“*Es como una bomba de tiempo* [It’s like a time bomb]”: A Qualitative Analysis of Perceptions of Diabetes Among First-Degree Relatives of Latino Patients With Diabetes

Erida Castro-Rivas, MD, MS, Carla Boutin-Foster, MD, MS, Maria Milan, MD, and Balavenkatesh Kanna, MD, PhD

Abstract

Background. The South Bronx, a largely Latino community, has become an epicenter of the diabetes epidemic in New York City. In this community, nondiabetic first-degree relatives of people with diabetes are prime targets for intervention. Therefore, the objective of this study was to explore the knowledge of diabetes and attitudes toward health behavior modification of Latino adults who are first-degree relatives of people with diabetes.

Methods. Participants were recruited from three settings in the South Bronx (a community-based organization, a faith-based organization, and a taxi station). The Common Sense Model was used to develop focus-group items. This model provides a framework for exploring illness representations along five domains: identity, cause, consequences, timeline, and perceptions of curability. Responses were transcribed verbatim, and data analysis proceeded in the following order: data immersion, assignment of codes, grouping of key concepts to form categories, and construction of higher-order themes.

Results. Of the 115 potential participants identified, 53 were found to be eligible, and 23 of these participated in the focus group. Of these, 20 were Dominicans, 2 were Puerto

Ricans, and 1 was Salvadorian. The mean age was 46.39 years, 35% were women, 61% were married, and 26% had less than a high school education. Qualitative analyses resulted in 547 codes that were grouped into 52 concepts, from which 9 categories and 4 overarching themes emerged. The dominant themes were 1) family, genetics, and culture play a major role in the etiology of diabetes; 2) being Latino and having a first-degree relative with diabetes makes getting diabetes inevitable, and, like a time bomb exploding, it is destined to happen; 3) once one develops diabetes, the physical and emotional consequences are devastating and destructive; and 4) diabetes can be “cured” through healthy eating and with insulin.

Conclusions. In this study, first-degree relatives of patients with diabetes were knowledgeable about the risks and consequences of diabetes. However, some participants felt that being Latino and having a first-degree relative with diabetes made one destined to have diabetes. Addressing this misperception through culturally tailored interventions has implications for diabetes prevention and may help to stem the diabetes epidemic in Latino communities.

Type 2 diabetes is a significant global public health problem that disproportionately affects the United States.¹ It is projected that, by 2030, 8.4% of the world’s population will develop diabetes.² The United States has already reached the global 2030

projection, with 8.3% (26 million) of the U.S. population living with diabetes. Unfortunately, of this group, an estimated 40% are unaware that they have the condition. In addition, ~ 79 million may have prediabetes.^{3,4} Diabetes is more common in

Address correspondence to Erida Castro-Rivas, MD, MS, Lincoln Medical and Mental Health Center, 234 East 149th St., Bronx, NY 10451

minority ethnic groups than in other populations.

The rate of obesity, coupled with a genetic risk, places Latinos at significant risk for developing diabetes.^{4–9} This is a concern given that Latinos are the fastest-growing population in many urban cities such as New York City, where many Latinos may go undiagnosed. In New York City, the prevalence of diabetes is ~9%. In communities with a large Latino population such as the South Bronx, the prevalence is twice as high (18%).^{10,11}

Lifestyle modifications focusing on dietary change and exercise may reduce the incidence of diabetes in this high-risk population.¹² Lifestyle changes are more effective than medication therapy in diabetes prevention.¹³ Preventing obesity also decreases the incidence of diabetes.¹⁴ However, lifestyle changes only occur to the extent that members of the at-risk population understand their own risk of developing diabetes and perceive a need for health behavior change.¹²

Genetic predisposition, coupled with unhealthy lifestyle behaviors in people with prediabetes, can lead to the accelerated development of the condition and progression to type 2 diabetes.¹⁵ Therefore, first-degree relatives of people with diabetes are at particularly higher risk of developing the disease.¹⁶

The accelerating rate of diabetes among the Latino population underscores the value of primary prevention. First-degree relatives are an optimal group on which to focus prevention efforts given their genetic predisposition and the sharing of potentially unhealthy habits through cultural norms. This article provides an ethnographic perspective on diabetes among adult Latinos who have first-degree relatives with diabetes but do not have diabetes themselves. The objective of this study was to explore the knowledge of diabetes and attitudes toward health behavior modification among these individuals.

