

In Brief

The management and impact of type 2 diabetes on the sense of self, lifestyle, and significant others of African-American men is not well understood. This article reports on a study to examine perceptions of managing and coping with diabetes among African-American men and summarizes its findings regarding the distribution of clinical biomarkers, participants' perceptions of the cause of their diabetes, its impact on masculinity, use of home remedies for diabetes care, and the degree to which effective coping skills and social support are engaged and available.

Views From Within and Beyond: Illness Narratives of African-American Men With Type 2 Diabetes

Leandris C. Liburd, MPH, MA;
Apophia Namageyo-Funa, MPH;
Leonard Jack, Jr., PhD, MSc; and
Edward Gregg, PhD

How African-American men manage type 2 diabetes and the impact of this disease on their sense of self, lifestyle, and significant others is not well understood. Despite the disproportionate burden of diabetes and its associated complications among African-American men, rarely has published research—clinical or ethnographic—been devoted specifically to diabetes in this population.

Why is it important to understand a patient's perspective of the psychosocial, cultural, and behavioral aspects of living with diabetes? While health care providers are often principally concerned with disease management, patients may contemplate their disease more broadly within an illness framework.¹ Disease management tends to be limited to efforts to correct "abnormalities in the structure and/or function of organs and organ systems; pathological states whether or not they are culturally recognized."²

Illness, on the other hand, is described as "how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability."³ How illness is perceived is culturally constructed and has meaning, and these meanings have implications for successful diabetes management.

In this study, we present the distribution of clinical biomarkers (e.g., hemoglobin A_{1c} [A1C], LDL cholesterol, and total cholesterol) of diabetes in African-American men as part of Project DIRECT (Diabetes Interventions Reaching and Educating Communities Together), a multi-year community diabetes demonstration project supported by the Centers for Disease Control and Prevention (CDC).⁴ The principal purpose of this article, however, is to offer a cultural analysis of the experiences of African-American men who live with diabetes.

Project DIRECT is a comprehensive public health intervention with three components: health promotion, outreach, and diabetes care.⁵ The health promotion component seeks to increase physical activity and reduce dietary fat intake in the general population. The outreach component engages community institutions, namely churches, in promoting diabetes prevention and control. The diabetes care component seeks to improve the access to and quality of care and diabetes self-management.

When the CDC first became interested in conducting this project, 1 in 10 African-American men aged 45–74 years in Wake County, N.C., had diagnosed diabetes.⁶ At that time, diabetes prevalence among African-American men was 80% higher than that of white men in the same community.⁶ Findings from the 1997 Project DIRECT baseline survey indicated that levels of diabetes preventive care services were comparable to U.S. estimates, “but the benefits of this care, as evidenced by glycemic and lipid control, were often inadequate for good health and to prevent future complications.”⁴

Gregg et al. hypothesize that “better health outcomes may ultimately depend on approaches that simultaneously improve delivery of preventive care services and enhance self-management.”⁴ In addition, these diabetes researchers posit that “it is also possible that current measures of use of preventive health care services and self-care behaviors do not adequately account for the wide range of psychosocial, behavioral, and economic factors influencing health outcomes.”⁴ This study elaborates on some of these factors by enlisting the voices of African-American men who live with diabetes to expose unique circumstances that influence health outcomes and that are often left unconsidered and unexplained. Most importantly, it provides needed information intended to improve diabetes education and self-management in the community by systematically collecting and responding to the views and expressed needs of this vulnerable population.

ILLNESS NARRATIVES

Illness narratives are one method by which we can obtain insight into the perceptions and experiences of individuals living with diabetes. In this study, we used the illness narrative framework proposed by medical

anthropologist and psychiatrist Arthur Kleinman.³ Kleinman proposes questions in five broad anthropological categories (Table 1) that allow providers to gain a deeper understanding of patients’ views and the social, spiritual, and psychological realities of dealing with an illness.³ Kleinman describes these categories as life history, patient and family explanatory models, symptom symbols, personal and interpersonal significance, and culturally marked disorder.

Life histories are brief synopses of individuals’ lives that include their “major continuities and changes in attitude, personality, major life goals and obstacles, and relevant earlier experiences of coping with illness and other serious conditions.”³ A diagnosis of diabetes is a significant life event

that causes patients to re-examine their life, behaviors, and future plans and options.

