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Knowledge, perceptions, and experiences of Dominicans with diabetes

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Abstract

Dominicans, one of the fastest growing Hispanic subgroups in New York City (NYC), have a high rate of diabetes. A qualitative study exploring Dominicans' knowledge, perceptions, and experiences in managing their diabetes was conducted. There were a total of 40 participants who were Spanish speaking Dominicans, 40 to 74 years of age, diagnosed with diabetes and NYC residents. Four focus groups were conducted in Spanish, which were recorded and then transcribed into English. Content analysis was used to analyze the text of the focus groups. Different themes emerged from the data, with apparent gaps in diabetes knowledge and of awareness of risk for diabetes complications.

Diabetes is a growing national public health concern, particularly for Hispanics¹. Of all United States (U.S.) Hispanics (45.5 million) in 2007, 4.7 million (10.4%) had diabetes². Furthermore, in 2006, diabetes was the seventh leading cause of death in the U.S.³, the fourth in New York City (NYC)⁴, and the fifth for Hispanics in the U.S.⁵. As noted by Aponte⁶ Hispanic subgroups are culturally diverse with different racial backgrounds, genetic compositions, and cultural and dietary customs, thereby making each subgroup unique. Although it is known that disparities in diabetes exist among Hispanic subgroups, clustering Hispanics as one homogeneous group, as is typically done by researchers, does not present an accurate picture of the differences among each unique Hispanic subgroup⁶.

Dominicans are the fourth largest Hispanic subgroup in the U.S., comprising 1.3 million (2.7%) of the total Hispanic population of 46.9 million⁷. The number of Dominicans in the U.S has risen. In 2000, the U.S. had 764,000 Dominicans (0.2% of the total population)⁸; by 2007, the number had risen to 1.2 million (0.3%)⁹ and by 2008 was 1.3 million (0.4%)⁷.

As the Center for Latin American, Caribbean & Latino Studies (CLACLS)¹⁰ (2011) reports, Dominicans are the second largest Hispanic subgroup residing in NYC, comprising 605,840 (25.3%) of the total NYC Hispanic population of 2.3 million. In NYC, from 2000 to 2007 there was approximately a 13% increase in the Dominican population¹¹. If the Dominican population continues to grow in NYC as it has, this Hispanic subgroup will become the largest in NYC by 2020¹⁰. The NYC Department of City Planning¹² reports that more Dominicans live in NYC than any other city in the world besides Santo Domingo, Dominican Republic (DR).

Diabetes & Dominicans

Although there is published information on diabetes in specific Hispanic subgroups, such as Mexican-Americans, there is a paucity of published research on Dominicans. In fact, a PUBMED database search of articles published from January 2000 to October 2009, using the keywords “*diabetes and Dominicans*,” was conducted and produced six results. Of the six studies, only two examined the rates of diabetes in Dominicans, with only one study being comprised of exclusively Dominicans. The findings in this 2008 study showed that 17% of NYC Dominicans had diabetes and another 20% were at risk for developing diabetes as a result of having impaired fasting glucose, more commonly known as prediabetes¹³. The second study assessed Puerto Rican and Dominican residents of Massachusetts. The findings in this study showed that the prevalence of diabetes in Dominicans was 2-to-3 times higher than for the general population¹⁴. Although both studies show that Dominicans are affected by diabetes, there is still a lack of research that contextualizes diabetes in this community, particularly related to diabetes self-management for this unique Hispanic subgroup.

Diabetes is a self-managed disease that relies heavily on behaviors and lifestyle changes, which makes it essential to examine diabetes management with a cultural lens. As studies have shown, cultural factors play an important role in influencing an individual's beliefs, attitudes, and behaviors¹⁵. Dominicans are one of the fastest growing Hispanic subgroup in NYC, yet there are no published articles on the self-management behaviors of Dominicans with diabetes. Hence, a need to explore the knowledge, perceptions and experiences of diabetes in this Hispanic subgroup is urgent.

Original Structured Questions

A study sponsored by the Florida Department of Health¹⁶ conducted six focus groups of Floridian Cuban, Puerto Rican, and Mexican people with diabetes to gain a better overall understanding of the knowledge and perceptions of diabetes among different Hispanic subgroups. Structured questions were developed in English and translated to Spanish for the focus groups and were pilot tested among Mexicans, Cubans, and Puerto Ricans to assure the validity of the questions among different Hispanic subgroups. The findings showed that no participants from any of the three Hispanic subgroups had difficulty understanding the questions.