Study Methods

This was a prospective study of Latino adults in the South Bronx neighborhood of New York City

from June to September 2012. Three different sites, including Lincoln Medical and Mental Health Center, a community-based livery cab company, and a community faith organization, were selected.

Participants were recruited using the purposive sampling method.¹⁷ Eligible participants were first-degree relatives of people with type 2 diabetes. Participants had to be > 20 years of age, speak either English or Spanish fluently, and be self-identified as Hispanic or Latino. Purposive samples were selected of participants who were best suited to provide a full description of the phenomenon being studied. Individuals previously diagnosed with diabetes (type 1 or type 2) and those with cognitive impairment that precluded their ability to provide consent were excluded.

The study design applied qualitative focus groups and quantitative surveys of participant characteristics. The study was approved by the local Institutional Review Board of Lincoln Medical and Mental Health Center. After informed consent was obtained, demographic characteristics were collected from all participants.

The focus group protocol was developed by the principal investigator (ECR) and the team of experts. Table 1 describes the questions used to guide the focus groups. The Common Sense Model of Kelly et al.¹⁸ was used to develop focus group items. This model provides a framework for exploring illness representations along five domains: identity, cause, consequences, timeline, and perceptions of curability. The purpose of the focus groups was to understand the perceptions of diabetes held by first-degree relatives of people with diabetes and to identify barriers to and facilitators of making lifestyle changes and suggestions for cultural resources for diabetes prevention.

The focus groups were offered in Spanish and English with a bilingual team and a moderator. Each focus group session was audiotaped. Each recorded session was transcribed from audiotapes by trained bilingual personnel.

Data analysis

Data analysis occurred in the following steps: data immersion, code creation, assignment of concepts to categories, and construction of themes.¹⁹ This was an iterative process that involved exploring new and evolving theory in the context of existing data until new findings emerge.²⁰

Participant responses were audiotaped and transcribed verbatim. In the data immersion step, all focus group transcripts were read line by line. The second step entailed assigning codes to all of the responses. Codes are descriptive labels or tags that represent key concepts being conveyed in the data. Codes can be actual responses or in vivo codes (select words from the transcripts or words that represent key concepts). The codes were then grouped into categories of information, and the categories were analyzed to identify the perceptions and knowledge of diabetes among first-degree relatives. Themes were then deduced from the categories of information.

To ensure trustworthiness of data, detailed notes of the coding process were maintained as field notes, all steps were conducted independently by a second reviewer for corroboration, and half of the interviews were reanalyzed to determine their fit into the categories. When there were discordant views regarding the interpretation of findings, the raw data were reviewed by a third corroborator, and new categories were derived until a consensus was reached.^{21,22}

Study Results

Of the 115 potential participants identified, 53 were found to be eligible, and 23 of those participated in the focus group. Of the 23 participants, 20 were Dominican, 2 were Puerto Rican, and 1 was Salvadorian. The mean age was 46.39 years (range 21–70 years), 35% were women, and 61% were married. Thirty percent reported having a level of education of grade 12 or a high school equivalency certificate (high school graduates), 22% had ≥ 4 years of college (college graduates), 17% had some college or technical school, and 26%

Table 1. Focus Group Questions

Topic	Question and Probes
Diabetes definition	When you hear the word diabetes, what do you think of? What does the word diabetes mean to you?
Etiology	What do you think causes diabetes? Why do some people get it or become diabetic? What are some health behaviors that lead to diabetes? What are some things that cause diabetes?
Prevention	How do you prevent diabetes? What can people do to decrease their chance of getting diabetes?
Consequences	When people become diabetic or get diabetes, what are some of the things that can happen? What happens with diabetes? How does diabetes affect your health?
Familial predisposition	As a relative of someone with diabetes, how does that affect your chances of getting diabetes? Do you think that you are at risk?
Prevention	What makes it easier for you to reduce your risk of getting diabetes? Knowledge or information Skills or family help/support
Prevention	What makes it hard or challenging for you to reduce your risk of getting diabetes? Knowledge or information Skills or family help/support
Culture	What can you tell me about being Latino and having diabetes? Family life: is there something different or special in terms of the culture or the family, i.e., home remedies, diet, special foods, etc.?
Intervention	If a program could be developed and was designed especially for Latinos to prevent diabetes, what would it look like? How would you teach people about diabetes? How could we help teach other Latinos about diabetes?
Intervention	What about using technology such as videotapes? What else would you like in a program? What about computers? Family members, incentives for participating, location?
Engagement	What are your recommendations for getting Latinos involved in such a community diabetes self-management program? How do we get people involved, such as at a community health clinic? Community involvement

