with the frequency of diabetes in African Americans and other populations (NIDDKD, 1999).

The first is genetics, which includes inherited traits and group ancestry. The second is medical risk factors, including impaired glucose tolerance, hyperinsulinemia, insulin resistance, and obesity. The third is lifestyle factors, including physical activity (NIDDKD, 1999, p. 1; Hu et al., 1999).

Delayed diagnosis is an additional risk factor associated with complications of diabetes, since the onset of diabetes can predate the clinical diagnosis for up to 10 to 12 years (McNabb et al., 1997). It is

unclear whether African American women perceive or believe that genetics, medical risk factors, and lifestyle factors may contribute to the development of type 2 diabetes. Much of the literature on black women and diabetes points to the importance of screening and early detection among high-risk women, and the need for improved quality of care and patient education services appropriate to the needs of these women. Clearly, low screening levels and late stage diagnosis contributes to poorer health outcomes when compared with the general population (Aman et al., 1998).

A review of the literature revealed that few studies have been done to determine the perceptions and beliefs that non-diabetic African American women have about diabetes and secondary complications that result from the disease. As a result of this gap in knowledge, there is a lack of culturally appropriate preventive programs or measures, including components for education, risk reduction, and screening that are tailored to African American women.

Therefore, the purpose of this study was to involve low- and middle-income African American women in focus groups to elicit their perceptions and beliefs about type 2 diabetes and to generate ideas for designing diabetes education, risk reduction, and screening programs tailored to African American women. Formative research utilizing focus group methodology as an assessment and program-planning tool for culturally specific diabetes education programs has been reported in the literature (Blanchard et al., 1999). Specifically, focus group methods are designed to discover the reality of a specific, well-defined population to meet their specific, self-defined needs (Blanchard et al., 1999, p. 819).

Although focus group studies reported in the literature have addressed perceptions, beliefs, and practices of African Americans living with diabetes, this methodological approach has not been used to explore the perceptions, beliefs, and behaviors of non-diabetic African Americans who may be at risk for developing diabetes. Morbidity and complications associated with late-stage diagnosis of diabetes will continue to be one of the health disparities unless screening and education prevention measures stimulate lifestyle behavior changes. The information gained from this study provides valuable information for the design, implementation, and evaluation of diabetes screening and education programs; diabetes education literature; and media messages to promote awareness, early detection, and treatment for diabetes.

### III. RESEARCH QUESTIONS

The following research questions guided this study:

1. What are the perceptions and health beliefs about NIDDM (type 2 diabetes) among African American women?
2. What are the perceptions and health beliefs about the risk factors for developing NIDDM (type 2 diabetes) among African American women?
3. What are the perceptions and health beliefs about the severity/complications of NIDDM (type 2 diabetes) among African American women?

### IV. METHODOLOGY

Focus group methodology was used to explore African American women's perceptions and beliefs about diabetes and to generate ideas for diabetes education, risk reduction, and screening programs tailored to African American women.

#### A. Population and Sample Selection

The study population consisted of low- and middle-income African American women who resided in urban, northeast Texas. For purposes of this study, the population was further delimited to African American women who (a) had no history of diabetes, (b) were self-defined as African American, and (c) were between the ages of 25 to 65. A convenience sample comprised of twenty-eight African American women was recruited through two churches, a beauty salon, and a public health clinic (WIC). Women meeting the eligibility criteria signed up at each site and were given an invitation to attend a scheduled focus group session. Four focus groups (6-10 women per group) were conducted during a four month period, one at each of the four sites from which the women were recruited.