The English and Spanish versions of these questions are available to the public. Only the Spanish version of the questionnaire was used in this current study. Since the participants in this current study were Dominicans and this questionnaire had not been previously pilot

tested with this Hispanic subgroup, the questionnaire was first pilot-tested for difficulties in the language, clarity and content of each question before being used for the focus groups.

Purpose

The purpose of this study was to gather and analyze qualitative data to provide a framework for future studies to develop strategies and interventions that are culturally-tailored for Dominicans with diabetes. A qualitative study that explores Dominicans' knowledge, perceptions, and experiences in managing their diabetes is an important first step to understanding the belief systems that drive their behavior.

METHODS

The qualitative approach used in this study is content analysis. Focus groups were used to gather insight and generate a better understanding of the cultural beliefs and experiences of NYC Dominicans with diabetes.

Participants—Forty NYC Dominicans with diabetes were recruited from the Inwood community, which has a large concentration of Dominicans. See Table 1 for the inclusion and exclusion criteria of the participants in the current study. Each individual participant received \$25 for compensation.

Recruitment—Convenience sampling was used to recruit participants. Recruitment flyers were posted throughout the Inwood community advertising a telephone number dedicated for recruitment. As interested participants left messages in the dedicated voicemail the research assistant (RA) or principal investigator (PI) called them back. A criteria sheet was used to ensure the interested participants were eligible to participate in the study. In addition, during this same telephone call the RA or PI briefly explained the purpose of the study.

The RA was a Hispanic bilingual (English/Spanish) speaking, undergraduate nursing student who was also able to speak, read and write in English and Spanish. The role of the RA was to be part of implementing the pilot testing of the questionnaires to the participants, and assist with the interviews and focus groups. The RA also screened interested participants, ensured eligibility, made appointments for those eligible to participate, and called each participant to remind them of their appointment. The RA then scheduled an appointment for the eligible participants to complete the questionnaire and participate in the interview on the same day. For the focus groups, the RA scheduled an appointment for eligible participants to attend either the English-speaking or Spanish-speaking focus group, depending on the patient's preferred language.

Prior to participating in the study consent forms were completed. Institutional Review Board (IRB) approval was obtained by the IRB of Hunter College, City University of New York (CUNY).

Setting—The study took place in a senior center located in the Inwood community. There was a private room in the senior center which was made available to the PI and RA in order

to conduct the study. The room was where participants completed the pilot testing of the questionnaires, the interviews took place, and where the focus groups were conducted. The space was comfortable and private, encouraging the participants to speak freely. Only the focus groups were audiotaped.

Data Collection

Original structured questions—Originally, for this current study, both versions of the questions were to be pilot tested (i.e., five English-speaking and five Spanish-speaking) but only Spanish speaking people interested and eligible to participate in the study responded to the recruitment flyer. Hence, only the Spanish version of the questionnaire was pilot tested by Dominicans for difficulties in the language, clarity and content of each question before being used for the focus groups.

Pilot testing of the structured questions—Ten eligible Dominican participants pilot tested the questionnaire and were interviewed. A separate set of questions asking about and focusing on difficulties encountered due to language, clarity and content of each question in the questionnaire was used for the interviews (see Table 2).

A total of 10 people pilot tested the questionnaire and completed the interviews. The first ten eligible participants who spoke Spanish were invited to participate in pilot testing the Spanish version of the questionnaire and to complete a Spanish speaking interview. Prior to participating in this part of the study, those who pilot tested the questionnaire completed a consent form.

Pilot testing: Not one of the 10 participants who pilot tested the questionnaire and completed the interview identified any difficulties in understanding the questions due to language, clarity or content. No modification of the original questionnaire was made and the original questions were used for the four focus groups.