Patient and family explanatory models are informal descriptions of the occurrence of a particular illness. Exploring with patients why they believe they developed diabetes exposes important disconnects between the biomedical understanding of disease etiology and indigenous views of disease causation. Patients may be less likely to follow clinical recommendations if they do not accept clinical explanations of what is occurring in their body.

Symptom symbols are “accepted forms of knowledge about the body, the self, and their relationship to each other and to the more intimate aspects of our worlds.”³ How patients interpret changes in their bodies and whether these changes code (signal) a

Table 1. Interview Guide

Life History

1. Tell me about where you were born, your family, and some memorable events in your upbringing.
2. Tell me about your life right now (e.g., where you work, your family, etc.).
3. When were you diagnosed with diabetes?

Patient and Family Explanatory Models

1. What do you think caused you to develop diabetes?
2. What is the chief way diabetes has affected your life?
3. What do you fear most about having diabetes?

Symptom Symbols

1. What was going on in your body that led to your diagnosis of diabetes?
2. At what point did you go to the doctor?
3. Have you had any episodes with diabetes that caused you to go to the emergency room? If yes, describe what happened.
4. What other problems have you experienced because you have diabetes?
5. What kind of treatment(s) do you prefer for diabetes?
6. Do you use over-the-counter (OTC) drugs or other home remedies to treat diabetes? If yes, what are some examples of OTC drugs and home remedies that you use?

Personal and Interpersonal Significance

1. Describe what you do to control your diabetes.
2. Is there someone (or a number of people) in your life who helps you control your diabetes? If yes, what are some of the things they do?
3. In what ways have people in your life treated you differently after learning you have diabetes?
4. Of all the things the doctor/other health care worker told you to do to control your diabetes, what are the most difficult recommendations for you to follow? Describe what makes these behaviors so hard to do consistently.
5. In what ways has knowing that you have diabetes affected the way you see yourself?
6. Do you find that having diabetes adds to the stress in your life? If yes, in what ways?

Culturally Marked Disorder

1. In your own words, what do your blood sugars mean?
2. How do you think diabetes affects your body?
3. How comfortable are you telling people you have diabetes?
4. What are some reactions when you tell people you have diabetes?

serious chronic disease or a condition that can be quickly resolved likely has implications for how they use the health care system, how and what medications they take, and their general orientation to preventive health care practices.

Personal and interpersonal significance involves factors external to the individual and how these factors influence individuals' experience of living with an illness. Having diabetes can affect one's employability and job security, sex appeal, and other social relationships. Moreover, changing one's lifestyle in the interest of managing the disease and the impact of diabetes complications on one's ability to meet routine obligations affect spouses, siblings, coworkers, and others, as well as the person with diabetes. The personal and interpersonal consequences of having diabetes can be profound.

A culturally marked disorder is the assignment of an illness as not normal. How common or normal an illness is perceived to be depends on the social context and time period/era. For example, before Project DIRECT, people in this community hid the fact that they had diabetes to avoid being alienated and misrepresented by community members who did not understand the disease or its management.

In some instances, people with diabetes and their clinicians share similar understandings of the anthropological categories above. Divergence in patient and provider views offers an opportunity to explore and gather essential data necessary to facilitate effective diabetes self-management.

METHODS

This was an exploratory study that used quantitative and qualitative research methods to examine and understand the psychosocial and behavioral perspectives of African-American men with diabetes.

The quantitative aspect of the study consisted of data collected as part of the baseline epidemiological survey for Project DIRECT. The Project DIRECT epidemiological survey was conducted in 1997 according to methods that were previously described in detail.^{4,6} In short, 2,310 people aged > 18 years were sampled using a multistage, population-based probability sample from census files in predominantly African-American neighborhoods in Raleigh and Greensboro, N.C. All participants underwent a

household interview for assessment of general health status, diabetes-related behaviors, and risk factors. A subsample of 407 people who had previously diagnosed diabetes gave blood for measurements of A1C, LDL cholesterol, and total cholesterol. As a companion to the anthropological study presented here, we examined the prevalence of different levels of A1C, LDL cholesterol, and total cholesterol among 220 men.

The qualitative aspect of the study constituted the collection of data using in-depth semistructured interviews. The questions used in the interview according to each anthropological category (life history, patient and family explanatory models, symptom symbols, personal and interpersonal significance, and culturally marked disorder) are documented in Table 1. These categories provide important information about the cultural context that stage and support preventive health behaviors (e.g., regular physical activity, blood glucose monitoring, and healthy eating).

