

“It Feels Like Home When You Eat Rice and Beans”: Perspectives of Urban Latinos Living With Diabetes

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Abstract

Background. Studies on Hispanics/Latinos with diabetes have largely focused on Mexican-American populations. This qualitative study explored psychosocial issues that affect diabetes self-management for Hispanic men and women of primarily Caribbean ancestry.

Methods. Thirty-seven adults with diabetes in Bronx, N.Y., were recruited to seven focus groups, which were conducted in Spanish and English, audiotaped, transcribed, and subjected to qualitative analysis.

Results. New themes emerged that are not well documented in the research literature for Hispanic/Latino populations with diabetes. These include the effect of diabetes on sexual health problems,

perceptions about the link between depression and diabetes, intergenerational issues and their impact on participants' beliefs about diabetes, and perceptions of discrimination and discontinuity in health care.

Conclusions. Findings suggest that perspectives among Hispanic/Latino populations about living with diabetes are diverse, and more research is needed. Social-cognitive theory and socio-ecological models of health may be useful to diabetes health care professionals in understanding patients' experiences with diabetes and informing the development of psychosocial and educational interventions that consider individuals and their environment.

In recent years, issues in diabetes self-management for Hispanics of Caribbean ancestry residing in urban, low-income communities have received greater attention,¹⁻⁴ although much of the previous research on diabetes has primarily focused on Mexican-American populations. Research has identified some similarities and differences on culturally relevant issues across diverse Hispanic groups with diabetes, but larger controlled studies are needed to evaluate these differences more extensively.⁵ Psychosocial, cultural, and environmental factors, as well as access to medical care, can strongly influence patients' approaches to self-care and affect overall medical outcomes.⁵⁻⁹

Focus groups have been used effectively to help inform the development of culturally

tailored diabetes self-management interventions for Mexican-American populations.^{10,11} Focus groups have also been used in community settings to help promote public health initiatives that increase diabetes awareness in low-income, high-risk communities.^{12,13} Qualitative studies conducted previously with Mexican-American populations with diabetes residing in the western or central regions of the United States have evaluated the following constructs: causal models of disease; diabetes knowledge, diet, and exercise barriers; family issues; social support; spirituality; and the use of alternative remedies.¹⁴⁻²⁰ Results from these studies emphasize the significance of these factors in influencing Mexican Americans' perceptions and approaches to diabetes care. Less

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information is available on other Hispanic groups with diabetes.²¹

Rates of diabetes in New York City have doubled within the past decade, with Hispanics having the highest rate (13%).²² The South Bronx has a prevalence of diabetes of up to 16.9%. The Bronx has one of the highest poverty rates in the United States and the highest number of cases of diabetes in New York City.^{22,23} Epidemiological studies of Puerto Ricans in New York City have emphasized the need to improve screening rates, address health disparities, and create culturally appropriate education programs.^{24,25} Recent studies of Puerto Rican populations in Boston, Mass., and Chicago, Ill., found that patients engaged in poor nutritional practices had physical disabilities, depression, cognitive impairment, and competing financial and family concerns that interfered with care.^{4,26,27} This study explored in greater depth the extent to which psychosocial issues affect diabetes self-management for English- and Spanish-speaking Caribbean Hispanic/Latino adults residing in Bronx, N.Y., and to determine whether new themes would emerge for this population that have not been previously observed or well documented in studies with Mexican Americans.

Methods

Hispanic adults with diabetes were recruited to participate in focus groups after they had completed their participation in the Vision is Precious (VIP) study. As background, the VIP study was a randomized, controlled trial that compared a behavioral telephone intervention (up to seven calls) to a standard print intervention (a booklet) to promote retinopathy screening in a multi-ethnic, low-income diabetes population in Bronx, N.Y. Subjects in the main study ($n = 598$; 42% Hispanic) participated in the 6-month intervention study offered in English or Spanish.

Individuals were recruited to take part in focus groups and were reimbursed \$40 for their time almost 2 years after their main study participation. Friends and family

did not attend the focus groups to reduce the likelihood that participants would feel inhibited sharing issues that affect their self-management. Men and women attended separate focus groups. The 2-hour groups were offered in Spanish or English. The focus groups had a sex-matched trained bilingual group leader and note taker. The group exchanges were audiotaped, and the note taker documented group exchanges to assist the transcriber in differentiating participants' comments. Informed consent was obtained before participation.