Focus groups—A total of four focus groups were conducted in Spanish. Given that the interested and eligible participants who responded to the recruitment flyer were either only Spanish-speaking or preferred speaking in Spanish, the four focus groups were conducted in Spanish. Based on the findings of the pilot testing of the Spanish version of the questionnaire, a final version containing the structured questions was used in the focus groups (see Table 3). Each focus group consisted of 10 participants and lasted approximately 90 minutes. Prior to participating in this portion of the study all participants completed a consent form to participate in the focus group and another form granting permission to audiotape during the focus group.

Given that the RA was fluent in English and Spanish, they were present during the four Spanish speaking focus groups and took field notes. The PI, was a Hispanic nurse and certified diabetes educator (CDE), who is also able to speak, read and write in English and Spanish and experienced with focus groups, conducted and moderated the four focus groups.

DATA ANALYSIS

The text of the focus group conversations were analyzed using content analysis. Hsieh and Shannon define content analysis as “a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns.”¹⁷(p1278) Nvivo, a qualitative research software was used during content analysis.

Focus groups: A Hispanic, trained bilingual (English/Spanish) transcriber prepared the transcripts from each audiotape verbatim. The audiotapes of the Spanish focus groups were transcribed into Spanish in order to maintain the integrity of each participant’s responses. The Spanish transcript was then translated into English. The final version of each transcript was in English.

A qualitative content analysis was conducted on the focus group transcripts. Responses from the four focus groups were analyzed by the PI and RA. Each person was trained in using qualitative analysis techniques. Following content analysis, transcripts were read multiple times by each person independently and notes on the transcripts were made to denote significant issues from the focus group discussions. Responses were coded into recurring concepts, which then were sorted and grouped into categories of similar content. When each reviewer reached the point of data saturation when no new concepts emerged from the text of the focus groups, the identified categories were labeled and themes were identified. Once the themes were independently identified, the two reviewers collaborated to review discrepancies, and resolve differences by in-depth discussion, and to negotiate consensus of the themes. A master list of themes was created once a consensus was reached. Themes that emerged from the text of each focus group and the significance of the themes based on the participant exchanges were recorded.

FINDINGS AND DISCUSSION

Of the ten people who pilot tested the questionnaire and completed the interviews, five were women and five were men; ranging from the age of 64–71 years; and only one was literate. The remaining nine people had the consent forms and questions read to them either by the PI or RA.

From the four focus groups comprising a total of 40 people, 15 were women and 25 were men, the age range of those who participated was also between 64–71 years; three were taking insulin, 27 took oral medications and only one took both (i.e., insulin and oral medications); four were literate and 36 were illiterate. Only one person was able to report their glycated hemoglobin A1c, but none knew their blood pressure range or cholesterol (i.e., triglyceride and low-density lipoprotein [LDL]) levels. In order for people with diabetes to take part in their diabetes self-management plan and reduce their risk for diabetes complications (e.g., heart disease, stroke), the American Diabetes Association (ADA)¹⁸ emphasizes the importance for individuals to be knowledgeable about their A1c (measures blood glucose control over the past 3 months); blood pressure, and cholesterol, especially triglyceride and LDL levels.

Emerging categories

Diabetes knowledge and self-management

Diabetes care: Although the first question was a general question about “staying healthy”, all participants addressed it as “staying healthy when living with diabetes”. While all understood the importance of losing weight, eating healthier, exercising and taking their medications, most participants had difficulties in maintaining such behavior.

Reasons identified during the focus groups for not eating healthier or exercising more were, “...leaving my food”, “...leaving alcohol”, “...I get tired when I walk, so I don’t walk too much” and “I’m lazy”. Most of the participants believed that they needed to stop eating their favorite foods (e.g., rice) in order to become healthy. All participants except two stated that they consistently took their medications as prescribed. One participant stated, “... we have to try to maintain our diet and take our medications because we can live longer...”. Three out of the 40 people stated that diabetes has made them eat better, lose weight and take better care of themselves. Overall, the frequency with which the participants saw their primary care provider was between once a month to every four months.

No one identified barriers in their diabetes care, and all except one person stated they were able to purchase their medications or glucose strips, and make their co-payments. When discussing barriers that prevent others from getting diabetes treatment they identified lack of health insurance, lack of money, fear, ignorance of diabetes, and denial of having diabetes. They mentioned that initially fear, ignorance and denial of diabetes were some of their feelings and what prevented them from seeking medical treatment sooner.