African-American men from southeast Raleigh, N.C., were invited to participate in this study by Project DIRECT. Using a nonprobability, purposive sampling method, men were identified from rosters of people who have participated in DIRECT interventions or by referrals of Project DIRECT Executive Committee members or health care providers. Eligible participants had to be 35–92 years of age and had to have been diagnosed with diabetes for at least 2 years. Participants were recruited regardless of employment, marital status, or education level.

The social, humanist, behavioral institutional review board at Emory University approved the study protocol, and all participants signed an informed consent form before the interview indicating that they understood the intent of the study and were participating voluntarily. Individual in-depth interviews were held in a private office in the Project DIRECT Community Office and were conducted by the principal investigator (L.C.L.). Each interview session lasted ~ 1 hour and was audiotaped and later transcribed by a professional transcription service.

Analysis

The quantitative analysis was conducted using SUDAAN software (Research Triangle Institute, Research

Triangle Park, N.C.) to account for the complex sampling scheme. The analysis focused on African-American male adults and clinical biomarkers (A1C, LDL cholesterol, and total cholesterol) associated with diabetes.

The qualitative analysis involved a content analysis of the transcripts by two members of the research team (L.C.L., A.N.-F.). The team members then met to confer and agree on major themes in the transcript. Consistent with usual procedures in reporting ethnographic research, direct quotes from the transcribed interviews of respondents are incorporated in the theoretical analysis and interpretation of findings. Names are replaced with pseudonyms. Findings from this study cannot be generalized to the larger population of African-American men with type 2 diabetes because of the study's geographic location, sample size, and sampling method, and the cultural and social diversity of this population.

FINDINGS

The mean age for African-American men in this quantitative analysis was 56.7 years. The mean score for the duration of living with diabetes was 8.5 years. Findings from the quantitative aspect of this study are presented in Figure 1, which shows distributions of A1C, LDL cholesterol, and total cholesterol levels among African-American men in the epidemiological survey. More than one-third had A1C results > 10%, and almost four-fifths had A1C results higher than the American Diabetes Association–recommended level of 7%. In addition, more than one-third had LDL concentrations > 130 mg/dl, and 44% had total cholesterol levels > 200 mg/dl.

Abbreviated life histories are reported in Table 2 for the 16 participants, whose ages ranged from 39 to 71 years and who had been living with diabetes for at least 2 years. The mean age for men in the anthropological study was 54 years, and the mean duration for having diabetes was 10.6 years. Six participants were diagnosed in their 30s, four in their 40s, three in their 50s, two in their 60s, and one in his 20s. Questions posed to the men generated rich and detailed data that cannot be fully discussed in the space allocated for this article. We briefly present findings for each category that capture recurrent themes or perspectives that are not commonly discussed in the diabetes care literature.

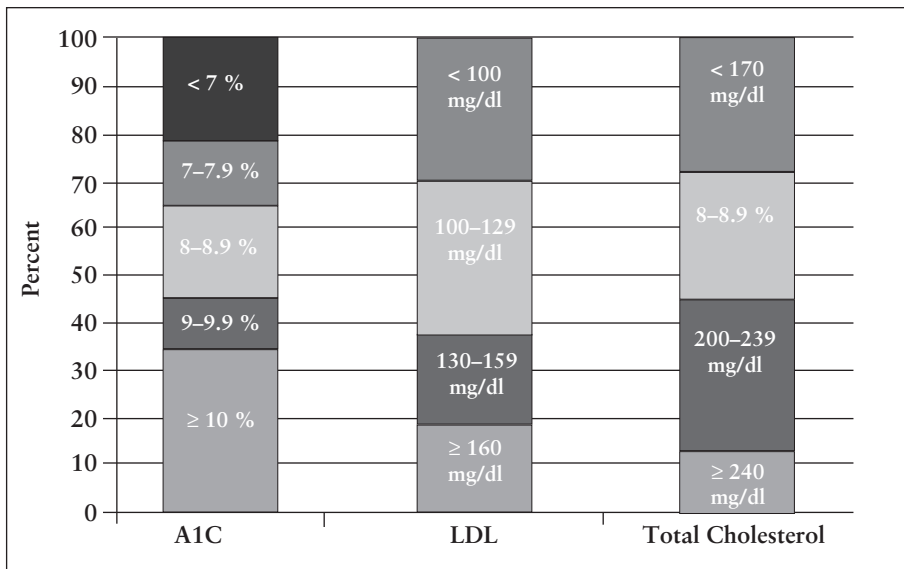


Figure 1. Distribution of A1C, LDL cholesterol, and total cholesterol values among African-American men with diabetes in Project DIRECT.

