Challenges to Healthy Eating for People With Diabetes in a Low-Income, Minority Neighborhood

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OBJECTIVE—This study used qualitative interviews with black and Latino participants with diabetes to further understanding about types of foods eaten, food preparation, sources of foods and meals, communication with providers, and effects of race and ethnicity on eating in this population.

RESEARCH DESIGN AND METHODS—Researchers recruited black and Latino adults from East Harlem, New York, to participate in four English and Spanish focus groups. Discussions were transcribed, coded, and analyzed to uncover prevalent themes, which were interpreted with the Common Sense Model of Self-Regulation.

RESULTS—Thirty-seven adults with diabetes participated in four focus groups. The following four major themes emerged from the analyses: 1) The food environment limited participants’ access to healthy foods; 2) understanding of diabetes and communication with clinicians about healthy eating was limited and abstract; 3) the short-term, negative consequences of healthy eating outweighed the benefits; and 4) stress, in large part from poverty and discrimination, was seen as a causal factor for both poor eating and diabetes.

CONCLUSIONS—Participants’ responses indicated that using healthy eating to control diabetes does not provide immediate, tangible results. Thus, these participants followed their own common sense to guide their diabetes management and improve their health. Clinicians may be better able to help patients eat healthfully if they consider these factors during medical visits.

Black and Latino populations have a higher prevalence of diabetes and its complications, even after controlling for treatment status (1,2). Healthy eating is a primary method to treat diabetes; however, black and Latino individuals, especially if they are poor, food insufficient, or undereducated, are more likely to have a diet higher in fat and lower in fiber, fruits, and vegetables than their food-sufficient, white, more-affluent and/or educated counterparts (3–6). Furthermore, individuals living in minority communities have more access to unhealthy foods and less access to healthy foods (7–9) and are more likely to experience food insecurity, which itself is associated with diabetes (10).

These data suggest that adults with diabetes living in low-income urban communities might benefit from programs with actionable information on healthy eating. However, information on how to develop such programs is limited. Qualitative studies on healthy eating habits in low-income and/or minority individuals indicated that cost, transportation, frustration, communication barriers (including language), and lack of knowledge prevent healthful eating (11–16). However, the results of these studies may not be applicable to adult minorities living in urban areas because all but one (13) were conducted in rural communities (11), involved parental discussions of dietary habits in children (12), primarily focused on general diabetes self-management (15), or were conducted >10 years ago (14,16). Furthermore, few studies assessed beliefs about healthy eating in low-income, minority individuals with diabetes, and none used a theoretical model to interpret the results.

East Harlem, New York, is an ideal location to investigate views of healthy eating among underserved populations because most of its residents are black or Latino (almost 90%), many live below the poverty level (38%), and East Harlem’s obesity, diabetes, and all-cause mortality rates are among the highest in New York City (17). East Harlem residents have poor access to stores that sell healthy foods (18), and among those with diabetes, 40% report being unable to afford a healthy diet, and 39% report being unable to shop or cook healthfully (18).

The current study used focus groups to identify the knowledge, attitudes, behaviors, motivators, and barriers to healthy eating for individuals with diabetes living in East Harlem. In addition, the Common Sense Model of Self-Regulation (CSM) (19,20) was used to clarify the processes underlying participants’ mental models of diabetes and its causes. The CSM assumes that perceptions of diabetes, medical treatment, and recommended diets (i.e., mental models of diabetes and treatment) are based on personal experience (e.g., perceptions and feelings when managing diabetes). Thus, the CSM suggests that patients are unlikely to adhere to advice if medical recommendations are not validated by or are inconsistent with personal experience. We hypothesized that barriers to lifestyle change would include the inaccessibility of healthy foods and the inconsistencies

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between physicians' prescriptions for and patients' experiences with healthy eating to control diabetes.

**RESEARCH DESIGN AND METHODS**—A research subcommittee organized by the East Harlem Diabetes Center of Excellence, a community-based coalition of community leaders and providers, conducted this qualitative study to develop new approaches to stimulate dietary improvements for controlling diabetes. Criteria for inclusion in the focus groups and a guide for conducting focus groups were prepared in collaboration with committee members. The guide was pilot tested with patients and revised. The final guide is presented in Table 1.