#### B. Instrumentation

The Pen 3 model has been utilized by researchers to attempt to understand the complex array of perceptions, nurturers, and enablers that influence behavior and attitudes (Airhihenbuwa, 1995). Under the

guidance of a panel of diabetes prevention and care experts, the researchers developed an instrument composed of two parts: a demographic profile sheet and an interview guide. A demographic profile sheet based on National Health and Nutrition Examination Survey (NHANES III, 1988-1994)(Centers for Disease Control [CDC], 2001), and instruments developed by Shaw (1995) and Vaughan (1995) were used to collect selected information about the participants. Questions included the following items: (a) age, (b) last grade in school completed, (c) income, (d) religion, (e) exercise behaviors, (f) weight perceptions, (g) race/ethnicity, (h) family history of diabetes, and (i) marital status.

The focus group interview guide consisted of four open-ended questions, with two parts to be answered under each question to solicit information regarding participants' beliefs and perceptions about diabetes. The content validity of the interview guide was established through a panel of experts, composed of two African American diabetes health educators, practitioners from three northeast Texas diabetes patient care sites, and an additional out-of-state site, the Michigan Diabetes Research and Training Center (MDRTC), which works with the African American community to screen for diabetes, collect survey data, and promote diabetes awareness and education.

**Table 1. Focus Group Interview Questions**

1. What do you believe are the major health problems of African American women?
    - a. How does diabetes affect African American women?
    - b. What health practices can you do today to be healthy and prevent or reduce the chance of getting diabetes?
  2. What is diabetes?
    - a. How would you describe/define diabetes to someone else?
    - b. What do you believe causes diabetes?
  3. What are the three most critical factors (things) that contribute to the development of diabetes in African American women?
    - a. What do you believe happens if diabetes is not treated?
    - b. What problems develop from having diabetes over a period of time and not knowing it?
  4. What do you feel diabetes education programs should include?
    - a. How would African American women describe the seriousness of the disease? Why would they describe it this way?
    - b. What do you feel can be done to get African American women to participate in diabetes education and/or screening programs?
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### Procedures

Researchers obtained access to the population with the site managers' permission; the site managers also agreed to recruit clients who were accessing services during a three-week period. Potential participants were identified from weekly clients who expressed interest in the study based on informational flyers posted at each site. Clients expressing interest in the study were provided invitations and asked to sign up and provide a contact number. Site managers submitted the potential participant list to the researchers at the end of a three week recruiting period. The researchers contacted each potential participant, provided them with the scheduled dates for the focus groups and advised them that study participation was voluntary and that they had the right to withdraw from the study at any time without penalty or undue attention.

Three weeks prior to each scheduled focus group session, the site manager confirmed participant attendance, reserved room space, and arranged for the refreshments. All participants were advised that they would be provided a consent form to participate in the study and that consent to audiotape during the discussion was included in the general

consent form. Provisions were made to conduct an individual interview if a participant preferred not to be audiotaped.

Each participant was asked to complete the demographic profile sheet prior to the start of each 1½ hour session. The facilitator used the interview guide script to narrate each session, always providing an explanation to participants about the purpose of the permission form and a rationale for signing the permission form. Additionally, the experienced facilitator provided ample time for participants to ask questions about the purpose of the study. The facilitator also explained that answers provided to the research questions would serve as a guide in developing strategies to recruit women into diabetes education and prevention programs by identifying effective approaches.

During the sessions, the facilitator recorded responses to the questions either on a flip chart with a marker or onto a data collection form if a modified interview style technique was used. A scribe also recorded responses independent of the facilitator, and each session was audiotaped. A transcript of each taped session was prepared by the researcher. The researcher reported themes that emerged under the following categories:

1. Perceptions and beliefs about type 2 diabetes or NIDDM.
2. Perceptions and beliefs about risk factors for type 2 diabetes or NIDDM.
3. Perceptions and beliefs about the severity/complications of type 2 diabetes or NIDDM.

Food was provided during each session and participants received a beauty product as a thank you gift. Each was also eligible to win one of two door prizes, a watch or a camera, through a drawing held at the end of each focus group session. Additionally, participants received a certificate of completion and a thank you letter in the diabetes education packet provided at the end of the session. Time was then allowed for participants to ask the nutritionist and diabetes educator specific questions about prevention, screening, and/or treatment of diabetes. Within two weeks of each session, thank you letters were sent to the facilitator, the agencies that offered professional advice during the course of the study, and the contact people at each focus group site.