A focus group guide was developed based on training the principal investigator (A.C.) received at the Riva Institute in Bethesda, Md., and feedback from a panel of experts. The guide contained the following components: introduction, group guidelines, and questions about diabetes self-management with carefully framed follow-up questions. The focus group guide was translated and back-translated from Spanish to English. The focus group questions were pilot-tested to ensure clarity. Table 1 provides sample questions from the focus group guide.

A bilingual transcriber prepared the transcripts from audiotapes and notes. The Spanish-language transcripts were analyzed in Spanish. Six of the nine reviewers were bilingual.

Not every reviewer had an expertise in diabetes, but all had experience working with minority populations. The reviewers had degrees in nursing, sociology, and psychology. Three were health educators with bachelor/master's degrees who worked in the community. Each reviewer was first oriented to the qualitative analysis process and encouraged to mark the transcripts for significant issues from the focus group discussions.

Each Spanish transcript was analyzed by four reviewers. Each English transcript was analyzed by five reviewers. Three bilingual reviewers (A.C., S.S., M.S.M.) then worked independently, and later jointly, to design a master list of themes. Once consensus was reached, coding templates were developed to record the themes that emerged in the groups and the significance of these themes based on the participant exchanges and reviewer feedback.

Demographic information on participants was retrieved from the main study database (Table 2). The study was approved by the institutional review board at the Albert Einstein College of Medicine.

Results

At the time of recruitment to the focus groups, 115 Hispanic men and women had completed the VIP

Table 1. Sample Focus Group Questions (Women's Version)

Topic	Questions
Challenges in diabetes	1. In your opinion, what does it mean for someone to be in control of their diabetes? 2. What are some reasons why it might be especially difficult for Latina women to take care of their diabetes?
Diabetes support	3. In what ways do you feel supported in taking care of your diabetes? 4. Do you think you are good at asking others for help when you need it?
Self-image	5. When you learned that you had diabetes, did it change the way you see yourself?
Social comparisons	6. Are the needs of Latinas with diabetes different from the needs of Latino men with diabetes?
Thoughts/ideas about getting help	7. Are there any things that others (doctors, friends/family, the community, or government) can do for you to help you take better care of your diabetes?

Table 2. Composition of the Groups (n = 37)

Group	Female n = 7	Female n = 8	Female n = 6	Female n = 2	Male n = 10	Male n = 2	Male n = 2
Language (English/ Spanish)	English	Spanish	Spanish	English	Spanish	English	English
Mean Age (years)	47	58	62	58	65	56	58
Employment							
Disabled	3	6	4		2	1	
Full-time	1	1			1		
Part-time	1				1		1
Retired	1	1	1		4	1	1
Unemployed	1		1	2			
Education							
< 8th grade		4	3		7		
9 th , 11 th grade	3	3			1		
High school graduate	1	1	1	1	2	1	2
Some college	3			1		1	
Trade/technical			1				
Unknown			1				
Insurance							
Insured	7	8	5	2	9	2	2
Uninsured			1		1		
Annual Income							
< \$15,000	5	6	6	1	8	1	2
\$15,000–30,000	1	1		1	1		
\$31,000–50,000		1			1	1	
Unknown	1						
Marital Status							
Single	2			1	2	1	1
Married	1	2	3		7		1
Divorced	1	2	2	1	1	1	
Separated	2	2					
Widowed	1	2	1				
VIP Group Assignment							
Phone Intervention	1	8	4	2	3	2	
Print Intervention	6		2		7		2

VIP, *Vision Is Precious* study.

study. Of the 37 who participated, 29 were Puerto Rican, 2 were Dominican, 2 were Ecuadorian, 1 was Peruvian, 1 was Nicaraguan, and 2 stated they were Hispanic but did not disclose their country of origin. Of the four sessions ($n = 23$) conducted with women, two were in Spanish. The mean age of the women was 58 (range 47–70) years, with 86% ($n = 20$) of the women either disabled, retired, or unemployed (Table 2). Of the three sessions ($n = 14$) conducted with men, one was in Spanish. The mean age of the men was 62 (range 39–75) years, with 64% ($n = 9$) of men disabled or retired.