had less than a high school education. More than half had lived in the United States for > 10 years. Seventeen percent reported having an annual income between \$40,000 and \$49,000, and 26% reported an income between \$20,000 and \$29,000. Two-thirds of the sample reported that they were employed; unemployed participants included homemakers, students, retirees, and disabled people. Table 2 presents participants' demographic data.

Participants' perceptions were derived from their experiences within their social network. One participant stated, "From personal experience, I know that it is a chronic disease; my parents are diabetics; it really has an influence on the high levels of blood sugar. A lot of symptoms are produced like urine incontinence."

Qualitative analyses resulted in 547 codes grouped into 52 concepts, which were allocated to 9 categories of information; 4 overarching themes

were then extracted from these 9 categories. The four dominant themes are described below.

1. Family, genetics, and culture play a major role in the etiology of diabetes.

Analysis of participants' opinions confirmed previously published data identifying the important roles of family history, genetics, and culture in the etiology of diabetes.^{23–25} Some participants were extremely knowledgeable and aware of their increased

**Table 2. Composition and Demography of the Groups
(*n* = 23; mean age 46.39 years [range 21–70 years])**

Characteristic	<i>n</i>	%
Spanish language	23	100
Sex		
Male	15	65
Female	8	35
Years in the United States		
< 1	0	0
1–5	3	13
> 5–10	8	35
> 10	12	52
Marital status		
Married	14	61
Divorced	4	17
Widowed	1	4
Separated	1	4
Never married	3	13
Part of an unmarried couple	0	0
Education		
Never attended school or only attended kindergarten	0	0
Grades 1–8 (elementary)	3	13
Grades 9–11 (some high school)	3	13
Grade 12 or high school equivalency certificate (high school graduate)	7	30
College, 1–3 years (some college or technical school)	4	17
College, ≥ 4 years (college graduate)	C	22
Refused	1	4
Employment status		
Employed for wages	4	17
Self-employed	10	43
Out of work for > 1 year	1	4
Out of work for < 1 year	1	4
Homemaker	1	4
Student	0	0
Retired	1	4
Unable to work	4	17
Unknown	1	4

continued on p. 54

risk for diabetes as a result of having a first-degree relative diagnosed with diabetes. Furthermore, some recognized the strong link between diabetes and family habits and culture and felt that a diagnosis of diabetes was imminent.

1.1 Etiology of diabetes

When asked about the etiology of diabetes, several participants expressed the opinion that diabetes is related to unhealthy behaviors (“bad diet and poor physical activity”), lack of insulin, obesity, and hereditary factors. The main factors associated with diabetes etiology were unhealthy diet and inadequate physical activity. One participant said, “Diabetes enters through the mouth, we are what we eat . . . Food is the main cause of diabetes. . . . It comes more from obesity and from eating junk food and stuff.” Another stated, “Lack of insulin in the body, insulin deficiency in the body . . . the lack of information . . . which is a bit . . . [uh] . . . limited . . . and that is why a lot of people do not take care of themselves and end up becoming diabetic.” Of note, many participants focused on dietary modification as a means of prevention, which was further highlighted when participants were directly queried about the prevention of diabetes.

1.2 Genetic/familial predisposition to diabetes

The discussion of genetic predisposition occurred in the context of describing the etiology of diabetes. Some participants knew that diabetes was related to familial risk, whereas others stated that it could not affect them through family because it is not “contagious,” which raised the issue of their understanding of risk. To highlight this, one respondent said, “It doesn’t directly affect the other person because it’s not contagious. Of course it is due to the eating habits that I have and a person close to me who learns those habits can get diabetes, but you don’t get it since it’s not contagious.”