### C. Data Analysis Methods

Data from the demographic profile instrument were compiled and entered using SPSS crosstabs, a Statistical Package for the Social Sciences (version 10.0). Descriptive statistics were used to characterize the sample. Audio recordings of each focus group were transcribed verbatim by the researcher with each review occurring in a timely manner following the session to maximize observations, discussion climate, and recall. Two experienced qualitative researchers assisted with reviewing and comparing transcriptions, facilitator-recorded flip chart responses, and the scribe's hand written field notes. A complete list of responses based on the audio transcriptions, flip chart, and scribe's notes provided the complete data set that was eventually used to identify the significant themes.

Data from participants in each focus group session were separately analyzed for individual group responses, but grouped together for a composite analysis. The facilitator, the researchers, and one other health professional completed the content analyses of the transcripts. Using large sheets of butcher paper, supporting focus group questions were grouped under each guiding research question. Participant responses were grouped under each focus group question. Each reader then identified themes of the data set specific to each focus group question, and indicated specific quotes that were particularly representative of the themes. Themes were defined as topics that were discussed more than twice within each focus group discussion.

Repeating themes or ideas were noted by marking the data with symbols. Common phrases were used to further develop analysis. Particular words or phrases used by participants to describe experiences and that were repeated at least twice were grouped and circled under the focus group question to identify repeat themes. These were then listed and grouped together by similarities. The frequency of statements (words or phrases) made per theme group was counted. Statements with a frequency of three or greater supporting a theme were placed into a text box, and the recurrent themes were numbered and listed under the text box.

**Table 2.****Research Question 1: What are the perceptions and health beliefs about NIDDM (type 2 diabetes) among African American women?**

Question: Focus Group Question 1: What do you believe are the major health problems of African American women?

- (a) too fat
- (b) obesity/overweight
- (c) high blood pressure --from cooking with too much fat
- (d) other: Stress --single parents/divorced/children in family
- (e) AIDS/Lupus/sickle cell
- (f) cancer (especially ovarian and breast)
- (g) diabetes
- (h) heart Problems
- (i) Put self last/postponed Dr. visits --no self-care

Responses: Focus Group Question No. 1

The recurrent themes that emerged from focus group question 1, **the major health problems of African American women**, were (1) hypertension and heart disease, (2) obesity resulting from a high fat diet, and (3) cancer (especially breast).

**Table 3.**

**Research Question 1: What are the perceptions and health beliefs about NIDDM (type 2 diabetes) among African American women?**

Question: Focus Group Question 2b: What do you believe causes diabetes?

- (a) heredity/trait
- (b) obesity/overweight
- (c) race/chemical make-up (African Americans, Asians, Hispanics)
- (d) how food cooked/food prep/what you eat/cooking/diet-too many sweets, rice
- (e) food cooked – salt, bacon
- (f) poor diet/eating habits
- (g) not being aware: no self-education
- (h) believe it won't happen to us
- (i) not an issue “until it's at our back door”
- (j) not seeing a doctor routinely
- (k) how raised
- (l) family hx
- (m) too many sweets/red meat/pork
- (n) not enough vitamins
- (o) not enough exercise (couch potatoes)
- (p) potatoes, starch turn to sugar
- (q) not eating well balanced diet
- (r) lifestyle
- (s) poor circulation/bad circulation of the blood
- (t) not enough rest HBP