Participants (78%) reported an annual income of <\$15,000, and 57% reported having less than a high school education. Only two participants lacked health insurance. Women were more likely than men to be separated, divorced, or widowed. Three of the sessions were attended by only two people. In the smaller sessions, participants provided more detailed accounts of their experiences.

Diabetes self-management barriers

In response to questions about diabetes self-management, men and women discussed the importance of monitoring their blood glucose, taking medications regularly, and maintaining a healthy lifestyle to reduce their risk of complications. They also discussed medical comorbidities and socioeconomic and environmental factors that interfered with effective self-management.

Strategies men and women used to manage diabetes included collecting written information, informing others of their dietary needs, and limiting their portion sizes. Men and women stated that personal control over diabetes was important, but many communicated difficulty exerting this control. As one man stated: “Diets do not work . . . the only diet you can have is self-control. Self-control means that you know that you’re gonna have this lifestyle for the rest of what life you got left.”

Barriers to diabetes self-management included disabilities that limited physical activity, perceptions

that healthy food was unappetizing, social pressures to eat high-fat/calorie foods, and forgetting to take medications. Socioeconomic barriers and language barriers with providers were also discussed, as well as limited access to information and reading materials in Spanish.

Many men and women perceived rice as a forbidden food. Some group members removed rice from their diet, others limited their portions, and some expressed difficulty in making changes. The following quote from a women’s group illustrates the significance of rice and the thoughts and feelings it engenders.

. . . It feels like home when you eat rice and beans . . . and when it’s not in the house, it’s cold . . . it’s a cold feeling . . . Like when you grow up, you grow up with that, your stove is always hot. The stove is what keeps the apartment warm.” (Another respondent:) “But then you have to do it yourself. And have to take care of yourself. So you can’t be having your whole . . . apartment warm.

Several similarities and differences in responses were identified in the women’s English- (WE) and Spanish-language (WS) groups. Women in both groups believed that medications for diabetes lead to medical problems (e.g., kidney or liver damage). Many identified God and prayer as a way to cope with diabetes, although one person perceived her diabetes as a punishment from God. Several women in the groups were also cancer survivors. Many agreed that their diabetes is “worse than cancer,” in that diabetes cannot be cured.

The WE and WS groups differed in their perceptions of how family influenced their cooking and food choices. The WE groups placed greater emphasis on family food preferences that competed with their dietary needs. In the WS groups, greater emphasis was placed on food preparation strategies to reduce fat and calories in traditional cooking. Use of alternative remedies was mentioned in the WE groups only, and the stories focused on remedies used a generation ago by other family members. Women in the

English groups expressed concerns about having limited access to media-advertised resources (such as diabetes medications sent by mail) because of their insurance status. These issues were not central concerns in the WS groups, who appeared to have less knowledge about diabetes and were more interested in general information.

Men’s groups, in contrast, largely focused on the accessibility of high-fat/calorie foods within their communities, the lack of access to healthy food, and their resistance to changing lifelong eating habits. They placed less emphasis than the women’s groups on their spiritual beliefs. The men also discussed medical comorbidities, such as surviving prostate cancer or having arthritis, heart problems, or extensive physical disabilities that required the use of a cane or wheelchair. Compared to men in the English-language groups (ME), men in the Spanish-language groups (MS) discussed having a partner closely monitor their food choices. As one man in the MS group stated, “When I am going to eat something sweet, she is watching me.”

Women and men in the Spanish groups communicated greater distress than English-speakers about offending people in social settings. They also had greater difficulty navigating these situations. While social pressures were also mentioned in the English groups, English-speakers appeared to have more strategies to manage these social settings.

Depression and loss

Although emphasis on the interconnectedness of stress, depression, and diabetes emerged primarily in the women’s groups, men also reported depressive symptoms related to living with diabetes. Women’s groups shared stories of loss, felt consumed by family problems, and expressed difficulties setting limits with family members who often relied on them for support and guidance. Some women wondered if diabetes caused their depression or whether depression caused their diabetes; there was a lack of consensus among the women. Several women mentioned personal and family histories of

depression before their diagnosis. Women also discussed overeating at times to manage their feelings. A small number of those in the WE groups reported receiving mental health treatment.