Volunteer outreach workers recruited participants by posting fliers written in Spanish and English in fast food restaurants, senior centers, churches, and housing projects. Outreach workers also solicited referrals from partners at hospital sites and community clinics. Eligible participants were East Harlem adult residents who spoke English or Spanish and self-reported diabetes. Groups were offered during days, evenings, and weekends and were convened in private rooms in medical center buildings. Experienced moderators conducted four focus groups: two with black participants and two with Latino participants (one in English and one in Spanish by a Latina moderator). Groups lasted roughly 1.5 h and were led by two moderators (one as a facilitator) trained to remind participants to discuss all diabetes care decisions with a physician. Each participant gave written informed consent, received a meal during the focus group, and completed a brief sociodemographic survey after the focus group. Each participant received a $40 gift card for participating. The Mount Sinai Institutional Review Board approved the protocol.

Sessions were audiotaped and transcribed verbatim; sessions in Spanish were translated by a professional translator. A grounded theory approach was used to analyze interviews and identify preliminary themes. After the identification of themes, the CSM was used for further interpretation. Because saturation was reached by the fourth group, no additional groups were conducted. Two investigators (C.H. and R.G.) independently read one transcript to form an initial set of codes. They then used ATLAS.ti software to code a second transcript to refine the codes. The resulting 38 codes (available on request) were used to analyze the final two transcripts for which interrater reliability was 0.82. Comments could be and often were assigned more than one code. After the transcripts were coded, we developed a list of dominant themes (i.e., those discussed in most or all groups) and important outlier themes by collaboratively reviewing codes, related quotations, field notes, and comments generated during the early analytic phases. In addition, four participants evaluated whether the themes successfully captured the discussion content or needed revision; they did not recommend any changes.

**RESULTS**

**Participants**

Thirty-seven adults with diabetes (63% of the 59 invited) participated in four focus groups. On average, there were nine members in each group (range 6–14). The mean age was 54.97 years (SD 14.15, range 27–80). Participants reported having diabetes for an average of 8 years, and 62% were foreign born (all from Latin America). Additional demographic information is presented in Table 2.

**Major themes**

The analyses yielded the following four major themes (Table 3): 1) The food environment limited participants' access to healthy foods; 2) understanding of diabetes and communication with clinicians about healthy eating was limited and abstract; 3) the short-term, negative consequences of healthy eating outweighed benefits; and 4) stress. By contrast, less healthy, although not always good-quality foods were convenient and readily available.

Understanding of diabetes and communication with clinicians about healthy eating was limited and abstract. Participants understood that diet affects diabetes, but many were unconvinced that dietary changes lower blood glucose levels. As a black man stated, “You can eat what you want because if you’re gonna have diabetes you’re just gonna have it anyway.” Many believed that they should avoid foods with starch...
Table 1—Discussion guide

Introduction

Speak one at a time
No right or wrong answers
The session will be audiotaped

Confidentiality

Purpose of the session: We are interested in learning more about your awareness, knowledge, attitudes, and behaviors around healthy foods and healthy eating as someone who lives with diabetes.

Role of the moderator: keeping the focus of the discussion, keeping time, making sure everyone has an opportunity to speak or be heard.

Definitions of diabetes: Sometimes people who have diabetes refer to it as “having sugar” or as “sugar in the blood.”

Icebreaker
[Going around the room] Please tell us your first name, where you’re from, and how long you’ve had diabetes.

Discussion topics and themes

I. Types, timing, and amount of healthy foods
   Describe what you think is the connection between food and diabetes.
   a) What kinds of foods should people with diabetes eat? What should they NOT eat?
   b) Can you describe a diabetic diet for me?
   c) How important is it for people with diabetes to stick to a diabetic diet?
   d) How important is it for people with diabetes to eat three times a day?
   e) Do you feel it is important to pay attention to what time you eat your meals, and if so, what’s important?
   f) Is it ok for people with diabetes to skip meals?
   g) Do you think the amount of food that you eat matters or is a problem if you have diabetes?

II. Culture and family
   Can people with diabetes eat the types of foods they grew up with and foods they loved, or do you feel they have to give up these foods?

III. Food preparation
   Do you cook most of your own meals and meals for others in your family?
   For those who cook:
   a) Do you cook a diabetic diet? Why or why not?
   b) Can and would your whole family eat this way?
   c) Do you cook differently for your family than you do for yourself?
   Do others cook for you, or do you eat somewhere else like a senior center, restaurant, etc.?
   For those who do not cook:
   a) Does the person who cooks for you know you have diabetes?
   b) Does that affect how they cook for you?

IV. Access to healthy foods
   Where do you and your family buy your food for eating at home?
   a) Do people shop at small stores/bodegas? Why? What do you buy there?
   b) Are the kinds of foods we talked about earlier—those that are good for people with diabetes—available in the neighborhood at these stores?
   c) How about at larger markets or supermarkets?
   d) Is it more or less expensive to buy the kinds of foods that are healthy for people with diabetes, or is there no difference in cost?
   e) Does the cost of foods make it hard to keep a diabetic diet or not?