Responses: Focus Group Question 2b

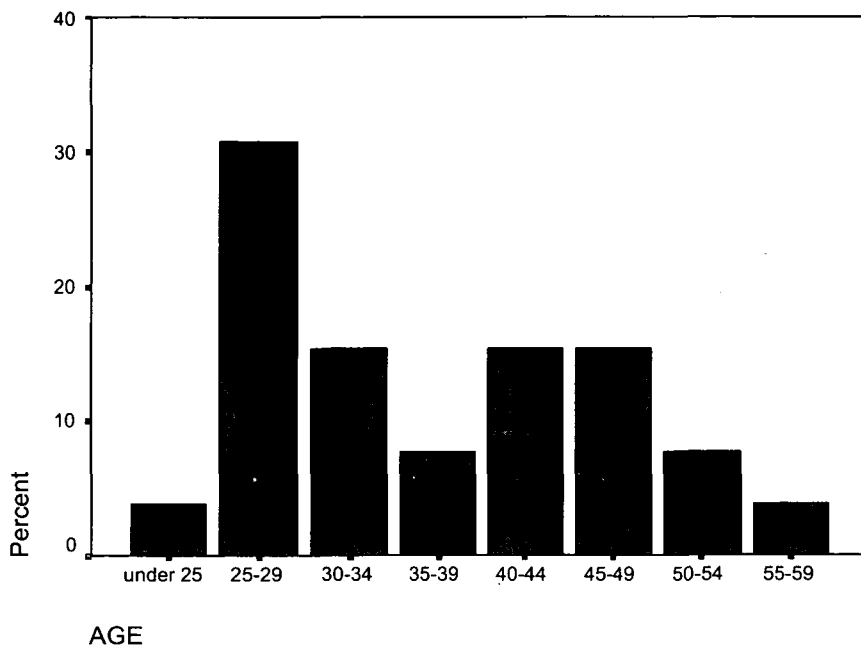
The recurrent themes that emerged from focus group question 2b, **the causes of diabetes, were** (1) heredity, (2) obesity/overweight, (3) poor diet, and (4) lack of exercise.

**Results**

A total of 28 African American females participated in the study. Two participants were disqualified from participation because of self-reporting a previous history of type 2 diabetes on the demographic profile sheet collected prior to the beginning of each session. The sample

population consisted of women 25 to 65 years of age, with the exception of a participant in the third focus group who was 21 years of age. As shown in Figure 1, the largest number of participants, approximately 31 percent, were drawn from the 25-29 age group.

**Figure 1. Age group distribution of focus group participants**



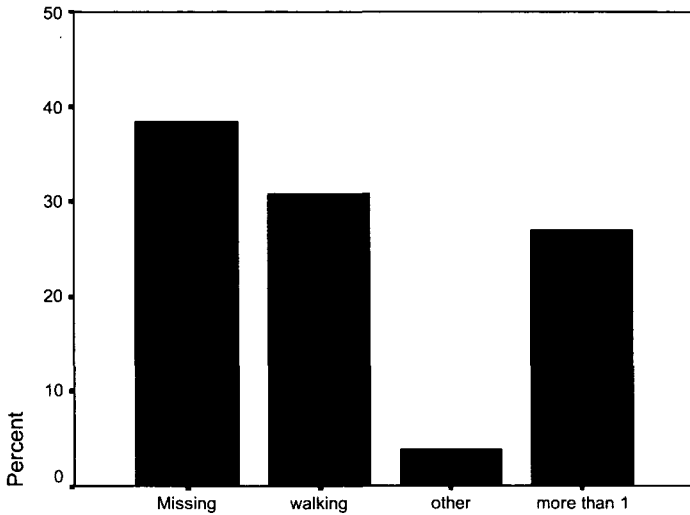
**Note.** Distribution consists of 26 total participants from four focus groups. **Approximately 42 percent of the participants were married and 38 percent of the participants graduated college, and approximately 8 percent attended graduate school. Religion was described as strongly influencing the daily lives of 77 percent of the participants.**

Lifestyle habits such as diet, exercise, and activity are modifiable risk factors. Modifiable risk factors were addressed by asking questions about exercise, activity, body weight perceptions, and diabetes perceptions on both the demographic profile sheet as well as in the focus group questions. Non-modifiable risk factors were addressed in the demographic profile and the focus group questions.