There was also a sense of the inevitability of developing diabetes. Some said that diabetes is preventable, whereas others said it cannot be prevented because diabetes occurs in

**Table 2. Composition and Demography of the Groups
(*n* = 23; mean age 46.39 years [range 21–70 years]),
continued from p. 53**

Annual income		
< \$10,000	1	4
\$10,000–19,999	1	4
\$20,000–29,999	6	26
\$30,000–\$39,999	1	4
\$40,000–49,999	4	17
≥ \$50,000	3	13
Not sure/don't know	1	4
Refused	2	9
Not applicable	4	17

families regardless of your behavior. One participant said, “It is a disease of a genetic origin . . . of course it has an influence . . . sooner or later you end up with diabetes.”

1.3 Diabetes and Latino culture

Latino culture was also implicated as a causal factor of diabetes development. Some felt that their culture was almost inextricably linked to high-risk behaviors. One participant stated, “Latinos don’t know how to eat healthily; they do not have a healthy diet. . . . What could you offer to a Latino who is not a diabetic but is at risk for diabetes? . . . If you bring a kid some turkey . . . he would say no . . . or some healthy food and he refuses it If you bring healthy food home the kids would say to you, ‘Dad, what’s going on?’ . . .” “Sometimes for us it is difficult to eat an apple when there is sancocho stew with white rice and avocado . . . cultural customs, habits are difficult for us Latinos” Another individual quipped, “The Latino is often associated with liking to drink a lot, we celebrate with foods, every party is full of food, intoxicants, and all of this together causes diabetes. We keep eating until the party is over and this lifestyle together with cigarettes” Another commented that, “The big disadvantage is from the seasoning of foods, the type of foods rich in flour and in sugars”

Regarding cultural factors, one participant noted that, “Unlike other

cultures and communities, like white people, they take time for themselves They exercise and they eat healthily. But we Latinos . . . when I don’t eat rice . . . I haven’t eaten, when I don’t eat bread . . . I haven’t eaten.”

2. Being Latino and having a first-degree relative with diabetes makes getting diabetes inevitable. Like a time bomb exploding, it is destined to happen.

There was a sense of the inevitability of diabetes. One participant said, “Of course it has an influence . . . sooner or later you end up with diabetes.” One participant summarized the inevitability of diabetes onset among Latinos because of their culture and lifestyle as follows: “It’s a time bomb!”

Some respondents seem resigned to getting diabetes as a result of their first-degree relatives because, they said, Latinos have poor preventive and health care behaviors and do not seek adequate information about how to lower their risk for diabetes. An example of the sentiment of resignation was, “If you have the risk . . . you will get diabetes no matter what you do.”

2.1 Preventing diabetes

Participants pointed out that diabetes can be prevented by adopting a proper diet and regular exercise. However, they said they found it is hard to diet, especially because of cultural or traditional food habits,

but also because it is “tedious” to exercise. Preventive behaviors were also noted to be difficult because of competing priorities such as a busy work schedule, lack of money, and the need to attend to family.

However, some said prevention is possible through self-education and self-efficacy. Participants generally reported that, “Eating healthier and doing exercise is the only way to prevent or stop the risk you have.” One participant said, “If I am the child of two diabetic parents and I don’t watch what I eat or exercise, I have a very high possibility of becoming diabetic, more than my siblings who take care of themselves.”

The problem of lack of education was an important concept. One participant stated, “Uh . . . the lack of education is what comes to mind . . . particularly in my case . . . until they diagnosed my mom with diabetes, there was no interest in looking for information, knowing that she was at risk to be so. I only knew that it was sugar in the blood.” Another said, “We are not interested in informing ourselves and even less in prevention. What Latinos need is education about it.”