Knowledge: When asked about the word “diabetes” and what it meant to them, all acknowledged “the need to eat properly, exercise and take the medications...”. However, most participants had a lack of understanding of diabetes, mentioning the reasons for developing diabetes as, “eating too much sugar”, “eating too much grease”, “...After arriving to the United States, you start to develop it”. The majority of the participants recognized there was a hereditary component to it since there had been a parent or sibling with diabetes.

Although most participants reported basic diabetes knowledge (e.g., what diabetes is), the analysis showed apparent gaps in their knowledge of diabetes, particularly related to how diabetes is acquired and cultural foods high in starch. There was a gap identified in the participants description as to the cause of diabetes and they associated their diabetes with fictional reasons. Many could not explain causes and risk factors of diabetes. There was also a lack of understanding related to portion control. The participants felt they needed to permanently eliminate their favorite foods (e.g., candy) from their diet to become healthy.

Although they mentioned the need to maintain their diet and eat foods low in starch, most participants talked about eating “yame”, plantains, and rice. Most knew rice was high in starch, some knew plantains were high in starch, but surprisingly all thought “yame,” a high-starch vegetable, was low in starch. Given that “yame”, plantains and rice are staple foods in the Dominican diet, the participants mentioned it was difficult to reduce the amount or frequency of eating such foods.

Fear: The participants knew that complications could develop in people with diabetes, but were unable to explain the relationship between uncontrolled glucose levels, obesity, uncontrolled blood pressure, hypercholesterimia and its effect in the development of diabetes complications. Each participant shared stories of a family member (e.g., parent, sibling) who has been negatively affected as a result of diabetes complications. “My brother died recently and they started amputating little by little”; “There’s no cure!”; “It completely affects your whole²² body, your organs begin to get damaged”, “my eyesight has gotten bad and that means I can’t eat the foods I want to eat”.

The participants identified a sense of fear related to diabetes. Their perception of factors that increased their risk of diabetes complications was evident. The fear of dying is most evident among those who have lost a family member with diabetes or know of someone whose death was diabetes-related. Some associated diabetes with feet problems and limb amputations, while others were concerned with losing their eyesight from diabetes.

Diabetes information

Resources: All participants stated that they receive diabetes information from their doctors, while some receive information from their insurance companies, pharmacy and friends. All indicated receiving information but were open to receiving additional information.

When asked about advice they would give a friend who was newly diagnosed with diabetes, all participants stated they would tell their friend to: “follow their doctor’s recommendations”, “take their medications”, “to not eat sugar”, “not eat greasy foods”, “to go on a diet”. The participants indicated there were three main things those diagnosed with diabetes should do: find a provider and follow their advice, take their medications and follow a diet.

Recommendation: When asked about methods to reach out to the community, the participants suggested: “invite a doctor to give lectures to the community”, “have talks within the community about diabetes”, “have community meetings”, “do things like having a walking group”, “have people of all ages with diabetes to talk about their experiences with diabetes and how they are managing”. All mentioned that the best way to reach out to the community is “word of mouth”, followed by flyers or announcements made in other events happening within the community.

According to the participants, providing educational lectures/seminars on diabetes would help many with diabetes understand how to better control their condition. They mentioned that optimal locations for the lectures/seminars would be local community centers or health clinics.

Before ending the focus groups, the PI provided education on what diabetes is and how it affects the body. The PI also educated the participants on diabetes complications, an explanation of what causes them to develop, how they develop, and methods to try to avoid them. The importance of maintaining a diet, losing weight and increasing exercise, and the relationship they have with diabetes was discussed. Given that many did not fully understand which cultural foods were high in starch, a review of their cultural foods and

healthy methods of preparing them were discussed. Also, the PI discussed the relationship starch has to blood glucose levels. The discussion on diet allowed for the participants to understand one of the primary goals of diabetes management is not to eliminate foods but to focus on portion control.

In closing, the participants made statements such as, “I learned how to take care of my diabetes better with being part of this discussion”, “I learned more about diabetes through this group”, “I plan to exercise more because I understand the importance of exercise with my diabetes”, and “I understand better about what to eat and what not to eat”. Overall, the participants stated that the focus group allowed them to share their stories and experiences while learning about diabetes. They mentioned learning from each other through the discussions and by hearing how others managed their diabetes. Although all participants mentioned they had support from family members and friends, they felt especially supported by each other, given that they all had diabetes and could understand each other’s struggles in managing the disease. In general, the participants stated the focus group was beneficial to them and were glad they participated.