Sixteen participants reported they exercised, while ten participants claimed they did not exercise. Exercisers reported engaging in exercise an average of three days per week and an average of 48 minutes per exercise session (Figure 2). Eight participants, or 30.8 percent, claimed to participate in walking, and seven participants, or 26.9 percent, reported performing more than one type of exercise. Other than walking, no other types of exercises were identified by the participants. In the focus group setting, activities such as chasing children were considered a form of exercise by participants. Housework was cited as a physical activity by

more than 80 percent, or 21 of the participants. Refer to Figure 2, which illustrates the types of exercises performed by participants, and Figure 3, which illustrates types of physical activities performed by participants.

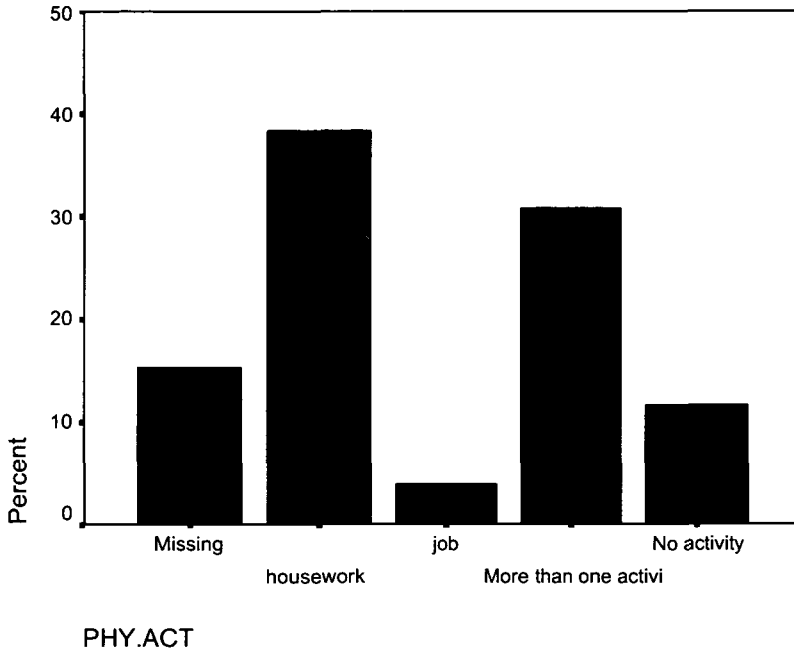
**Figure 2. Types of exercise reported by participants**



EX.TYPE

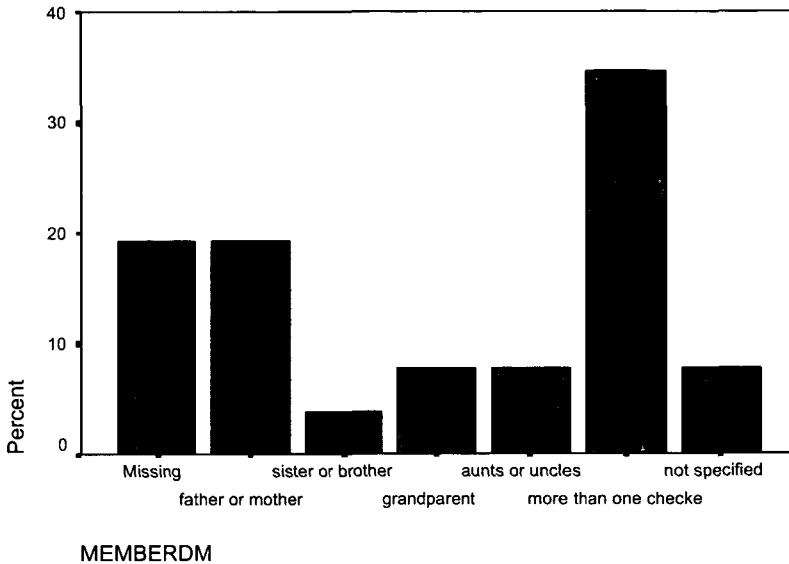
Note. Types of exercise included walking, other, and more than one activity. Ten responses were left blank as participants indicated that they did not exercise.