2.2 Environmentally interconnected

There was a note of blame in some of the responses. The general consensus was that diabetes is interconnected with several factors in the environment. Latinos have a high risk of diabetes as a result of their lifestyle, personal habits, ethnicity, food, and lack of exercise. Competing priorities were a common barrier for healthy behaviors. As one respondent said, “We eat on the run because we have to work for 12 hours to pay the rent, and we do not take care of ourselves with the excuse that there isn’t time to do it. . . . You have to work, and you have to support your family, even more so when you have a family, children . . . the priorities are work and money”

Participants stated that prevention is possible if nutritious food is available and community education could be provided. Said one, “I have noticed that in our neighborhoods they have put in a lot of fast-food restaurants right next to each other. I think that it would be very good

if there would be information and flyers around these areas, so people notice what is in the streets. And asking the public to cook more often at home.” Another opinion was expressed as follows: “Appeal to small businesses, since this can also help the economy, the production and creation of restaurants that are specifically dedicated to the production and to the cooking of healthy Latino foods”

3. Once one develops diabetes, the physical and emotional consequences are devastating and destructive.

Some participants described diabetes as causing physical damage to the kidneys that can be both serious and worrisome. One respondent emphasized, “It is an even worse disease than other chronic diseases such as AIDS

. . . . Being diabetic, it is a disease that damages all of your organs It is worse than mentioning another disease, like AIDS This is a chronic disease.” Another participant said, “When I hear the word diabetes, it is something very serious; it is a devastating disease to me.”

3.1 Definition of diabetes

When asked what the word “diabetes” means to them and what they think when they hear this word, participants described diabetes as a common, chronic, and “destructive” disease that is related to physiological dysfunction of blood glucose levels requiring medical treatment.

3.2 Consequences of a diabetes diagnosis

Participants described emotional, psychological, behavioral, and physical changes that occur as a consequence of having diabetes. They also noted that with diabetes comes a greater responsibility that requires both individual coping and family support. One participant said, “It is an extra responsibility that involves managing this disease It is necessary to take care of things religiously, and everything that you do and you eat can have an influence primarily on the control of the disease This causes a lot of depression. There is a serious need for help from family members in

order to deal with this disease . . . because they think that everything can be lost from one moment to the next.” Another comment about the physical and psychosocial changes that may occur as a consequence of diabetes was, “It changes a lot emotionally, the way of behaving, of thinking It is not easy to take so many medicines Worries increase Mood, weight, the worry that you can die easily if you do not take care of yourself”

4. Diabetes can be “cured” through healthy eating and with insulin.

The participants felt that diabetes could be cured and controlled when people take care of themselves or are “mentally prepared.” There was also the perception that a cure depended on individuals’ ability to care for themselves. One respondent said, “It is a common disease in people because there are a lot of people with diabetes. But if you take care of yourself with eating, you can get better and even be cured.” This concept of cure was a reoccurring theme in respondents’ definitions of diabetes.

In addition, there were other themes that did not fit into the four categories described above. These included:

A. Interventions to prevent diabetes

At the conclusion of the focus groups, participants provided their opinions on prevention and intervention strategies. Several participants felt that, in first-degree relatives of type 2 diabetes patients, diabetes can be prevented through educational interventions focusing on disease, lifestyle, diet, and exercise.

Educational interventions must be instructional and offer continuous guidance, some of them said. For example, “Doing follow-ups, having a steady person there at a given place in order to provide answers for people who need help. Because if they do not follow up with us Latinos, it is very difficult to do what is planned, more so for this preventive situation when we do not yet feel sick.” Interventions must be culturally and linguistically tailored, they said. “We need follow-up, so that the education reaches the person. The person conveying the information . . .

should have an ease in communicating [and be] understandable. Because if we do not understand what we are being told in our own language . . . I think that we are not going to come to this program. It should be understandable.” Participants also noted that programs need to be flexible and personal. One said, “A way of guaranteeing that Latinos attend is by choosing a good day for the activities, like a weekend when people are not at work, checking for a place that is accessible to everybody, flexible for the time and place” Participants suggested using different media and modes of communication such as video, audio, and print. All interventions must be community based, they said, such as “in Latino beauty salons, in Latino barbershops, in Latino places and clubs, and of course at the Latino taxi hubs.”

One participant suggested, “Making us understand that you learn to eat better not just to try to prevent diabetes, but also other diseases” Another suggestion was, “They should give us a form for a month . . . in order to know about everything that we need to do daily with regard to food and exercise . . . something in calendar form and then provide us with follow-up.” Another said, “It’s necessary to think about what we Latinos like and work on that point.”