V. Communication with health provider
   How many people ever had a discussion about healthy eating with their health provider (doctor, nurse, nutritionist, or dietitian)?
   For those who do:
   a) Did you understand what they told you?
   b) What kinds of things did they recommend? Did they recommend specific foods you should eat that seemed familiar to you or were the kinds of foods that you eat anyway?
   c) Do you find it hard to eat the kinds of food your provider recommended you should eat? Why?

VI. Intervention ideas
   We would like to make it easier for people with diabetes to eat healthy diets.
   a) What kinds of suggestions do you have for people who are trying to eat right to control their diabetes?
   b) What about suggestions for doctors and nurses who treat people with diabetes?
   c) Could they help people with diabetes eat better?

Questions were asked in this generic form and with regard to participants’ personal experiences with diabetes. This was done to allow participants who might be uncomfortable personalizing responses in a group setting to speak their minds.
Participants dismissed suggestions that they considered unrealistic, such as when foods or preparation methods were unfamiliar or recommended portion sizes were “not enough to live on.” Others misconstrued the intent of practitioners’ recommendations; for example, several participants interpreted the suggestion to eat less as a recommendation to skip meals. They also felt as though they were treated generically. One black woman stated, “You’ve got to deal with the person individually. … You don’t give us each the same prescriptions, you should not give us each the same [meal] plan.”

Some participants turned to home remedies to fill gaps in nutritional knowledge, mentioning self-proven ways to lower blood glucose levels (e.g., using cinnamon or cold water as hypoglycemic agents or drinking coffee to suppress appetite). A Latina said,

This also I’ve proven, water is good to lower the sugar…. I eat all kinds of things since I’ve seen if I drink two or five bottles of water it truly lowers the sugar. It removes the urine and the urine leaves the sugar, and I have checked.

Participants validated the success of dietary modifications through patient-centered outcomes, such as decreased stress, symptoms, weight, and blood glucose levels. Because many did not achieve these outcomes rapidly, if at all, they stopped changing their diets. Very few reported experiencing tangible benefits of healthful eating. In summary, participants failed to see a causal relationship between diabetes and changing diet; received advice that was sporadic, generic (did not address the individual’s life), and vague (abstractions not anchored in perception, e.g., portion size); and generated, as a result, a variety of common sense procedures for controlling blood glucose levels (e.g., drinking water, skipping meals). The short-term, negative consequences of healthy eating outweighed the benefits. The potential benefits of healthy eating were filtered through participants’ concrete life experiences. Factual nutritional information was of little value to participants who experienced either no relationship or actual contradictions between medical facts and the facts of personal experience. For example, a Latina woman said, “We should not be on a diet…. I told my doctor it’s not my fault because everything I eat makes the diabetes go up.” Many questioned the value of giving up diets that did not make them sick in their native country or in the American South. As one black woman said, “In the South, no one had diabetes, now that we moved to the North, everybody has it.”

Beliefs about healthy eating and efforts to restrict diet were also affected by experiences with friends and family. Participants described having to choose among three dining options: eating the same unhealthy foods as their families, converting their families to healthier foods (which most participants’ families were unwilling to do), or eating separate meals (which was socially isolating and expensive). As a black man said,

But when you’ve got a family, like myself… I can go by diabetic rules, but what about them? They don’t like broiled food… then you go get a chicken, you boil it for yourself, then you get the vegetables for yourself, okay you spend $6 just for yourself.

Restriction itself was also considered harmful. Several participants believed that people with diabetes crave sweets and experience greater-than-average hunger, which if not sated, leads to emotional lability. Others believed that smaller portions caused other health problems and symptoms of hypoglycemia, which was considered more dangerous than hyperglycemia. A black woman said,

I’m not going to walk around starving myself… my mother, she’s a diabetic… she went into bad health because she didn’t eat enough… So I put it like this here, excuse my expression, damned if you do, damned if you don’t with diabetes.