**Figure 3. Types of physical activities reported by participants**



Note. Types of physical activity included housework, gardening, and sewing. Four participants left this question blank.

Twenty-one (81 percent) of the respondents indicated they had a family history of diabetes with approximately 40 percent perceiving themselves at risk. Figure 4 reveals the distribution of family members reported as having diabetes.

**Figure 4.** Family members reported as having diabetes

The focus group findings revealed that participants having family members with diabetes have a higher awareness of the seriousness and severity of diabetes than participants who do not have family members with diabetes. Additionally, all of the participants expressed concerns about diabetes-related complications such as amputation, blindness, and death due to personal experiences.

### *Limitations*

The study was limited in scope by the small sample size; therefore, generalizability was decreased. Additionally, the study was limited to the inclusion of only African American women who self-reported that they have never been diagnosed as having diabetes. The sample was drawn from one metropolitan area in the southwestern region of the country, which may not reflect the perceptions, beliefs and experiences of all non-diabetic African-American women.

## V. DISCUSSION

Diabetes and the severity of complications represent a major health problem, which contributes to health disparities that continue to exist between African American women and other groups (U.S. Department of Health & Human Service, 2000). This study examined the perceptions and



health beliefs among African American women in regards to NIDDM (type 2 diabetes), risks factors for developing NIDDM (type 2 diabetes), and the severity/complications of NIDDM (type 2 diabetes) in an effort to generate ideas for diabetes education, risk reduction, and screening programs tailored to African American women.

Study participants believed that stress may lead to diseases, such as high blood pressure, diabetes, and cancer. They also reported that inadequate rest, poor diet, and not exercising were factors that lead to the same diseases. Although walking (Figure 2) was indicated as an important form of exercise for African American women, normal routine activities such as housework (Figure 3) were also considered to be a significant form of exercise. Obesity and heart problems were perceived as health issues for African American women. Death and amputations were popular beliefs of common occurrences from diabetes, especially given personal family experiences with diabetes-related deaths and complications. While 80.8 percent of participants identified a family history of diabetes, only 38.5 percent perceived themselves to be at risk for developing diabetes. Participants mentioned that genetics, race, and physical make-up played a role in developing diabetes. Severity and complications of diabetes, such as vision loss and amputations, emerged as repeating themes regardless of whether the focus group questions were addressing general diabetes beliefs, or diabetes beliefs related to severity and complications.

Data analysis revealed that participants viewed diet as a factor in preventing diabetes; specific themes identified included the need for consuming fewer carbohydrates, drinking more water, limiting salt, limiting certain meats (such as pork), and losing weight. The study listed exercise; weight loss; and limiting starch, pork, fat, fried foods, sugar, and carbohydrates as health practices that may prevent or reduce the risk of getting diabetes. Obesity was listed as a major health problem of African American women and a contributor to diabetes. Food item selections rather than overeating were stated to contribute to obesity. Study findings confirmed what the literature reports, namely that many African American women consider weight loss to be appropriate for health improvement, but not necessarily for appearance (Haire-Joshu, 1996; D'eraimo-Melkus, et al., 1996). Beauty shop participants indicated that an overweight person was considered to be 50 pounds above normal weight, and an obese person 100 pounds above normal weight. Two-thirds of the participants in the study indicated dissatisfaction with their weight

Participants recommended that reading simple diabetes-related literature and attending health fairs would help women of color become more knowledgeable about diabetes and how to reduce risk. They also

reported awareness that healthy eating habits and increased physical activity may prevent the onset of diabetes. Food choices selected were identified as contributors to the body's control of sugar increase or decrease. Blood pressure or blood circulation in combination with an increase or decrease in blood sugar levels were noted as causes of diabetes.