B. Community engagement in diabetes prevention

Suggestions about strategies for community engagement were provided by the participants. According to the group, some of the barriers to diabetes prevention included access and time flexibility. They felt that community group activities and incentives would facilitate participation in diabetes prevention programs. Participants suggested “Encouraging these same participants to invite other participants, so that they share the information. Involving other places, other people who may or may not have diabetes . . . because we all have someone close to us with diabetes. Trying to mutually help one another” will help with community engagement. One participant suggested “going to places where there are people who are already orga-

nized, together, who share and invite leaders to create groups in order to move forward: schools, social clubs, universities, churches, and offering them a free educational program, the word spreads and the information sticks. It is easier than getting together independently. We need a spokesperson that motivates us, in each group for each organization.”

Several individuals also suggested that small incentives could attract people to programs, for example, “Incentives, food, free things . . . that attracts people like in the church when I ask what do you like about church, the answer is ‘that they give bread and coffee on Sundays.’”

Discussion

This qualitative evaluation in first-degree relatives of people with type 2 diabetes provides important insights on the identity, cause, consequences, timeline, and perception of curability of diabetes. These responses also provide avenues for developing strategies to address this expanding health problem. Four dominant themes emerged that provide a summation of how this cohort perceives diabetes.

First, the role of family, genetics, and culture was viewed as a major part of the etiology of diabetes. Some respondents acknowledged the role of culture in perpetuating unhealthy lifestyles. This has implications for prevention through education.

Second, participants described diabetes as being inevitable, like a ticking time bomb. This response may be a representation of the common fatalism in Latino and other racial and ethnic groups.^{26,27} Understanding how cultural beliefs influence behavior is an important consideration for future studies.

Participants were also aware of the potentially devastating impact of diabetes. They expressed a belief that, once a person develops diabetes, there are multiple serious physical and emotional consequences. This perception of diabetes as a destructive illness may evoke fear in some individuals without necessarily motivating change. Therefore, helping to place these fears or concerns in the proper perspective may help to alleviate

excessive fear and move individuals to change their behaviors. It is also important to create educational information that does not perpetuate this fear.

Providers should understand that these views of diabetes are not only culturally mediated, but also potentially passed through social networks. Social network influence was an important factor that helped to frame participants’ perception of diabetes. Tapping into the power of social networks as a resource has implications for encouraging change in communities. Social network experiences must also be framed properly, with the caveat that outcomes may not be the same for everyone.

There was also a belief in the “curability” of diabetes. Diabetes is a chronic condition and can be controlled to a point at which someone does not require medication, but that does not mean that it is cured. Health messages should emphasize the chronic nature of the disease and the importance of persistent self-management through diet and physical activity, even when blood glucose levels are within the target range.

And finally, these results point to many avenues for intervention such as involving community stakeholders and community engagement. Identifying culturally relevant media to deliver health messages is crucial. Participants suggested nontraditional venues such as schools, social clubs, and churches. Modifying and enhancing the physical environment and investigating the excess density of unhealthy options must be addressed.

There are limitations that may affect the generalizability of these findings, including the fact that participants were a relatively homogenous group of Latinos. The small sample size precludes analysis by source of referral (community organization, faith-based organization, or taxi cabs). However, these data provide important insights into the conceptualization of diabetes among participants who do not have diabetes but who are at high risk for developing it. These results can

be used to generate new hypotheses about disease prevention in the Latino population.

Acknowledgments

The authors thank Jennifer Melendez, Jessica Segni, Delvis Lopez, and Yury Lopez for their support and assistance in conducting this study. The study was supported by the Center for Excellence in Health Disparities Research and Community Engagement.

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Erida Castro-Rivas, MD, MS, is the lead clinical research coordinator; Balavenkatesh Kanna, MD, PhD, is the institutional review board chairman and associate graduate medical education director of research; and Maria Milan, MD, is a research assistant at the Lincoln Medical and Mental Health Center in Bronx, N.Y. Carla Boutin-Foster, MD, MS, is an associate professor of medicine in the Clinical Epidemiology and Evaluative Sciences Research Department at Weill Cornell Medical College in New York, N.Y.