Thus, instead of using healthy eating to control blood glucose levels, participants attempted to lower stress (e.g., by screaming to release tension) or used home remedies (e.g., drinking water). The experienced-based common sense logic of location (“we ate the same thing there without becoming diabetic”), social context (“my family won’t change what they eat”), and observed risks of hypoglycemia undermined the acceptance of nutritional information and healthy eating. Stress, in large part from poverty and discrimination, was seen as a causal factor for both poor eating habits and diabetes. Participants repeatedly focused on the causal links among healthy eating; stressful life experiences from finances, the health care system, and racism and discrimination and stress from diabetes, its stigma, and its management. Several participants noted that “diabetics are
Table 3—Participants’ daily decisions and trade-offs related to healthy eating

<table>
<thead>
<tr>
<th>Decisions and trade-offs</th>
<th>Food environment</th>
<th>Understanding and communication</th>
<th>Consequences</th>
<th>Stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Convenience</td>
<td>Convenience: local small stores with limited quality and selection vs. distant, better, larger stores</td>
<td>Trusting personal experiences with healthy eating vs. trusting clinicians’ recommendations</td>
<td>Eating unhealthfully with no immediate negative consequences vs. eating healthfully with no immediate positive consequences</td>
<td>Eating familiar, comforting, unhealthy foods that could lower stress and glucose level and improve health vs. eating healthy foods in a way that will cause stress and worsen diabetes</td>
</tr>
<tr>
<td>Cost</td>
<td>Cost: affordable unhealthy food vs. expensive healthy food</td>
<td>Skipping meals when blood glucose level is high vs. eating healthy, small portions regularly</td>
<td>Eating unhealthy foods vs. eating unhealthy food made with alternative remedies</td>
<td></td>
</tr>
</tbody>
</table>

always in stress” and described a vicious cycle in which stress caused and exacerbated diabetes. Stress was also perceived as a barrier to adopting and sustaining healthy eating. As a result, many participants believed that a healthy diet could do more harm than good because it ultimately increased stress. A woman described her experience during pregnancy:

The day I stopped worrying, I said, “I’m going to eat everything. I don’t care about diet or sugar or anything.” I checked the sugar, and it was good. And so stop worrying because if you have in your mind diabetes, diabetes, diabetes, you are traumatizing yourself with this illness. It’s not good for us and we’re missing ourselves.

Racism and economic discrimination were woven throughout descriptions of stress, diet, and illness. Individuals in all groups described experiences of unfair treatment in the health care system that they attributed to race, ethnicity, primary language, or economic status. They reported discrimination leading to unemployment; a stressful work environment; a lack of affordable healthy, quality foods in minority neighborhoods; and a lack of quality health care, including nutrition education. Participants believed that these factors helped to cause diabetes, made diabetes difficult to control, exacerbated complications, and led to stress-related eating.

Participants also believed that their food environment was shaped by racism and poverty, that it was common practice to send foods left unsold in white neighborhoods to minority neighborhoods. Some black participants traced the roots of traditional, unhealthy foods to slavery. As one woman explained,

Our diet goes way back, back to slavery days when the massa was eating the good healthy meals that the black nanny was cooking for them. They ate healthy foods, and what was left from those meals were thrown to us. You know, the cracklin’ bread, chicken feet... So the diabetes started as far back then, and it came right on up through, as [another participant] said, through our blood lines.

In summary, stress was viewed as an important link between diabetes and an array of external factors, including racism, low income, negative experiences with the health care system, stigma, problems with diabetes management, and the unavailability of healthy foods.

**CONCLUSIONS**—Qualitative analyses identified four barriers to healthy eating faced by low-income, urban, African American, and Latino patients with type 2 diabetes in East Harlem. First, focus group participants were overwhelmed by inexpensive, unhealthy, poor-quality foods, with better-quality foods out of geographic and financial reach. Their comments described a map of their physical, social, and economic environments filled with barriers and few opportunities to implement behavioral change. Second, participants perceived the scant information from clinicians as abstract and unrelated to their concrete experiences of daily life. They expressed an array of views about diabetes that included few medically recommended procedures for management, and their ideas ranged from fatalistic (e.g., diabetes as unresponsive to dietary changes) to folk treatments (e.g., water to dilute or remove sugar). These comments showed a lack of clear bidirectional communication with practitioners. Third, participants’ daily experiences with healthy eating led them to doubt its necessity and benefits—why eat what others tell you is healthy when it is difficult, expensive, isolates you from your culture and family, and does not improve your physical or mental health? Finally, participants saw stress caused by racism, discrimination, poverty, and attempting to eat healthfully as a cause of diabetes and negative health outcomes.

These findings support those of studies conducted in other populations (11–13,21–23), suggesting that the challenges to healthy eating faced by urban, low-income, minority patients with diabetes are similar to the challenges faced by those without diabetes and those in rural contexts. The present data also support the quantitative findings that healthy eating is difficult in low-income neighborhoods (7–9) and the findings that stress and negative emotion are common in patients with diabetes and adversely affect mental and physical health outcomes (24). Participants in the present study also wanted more concrete information from physicians. Indeed, patients are more likely to adhere to treatment when providers clearly describe what a treatment is, how to perform a treatment, and what to expect from a treatment (25).