In contrast, when symptoms of depression were mentioned in the ME group, it was often in relation to feelings of loneliness and isolation. In addition, men preferred not to disclose their diagnosis of diabetes to others. This lack of disclosure contributed to difficulties managing social situations and affected significant relationships. One man in the MS group shared his reasons for not seeking diabetes care:

And when she was informed that I—that is to say I gave the news to her, ‘Look, they told me that I have diabetes.’ That woman shouted, ‘¡Ay! What happened? I will leave you right away if you have diabetes.’ I have mine [my diabetes] for many years. I love my wife very much. Perhaps that is the principal reason why I have an immense resistance in accepting that I have diabetes.

When comparing the exchanges between groups, women were more likely than men to tell others that they had diabetes. Women also reported greater symptoms of depression than men, with women in the Spanish groups reporting greater levels of untreated depressive symptoms than women in the English groups. Spanish-speaking men appeared to be less depressed, but they were also more likely to be married and had more support available than participants in the other groups.

Social support

All participants were asked questions about social support. Women generally reported not feeling supported by others. Their children were “too busy,” and they often had to attend medical appointments alone. They discussed being offered high-fat and high-calorie foods, despite having told their family they could not eat those foods. In the WE group, several women stated that family members thought they were

“inventing” their symptoms. As one woman stated:

... Encouragement? I don't get much . . . They don't want to because they think what we're asking is for pity. We don't need pity. We just only need somebody to be there for us when we don't feel good . . . According to our family, because I think all the Latinos feel the same way, they just think that [when] we say we have a headache or that we are—have a pain in our shoulder—we're inventing it . . . or because we want attention.

In contrast, men in the Spanish groups were more likely to report receiving support from their spouses. Men in the English groups reported not receiving support from others, but also stated they did not want it. One man felt his children's efforts to help were, at times, intrusive. When asked what type of support a person would need to stay in good diabetes control, an English-speaking participant responded, “I would need a girlfriend.”

Impaired sexual health

Although participants were not questioned about their sexual health, the theme emerged in four of the seven groups. Many women were distressed and expressed feelings of shame and embarrassment about changes in their bodies because of diabetes. Women attributed these changes to their use of medications for diabetes. Others were uncertain if problems with sexual health were a direct result of their diabetes. Women complained of vaginal dryness and decreased libido. A woman in the WS group discussed how this problem affected her marriage:

I divorced because of this problem. My husband did not want to accept that I was sick. I said, ‘Well, so, then let's get a divorce because I do not want what you want. I can't do anything. I can't please you—I can't satisfy you.’ That's how we stayed. . . we're friends. I'm almost 15 years alone. I have my daughters.

When asked how women felt about discussing this issue with

providers, responses differed. Spanish-speaking women stated that they were generally uncomfortable. In the WE group, some participants stated that they were more comfortable discussing the issue with female physicians. Others stated they were more likely to develop a friendship with a female physician and would prefer to speak with a male physician about sexual problems because the relationship would be more formal and distant.

Men primarily focused on problems with impotence. Some men reported that they had stopped engaging in sexual activity because of this issue, whereas others pursued multiple medical treatments to help manage the problem. According to participants, the interventions had limited or no success.

Vicarious learning and intergenerational experiences

Intergenerational issues also emerged as a theme in the groups, and knowing others with diabetes provided opportunities for learning. Many women reported extensive family histories of diabetes and viewed their experience as part of a larger legacy. As one woman stated, “I feel like my mother carried a cross, and now it is my turn to carry it.” Despite having family with diabetes, women reported limited knowledge of the disease until they developed it. Some hoped they could prevent their children from sharing a similar fate, but many believed their children were not interested in learning about diabetes. In one of the WS groups, diabetes prevention was viewed as unachievable, because diabetes was hereditary and, therefore, not preventable.