Patient and Family Explanatory Models

The majority of participants in this study identified poor diet (particularly a diet high in refined sugars) as the principal reason they developed diabetes. Some participants mentioned heredity, and others said both a genetic predisposition and poor diet were the reasons they developed diabetes. Donald Owens, for example, believed the diet he was raised on set him up to develop diabetes:

“I think I acquired the diabetes, not that it is hereditary, but I acquired it through eating what my parents ate. . . . They used to eat like so many starches all the time, so many beans, so many sweet potatoes, chicken breasts, chicken fried, and we used to eat a lot of fried foods all the time. . . . sneaking in when I was a kid, sneaking in to make so many sugar sandwiches. Sugar and butter sandwiches, full of sugar like that thick, and I think that is really what got to me.”

When men reported in their life histories family dietary traditions that they have since determined to be unhealthy along with a strong genetic history of diabetes, it may seem that they assumed a certain inevitability about acquiring the disease themselves. At a minimum, they were not surprised at the diagnosis. They did not mention having beliefs about being able to prevent the onset of diabetes or having taken any actions that might offset their chances of developing the disease. Once diagnosed, and

in spite of their own attributions about why they developed diabetes, many men struggled to change established eating habits, even though they knew they should make healthier choices.

Symptom Symbols

A majority of participants experienced symptoms associated with undiagnosed diabetes (e.g., excessive thirst, frequent urination, and unexplained weight loss). Those without symptoms discovered that they had diabetes while seeking health care for some other condition or while undergoing a routine physical examination. It is unclear whether these men had symptoms of diabetes that they may have ignored, or simply did not recognize these symptoms as being related to undiagnosed diabetes. Vincent Washington, for example, was diagnosed at about age 32. In thinking back on symptoms that he could not identify, he recounts the following:

“ . . . Yeah, well see I didn’t know what was wrong with me. Back in ’85, I didn’t know what was wrong with me. I would eat like three Big Macs, a whole big old trail of French fries. I didn’t know what was wrong with me. I was young. I could eat anything. I still didn’t know. I just

Table 2. Brief Profile of Participants

Simon Smith, 71, retired. Has had diabetes for 5 years. Pain associated with finger stick makes monitoring diabetes difficult.

Marcus Jones, 46, property manager. Has had diabetes for 25 years. Limited income affects his diabetes management.

Tom Hill, 55, single, owns a cleaning company. Has had diabetes for 2.5 years.

Randy Taylor, 53, religious leader, single, lives alone. Has had diabetes for 15–20 years and has complications.

William Brown, 57, unemployed, lives with wife. Has had diabetes for 20 years.

Michael West, 39, self-employed, married, cares for his son, does not have health insurance. Has had diabetes for 8 years.

John Ingram, 47, quality control check engineer. Has had diabetes for 2 years.

Jason Doe, 47, married, is a document specialist and reads about diabetes self-management. Has had diabetes for 8 years.

Lloyd Dixon, 43, is on disability. Has had diabetes 4 or 5 years and has not been managing his diabetes.

Percy Holmes, 45, caterer. Has had diabetes for 15–16 years and has heart disease. Is only recently attentive to his diabetes.

Vincent Washington, 52, is on disability. Has had diabetes for 15 years.

Allen Christian, 53, building inspector, lives with diabetic wife, is well read on diabetes and medications. Has had diabetes for 9 years.

Joe Williams, 67, construction worker. Has had diabetes for 12 or 15 years.

Donald Owens, 52, single. Has had diabetes for 2 years. Does not exercise because he does not want to lose weight.

Neil Gun, 70, retired, married. Has had diabetes for 4–5 years.

George Crowe, 69, retired, married, and believes diabetes is an eating disorder. Has had diabetes for 12 years.

couldn't get satisfied. And you keep on drinking these sodas about that big [hand gesture]. But after I found out I had sugar, one day I was working the register at work and I just went blind. They had to take me to the hospital and I found out I had sugar."