The current study adds unique information on the specific mechanisms underlying patients’ responses to diabetes and provides a framework, based on the CSM, with which to understand how these barriers interact to influence eating habits. A major finding is that what could be construed as nonadherence to dietary recommendations often was participants acting on their own common sense understandings of diabetes and its management. Participants searched for symptoms and functional changes as markers of their diabetes status, and these markers were either unchanged or worsened by healthy eating. Participants were largely unable to connect dietary changes with improvements in health. They searched for the palpable benefits of healthy eating, but instead discovered and settled on highly salient negative outcomes, such as hypoglycemia, isolation, and stress, which seemed to encourage actions that prevented those perceived
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negative consequences but increased risk (e.g., comfort from comfort foods). Participants repeatedly discussed how they substantiated the benefits of actions with statements such as, “I have checked.” As a result, outcomes were misattributed; that is, positive actions were devalued and harmful behaviors positively valued. Thus, this study demonstrates that abstract dietary concepts that are not supported by and anchored in concrete experiences are devalued. This information could be used to improve diabetes outcomes (e.g., by influencing interventions or policy changes).

Those few participants committed to dietary change faced an array of barriers in their environments and social interactions. These barriers existed at the starting point for virtually every pathway toward the goal of healthy eating. At the outset, costs often outweighed quality, and preparation was complicated by unfamiliarity with balancing health with taste, convenience, satiety, and family members’ preferences. Obstacles appeared every day at every meal, and when efforts to overcome barriers failed to produce immediately perceptible benefits (i.e., improvements in physical or mental states), participants became frustrated and further doubted the need to change dietary habits. The complexity visible in these efforts contrasts sharply with suggestions that eating is a singular behavioral entity that readily lends itself to adaptation (26,27). Dietary change requires controlling highly automatic action sequences from food purchase through preparation. For participants, barriers to dietary change eventually undermined the goal of healthy eating, allowing them to remain on the far-simpler path of eating culturally preferred foods that generated palatable sensory and emotional benefits, and doing so had the added benefit of reducing a perceived cause of diabetes: stress. Each meal was generated within the context of participants’ social, cultural, and familial networks. Clinicians may not be completely aware of these networks and, therefore, may not address them during medical visits. Clinicians attempting to change diet without being aware of these factors may be ineffective, become frustrated with themselves and their patients, and inadvertently project negative affect toward their patients. This is borne out in the literature on clinicians’ negative treatment of overweight individuals (28).

In light of these barriers, how can clinicians work with patients with diabetes as well as with others who could benefit from healthier diets? First, clinicians need to understand how patients view diabetes and effective self-management, including acknowledging that racial discrimination and stress may be associated with the development of diabetes and can affect its management. Second, patients and clinicians need to come to a shared understanding of diabetes and management that can improve glucose control and quality of life. Clinicians will be most effective when they weave medical expertise with patients’ own experiences to help patients understand the big picture of healthy eating. Finally, to ensure that action plans are individualized, clinicians should provide concrete, visual information on portions, preparation, and specific actions, including determining whether patients can find, afford, and prepare healthy foods.

Limitations of this study include the small sample size and recruitment of participants from a single neighborhood. We did not collect data on Latino subgroups, although we used a professional translator and conducted focus groups in broadcast Spanish. In addition, the opinions of those willing to attend focus groups may differ from the opinions of those unwilling to attend. As in most studies of this nature, there were fewer male than female participants. Qualitative research methods are designed to explore new phenomena, not to test existing hypotheses or determine the prevalence of beliefs and behaviors. Thus, future qualitative and quantitative studies must continue to explore these new ideas (e.g., intervention studies that test whether prescribing individualized treatments are effective). Future studies should further explore the unique effects of race, ethnicity, and socioeconomic status on healthy eating.

Counseling patients about diet is an essential aspect of chronic disease prevention and management. However, clinicians cannot prescribe diets to which patients cannot adhere. Oversimplifying this challenge can lead to mutual disappointment and obviate meaningful change: clinicians who are frustrated by patients who do not follow basic suggestions and patients who are frustrated by clinicians who do not understand the barriers faced when trying to eat healthfully in an underserved community. The data presented herein suggest that using a more sophisticated understanding of healthy eating—one that melds empirical data, medical expertise, and patients’ personal experiences—will help clinicians help patients change their eating habits for the tenuous promise of better health.

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