Suggested sites for health screenings and exercise classes included churches, health fairs, community centers, grocery stores, and WIC clinics, schools, and other public health clinics. None of the participants were aware that free diabetes screening programs were offered in a local neighborhood convenient to two of the focus group sites. Transportation and childcare issues also surfaced as concerns for getting to or being able to attend community programs.

Finally, many of the focus group participants concluded that health care was too expensive, there were too many preventative health service sites to visit (not all services under one roof), physicians did not talk at their level, and that simple written materials were not provided. Participants generally expressed knowledge of the severity of diabetes and its secondary complications, including heart disease, renal failure, kidney disease, blindness, and amputations.

## VI. CONCLUSIONS AND IMPLICATIONS

Although this exploratory study provides information that may be useful in designing, implementing, and evaluating diabetes education and screening programs for African American women, the reality is that the problem of health disparities extends beyond perceptions and beliefs of health consumers. The information derived from this study will need to be considered by transdisciplinary teams of researchers, practitioners, policy makers, and even the community before the elimination of the unequal burden of type 2 diabetes among African Americans becomes a reality.

Among African American women, the primary resource for learning about diabetes and its implications is from other African Americans — family members, friends, co-workers, and church family. African American women who are living with diabetes should be trained and utilized to deliver accurate information as *lessons to be learned* based on their experiences. The importance of family story sharing should not be minimized as an effective strategy in the campaigns to promote awareness and information exchange (i.e., move women into the contemplation stage of changing modifiable behaviors that ultimately contribute to the onset of NIDDM or type 2 diabetes). Structured social support nurturers (informed

and functional) can potentially influence perceptions and beliefs about diabetes among non-diabetic women.

Health beliefs and behaviors are the result of how people receive, process, and decide to act on information, resulting from the complex interaction of perceptions, enablers, and nurturers that signal the need for behavior changes within a family and communal structure. Community health educators, health care providers, voluntary health organizations, and other stakeholders should consider the following suggestions when designing culturally appropriate interventions aimed at preventing type 2 diabetes among African American women:

- 1) Partner with existing community organizations such as the African American church, beauty shops, nail salons, schools, and sororities to encourage diabetes screening and the adoption of healthy lifestyle behaviors
- 2) Utilize the family system to encourage younger African American women to participate in early detection screening programs.
- 3) Provide forums for participatory dialogue to answer questions and offer support for modifying lifestyle behaviors to reduce risk for the onset of type 2 diabetes.
- 4) Use peers to support behavior change -- eating healthier and exercising regularly.
- 5) Develop lay health community advisors to provide accurate and reliable type 2 diabetes prevention information.
- 6) Compile a resource inventory of affordable community services that support lifestyle behavior change, provide screening, and offer treatment if needed.

This formative research study reveals the importance of analyzing *lived experience* stories which convey information about perceptions, beliefs, and behaviors of African American women considered high risk for developing type 2 diabetes. The author finds that people clearly make decisions about seeking preventive care services either on their own, or

with support from others. Some people muddle their way into the preventative care system or let others (family members, friends, significant others) push them to seek preventative care. Type 2 diabetes is a preventable disease — clearly linked to lifestyle behaviors. Lifestyle behaviors among African American women are linked to social networks that include family and community. Informed, structured social networks that are large and closely tied together have the social capacity to get individuals into preventative care services and enhance opportunities for African American women to adopt healthier lifestyles. Whether African American women will engage in healthy lifestyle practices (healthy eating habits, exercise, and weight management) to reduce or delay the onset of diabetes may depend on their perceptions and beliefs about diabetes, its severity, and informed, structured social support networks developed through culturally appropriate interventions that consider the cultural norms, beliefs, and values of the community. These informed, structured social support networks may encourage African-American women to engage in self-regulatory behaviors that decrease risk for the onset of type 2 diabetes.

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