In contrast, men discussed diabetes differently. Based on their experiences and observations, they were more skeptical about recommendations on how to best manage the disease. The excerpt below describes one man's skepticism:

I had a friend of mine . . . My ‘boy’ [sic-friend] did everything by the book. He would sit down and [eat] lunch. I would sit down. I had my beer. [mimicking friend] ‘Abh L--, you and your damn beer.’ I said,

'Drink your water. Eat your salad. And shut up. Leave me alone.' . . . A year later, my 'boy' [sic] dies. I go to the funeral. I stood there by the casket, and I told him, 'Ya see? What did I tell you? You took too good care of yourself. Look at where you [are] right now. Dead!' . . . You can't take everything so seriously. That'll hurt you more than the illness.

Perceived sex differences in living with diabetes

Each group was asked to share their perspectives about similarities and differences between Hispanic/Latino men and women living with diabetes. The responses to this question varied. In the WE groups, women described two types of men. The first were single men with "machismo" (macho) who made efforts to stay healthy and not develop diabetes. They contrasted it with other men who required greater caretaking and would not be in good control of diabetes unless their spouses were caring for them. In the WS group, men were also described as "cobarde" (cowards); they perceived themselves as stronger than men and more capable of enduring pain.

Men did not perceive differences by sex in living with diabetes. In the ME groups, participants stated that diabetes did not discriminate by sex, and, therefore, no differences existed between men and women. Sex differences were not mentioned in the MS groups, but men reported that their spouses closely monitored their food intake.

The health care system

Although participants were not questioned directly about experiences with the health care system, many offered opinions. Both men and women expressed frustration in only learning about diabetes complications from providers after they developed a problem. Many felt discriminated against and believed physicians who shared the same race or cultural background as their patients provided better care to those patients than to patients of different backgrounds. Spanish-speaking men and women differed from English-speakers in that they were

more likely to report satisfaction with their care despite experiencing language barriers in communicating with providers.

In the WE groups, issues with the health care system included waiting hours to see a physician and difficulty in managing multiple appointments. Some experienced their providers as dismissive to their needs and concerns and were therefore uncertain whether to follow through on recommendations. In one of the WE groups, they shared experiences with physicians-in-training ("residents"). They questioned their ability to provide good medical care and were glad they were supervised. One participant stated, "He was so insecure . . . I don't feel like if he tells me something I could trust that." They also discussed the change in residents every 2 years stating, ". . . they treat you for a while, and they know you, and you get to know them. And when you talk to them, you feel like they're understanding you . . . Then somebody else comes, and it's like, 'Alright, here we go again.'" Another participant stated, "He just graduated and left me." For this participant, the separation was so difficult that she did not want to return to the clinic for care but eventually did. WE groups appeared to be less happy with their care than the WS groups. WS groups reported more positive experiences, although some complained of requesting interpreters and not getting them.

In the ME group, some complained of being treated by "students who don't know what they're doing." Others stated that physicians often prescribed medications without explaining what they were used for and believed that the health care system's need for revenue compromised the quality of patient care. As one man stated:

The atmosphere in the Bronx is . . . is that if you're Hispanic, and you're in pain, and you want a painkiller, you must be a drug addict. You know, everything seems to be that you may be involved with drugs if you're Hispanic and you live in the Bronx . . . They always treat

Hispanics, you know, Spanish and blacks, like they are different.

Similar to the WS group, the MS group reported greater satisfaction with their care, although many wanted to learn more about diabetes from their providers. A few did express some concerns about their care. For example, one man shared his bewilderment with other group members when he was diagnosed: "Why did this happen to me if the doctor told me that I was well?"

Discussion

This qualitative study provides a new perspective on important psychosocial issues in diabetes self-management for Hispanics/Latinos of Caribbean ancestry. Similar to previous research with Mexicans and Mexican-American populations, men and women in this study identified the following barriers to diabetes self-management: medical comorbidities, language barriers, socioeconomic/financial barriers, limited social support, and disabilities that limit physical activity.^{3,18,19,28,29} New emerging themes that are not as well documented but were discussed by participants include biopsychosocial perspectives about diabetes, intergenerational issues, perceptions of impaired sexual health due to diabetes, and perceptions of discrimination and discontinuity in health care. These results suggest that more research is needed to understand and design appropriate interventions that recognize the diversity of the Hispanic/Latino community.