Vincent perceived that he was protected by his youth (i.e., "I was young. I could eat anything.") because he believed being young precluded the possibility of developing a serious, chronic disease such as type 2 diabetes. He continued to meet his obligations, namely, to work, in spite of the symptoms until he could no longer ignore them. Had he not gone "blind" at work or experienced some other acute event, his diagnosis would have been further delayed because he did not know how to respond to "something making me want to eat, eat, eat." Desiring large portions and consuming foods high in starch and sugar were not perceived as sufficiently outside social norms to cue that something might be wrong or that medical attention might be warranted.

Personal and Interpersonal Significance

Initially, accepting the diabetes diagnosis and prescribed management regimens were difficult for many participants. Joe Williams did not want to admit he was "sick" and preferred to attribute some of his symptoms to aging, which is "normal," versus the intrusion of a disease in his body. He said:

"... I've never been to the doctor. I never had to go to the doctor. In fact, when I messed my back up I healed that with herbs and so I don't think I'm deteriorating but you have a sense of, hey, look, I am older. I get tired but at 67 years I should be."

All participants indicated that managing diabetes was their primary responsibility and not that of their wives, siblings, coworkers, or other significant others. Whether they checked their blood glucose levels, took prescribed medications, engaged in physical activity, or modified their diets as suggested, they maintained all rights to decide to do so or not.

The men felt they knew their bodies better than anyone and were unwilling to suffer, particularly the effects of low blood glucose, regardless of what their providers prescribed. They frequently made changes in their regimens based

on self-diagnoses and self-judgment. Overall, if participants were not satisfied with how they felt after following the regimen prescribed by clinicians, they would change to an alternative, self-prescribed care plan. These alternative therapies often included herbal remedies and over-the-counter drugs, such as Korean ginseng root, uva ursi, capsicum, chromium picolinate, aspirin, herbal tea, and garlic tablets.

Managing diabetes is stressful for the men and their partners. They reported being distracted by thoughts of disability, loss of independence, and death. They expressed optimism about the future but feared future possibilities (e.g., lower extremity amputations). Marcus Jones described the stress of having diabetes for 25 years as culminating in his "deterioration:"

"You know my fear is that as I get older, all the components that diabetes has, what it is doing now. I have high blood pressure, glaucoma, kidney problems, amputations, dialysis. I see all that as I get older. Sometimes I say to myself, if I have to go on a dialysis machine or this and that, why continue? ... My fears? All my problems would just deteriorate and I don't want to be a bother to the kids. I've got four boys, and my wife to have to wait on me."

Changes in ability to perform sexually are also particularly stressful, as described by Joe Williams:

"In the past, well all my life, sex has been a dominant, not dominant, but very important part of me and not to be able to function, maybe not at the same level because I am not supposed to be at the same level that I used to, but not to be able to function to the level that I am satisfied with is more stressful than anything else ... I'm a man for and then when it does not function like I would like for it to, it's kind of diminishes me, to the point that I'm not satisfied. I'm uncomfortable with that."

Diabetes exacts an emotional toll on participants in various ways. Some are depressed and dwell too much on diabetes. Some are more cautious in what they do, and fear of the disease adds to difficulties associated with good self-management. Several participants reported benefits to having diabetes. Those who perceived such benefits described it as a "wake-up call"

that forced them to pay better attention to how they treated their bodies and took care of themselves. According to Percy Holmes, who had suffered a heart attack and other complications of diabetes:

"Well, I think the biggest benefit now is that I'm doing what I should have been doing the last 5, 10, 15, 20, 25 [years] and I can keep going, is eating right, getting back into some type of exercise program, and I guess the ultimate thing is just being a better manager of my body."

Culturally Marked Disorder

The high prevalence of diabetes in this African-American community suggests that diabetes is a normative disorder. At the time of the study, participants felt comfortable telling people they had diabetes. Several of the men, however, expressed a different attitude about disclosing their condition when they were first diagnosed. Lloyd Dixon initially felt shame in response to the diagnosis:

"I think something's wrong with my blood, that I am not normal ... I didn't want to admit something was wrong with me, that I had a problem. I was ashamed and that ain't the way to be. ... I am finding out now more and more and more people have it. ... I had nothing all these years to be ashamed of."

Similarly, Percy Holmes did not want people to know he had diabetes and shared:

"I didn't really want people to know what my health history was ... most black men hate to go to the doctor ... some say 'hey I'm close to this macho man and I am not supposed to get sick or I can beat this thing.'"

Themes of masculinity run throughout the comments of participants who did not want others to know they had diabetes. Jason Doe shared that he would not want other men to know he had diabetes:

"... if a person finds out that they are a diabetic, or that they have any type of illness ... a person may tend to take advantage of them by thinking that they may be a weaker specimen."

Among the men who freely shared with people in their social networks

that they had diabetes, the reactions were characterized as very supportive and caring. When other people with diabetes were in the room, the disclosure of having diabetes resulted in an exchange of information and strategies about how each managed the disease. Other reactions included surprise at the revelation that the participant had diabetes because he “did not look sick.” For participants who experienced noticeable changes in their physical appearance, people would often “misdiagnose” what this meant. Michael West, for example, lost > 50 lb in the process of managing his diabetes. For much of his adult life, he had been a bodybuilder and preferred to have a “big” body. His self-esteem and sense of sexual attractiveness were compromised as he sought to construct a new (smaller) body image:

“ . . . like my wife, when she met me I was a big guy, so she liked that. So she’s like, it’s hard for me to get adjusted to you being this size because now she feels like, and she likes big guys. And that’s the thing because I guess because, everybody’s society has always looked up to big guys. . . . I was talking to one guy who . . . was saying the same thing. He was a bigger guy and he lost some weight and everybody was like well, are you okay, do you have AIDS? . . . ”

If diabetes is a stigmatized condition in the community, people with diabetes may be reluctant to acknowledge having the disease, seek social support, or make needed lifestyle changes if it alters or compromises their social position in significant ways.

DISCUSSION

The illness experience of diabetes among African-American men in this study is complex and does not easily fit into a medically prudent plan of care. Study participants have characterized having diabetes as inescapable, a form of social inequality, a “private hell,” and a loss of one’s identity as proud, robust, sexual, independent, and invincible (i.e., masculine).

The younger the men were at diagnosis, the more likely they were to ignore having diabetes and to fail to take action to control it. They saw diabetes as robbing them of entitlements of youth, including being care-

free and reckless in pursuing their desires. One participant said he did not “respect” diabetes in his youth but now fears for his life and independence. Another thought he could “beat it” by ignoring the diagnosis and going on with his life plans.

As the men experienced the consequences of uncontrolled diabetes, they had to confront the reality that they could no longer safely engage in routine activities that other men their age participated in without paying special attention to the timing of their medications and to protecting themselves from minor injuries, among other things. For example, one man complained that cutting the grass could lead to a significant drop in his blood glucose and possibly cause him to pass out. Another said he could no longer crawl under the house or do work that might lead to an injury from nails or other punctures because of the time it takes to heal. Watching other men play basketball and other contact sports reminded a 39-year-old participant that he could no longer engage in these activities because he was easily fatigued.

This study highlights the need for greater understanding of the intersections among masculinity, men’s health, and chronic diseases. That is, additional research is needed to establish stronger theoretical and empirical associations among African-American men, black masculinity, and the prevention and control of type 2 diabetes.

Diabetes is an emotional stressor for men who tend to have few outlets for expressing and reconciling their emotions in a healthy and constructive way. Knowing that they have a disease that can quietly destroy their bodies, and therefore their independence and ultimately their lives, is a source of torment for these men. In spite of it all, they project a positive and empowered public perspective on their ability to successfully manage and overcome the potential devastation of this disease. Yet, we know from a previous epidemiological survey in this population⁴ that glycemic control is poor, and additional intervention strategies are needed.⁴

IMPLICATIONS

Clinicians and diabetes educators can support African-American men with diabetes by acknowledging that they are aware of and sensitive to the mul-

tiplied and complex psychosocial and cultural struggles these men must face and negotiate. Specifically, providers are encouraged to 1) discuss with patients questions from Table 1; 2) correct misinformation (e.g., discuss potential problems associated with the interactions of herbs and prescription drugs); and 3) use the answers to questions in Table 1 to make referrals to needed specialty and social services. Findings from this study also argue for peer-educator interventions or support groups where men can share diabetes management strategies and social support beyond clinical encounters.

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Leandris C. Liburd, MPH, MA, is chief of the Community Health and Program Services Branch of the Division of Adult and Community Health; Apophia Namageyo-Funa, MPH, is a fellow in the Program Development Branch of the Division of Diabetes Translation (DDT); Leonard Jack, Jr., PhD, MSc, is chief of the Community Interventions Section in the Program Development Branch of the DDT; and Edward Gregg, PhD, is an epidemiologist in the Epidemiology Branch of the DDT of the National Center for Chronic Disease Prevention and Health Promotion at the Centers for Disease Control and Prevention in Atlanta, Ga.