Social-cognitive theory³⁰ and the socio-ecological model³¹ of health may provide some basis for understanding the results of this study. According to Bandura, "people are producers as well as products of social systems."³⁰ The interplay of these factors provides opportunities for growth and imposes barriers to that growth.³⁰ Socio-ecological models consider the interplay of five domains (individual, interpersonal, organizational, community, and public health) and their effect on individuals within their environment.³¹ For participants, these various domains shaped perspectives

about living with diabetes. In addition, the health care system and their experiences in it reciprocally influenced their motivation and thoughts about how to best manage their disease. Therefore, social-cognitive theory and socio-ecological models of health may help inform the development of interventions that not only focus on individuals, but also consider socio-cultural context.

From a public health standpoint, racial and ethnic disparities in health care are receiving greater attention. A report by the Institute of Medicine on health care disparities supports some of the observations made by participants in this study. The report discusses inequities in health care for ethnic minorities and shows that minorities are less likely to receive standard medical care and services compared to nonminority groups.³² The reasons for these disparities are multi-faceted but include differences in health-seeking behavior as well as the effect of unconscious stereotyping, biases, and prejudices on the part of providers.³² A qualitative study conducted in the South Bronx also found that patients did not trust their health care and experienced difficulties in communicating with providers.³³ To date, only one quantitative study has evaluated perceptions of discrimination in health care among patients with diabetes. Results from the discrimination study showed that patient-provider relationships strongly influenced these perceptions and that race and age discrimination significantly correlated with more reported diabetes symptoms.³⁴ In the present study, participants' perceptions of discrimination and discontinuity in health care resulted in reluctance to follow through on provider recommendations.

Identifying and treating depression within the Hispanic/Latino population has also received greater attention^{22,35} and emerged as a theme in this study. Women debated about the link between depression and diabetes. Depression is associated with hyperglycemia and an increase in diabetes complications, which include retinopathy, nephropathy, neuropathy, sexual dysfunction,

and macrovascular complications.³⁶ Previous research has shown that people with diabetes are more likely to report depression than the general population.³⁷ The prevalence of depressive symptoms in these groups may partly explain some of the difficulties men and women described related to their sexual health.

Although much has been written about male sexual functioning and diabetes, less is available about the sexual health of women with diabetes.³⁸ The issues for women are complex and require the evaluation of biopsychosocial factors.³⁸ In our study, women, without prompting, were willing to discuss these issues with other group members. When asked about their willingness to discuss these issues with providers, the results were mixed. Greater education on sexual health issues could help patients better manage problems related to self-image and relationships with partners.

Witnessing others experience diabetes complications provided opportunities for learning about the disease for study participants. It was viewed as part of a larger legacy and not preventable and fueled greater skepticism about following treatment recommendations. Such skepticism can pose challenges for diabetes educators and providers because patients and their families may not readily embrace the merits of making lifestyle changes to reduce their diabetes risk.

Conclusions

Based on the results of this qualitative study, diabetes educators, health care professionals, researchers, and other providers have a significant role to play at the individual, family, community, and public health level in educating Hispanic/Latinos of Caribbean ancestry about diabetes. Future research on psychosocial issues in diabetes self-management should consider differences across various Hispanic/Latino groups and design interventions that are socio-ecological in their approach and that integrate relevant social-learning paradigms geared toward fostering long-term behavior change.

This study has a limitation inherent to focus group methodol-

ogy, which is the relatively small sample size. Although participants were recruited from a randomized, controlled trial that compared phone versus print intervention, the intervention was focused on the screening behavior of having a dilated eye exam and was short term, and many participants had completed the study more than a year before the focus groups. A limitation to generalization of results is that participants in this study were mostly middle-aged, disabled, or retired. Therefore, it is unclear whether these issues are central to all Hispanics/Latinos with diabetes in Bronx, N.Y., or whether they are issues shared by other groups who use the same systems of care and who share similar socioeconomic and cultural characteristics.

Nevertheless, the current study supports differences across Hispanic/Latinos in the United States and speaks to the need to educate patients and their families about ways to adopt better self-care practices and confront individual and institutional barriers to change. Such efforts could help increase patients' self-efficacy and enable them to serve as positive role models for their families and communities.

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