Although this study was limited to those who are Spanish speaking Dominicans and residents of NYC, it provides valuable diabetes information on a population that has been understudied. Due to the limited understanding of the nutritional aspect of cultural foods related to diabetes, and the limited literacy among the participants, this study shows the need and importance of incorporating culturally tailored appropriate diabetes information (e.g., foods) in more audiovisual interactive way (e.g., videos, pictures) or face-to-face. Another major finding in this study was the gap in knowledge related to the Dominican population’s staple foods, such as, methods of preparing (e.g., baking instead of frying) and incorporating those foods in a healthier manner (e.g., portion control).

Overall, greater efforts by health care providers (HCPs) are needed in allowing their patients to discuss their perceptions and understanding of diabetes and of diabetes-management. This allows patients to discuss their cultural beliefs and enables HCPs and patients to work more collaboratively in identifying effective diabetes treatment strategies and address issues that potentially influence patients’ motivation in behavior change.

CONCLUSION

This is the first study to assess Dominicans’ perceptions and beliefs about diabetes. For Dominicans who participated in this study, there was a knowledge gap in the following areas, their understanding of: 1) diabetes prevention, 2) reasons and ways one develops diabetes, 3) an understanding of the physiological short and long-term impact of not maintaining healthier lifestyles and what this means. Based on the findings of this study, the participants indicated fear of having diabetes which in turn was a barrier, keeping them from seeking health care services. Hence, further community outreach activities in Dominican communities are needed to provide diabetes awareness on the importance for seeking early and prompt health care services. In addition, awareness is greatly needed on the long-term effects (e.g., diabetes complications) of not receiving diabetes care in a timely fashion.

Based on a meta-analysis by Caban and Walker¹⁹ conducted on US based studies, there was a lack of clarity on the differences and similarities which exist among different Hispanic subgroups (e.g., Mexicans, Guatemalans, Puerto Ricans and Cubans) with diabetes. They as well as Weller, et al²⁰ indicated that differences in educational attainment, acculturation, regional differences, differences due to lack of access to medical care, and limitations in research study design may account for some of the variability in diabetes outcomes across studies among different Hispanic subgroups. In addition, although the study sponsored by the Florida Department of Health¹⁶ conducted two focus groups on each Hispanic ethnic group (i.e., Floridian Cubans, Puerto Ricans and Mexicans) the study findings were reported on “Hispanics” not based on the specific unique Hispanic subgroup. Given the lack of clarity and understanding of the differences or similarities in the cultural beliefs and health practices that may exist among Hispanic subgroups, distinctions among subgroups should be made and further studied.

Moreover, as a growing subgroup, Dominicans should be included in those studies. These data are needed in order to develop tailored interventions to promote health-promoting behaviors among Hispanics with and at risk for diabetes.

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Table 1

Sample Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
a. Have diabetes	a. Is participating in another study
b. NYC residents	b. Women who are pregnant
c. Country of origin is the Dominican Republic	c. Diagnosed with a cognitive

Table 2

Sample of questions used for pilot testing

Introduction Question (Q.1)		
Q.1A. Did you understand all of the words in the question?	Yes	No (<i>please circle</i>)
<i>If yes, SKIP to next question.</i>		
If no, what word(s) were not understood? _____		
Q.1B. Did you understand the overall question?	Yes	No (<i>please circle</i>)
<i>If yes, SKIP to next question.</i>		
If no, give an example(s) that may help other people understand this question. _____		
Q.1C. Was the question clear?	Yes	No (<i>please circle</i>)
<i>If yes, SKIP to next question.</i>		
If no, what in the question was not clear? _____		
Q.1D. What do you think this question is asking?		
Q.1E. Did any of the words make you feel uncomfortable?	Yes	No (<i>please circle</i>)
If yes, which words? _____		
<i>If no, SKIP to next question.</i>		

Table 3

Focus Group Questions

Introduction Question	What do you do to stay healthy?
Transition Question	When I say diabetes, what is the first thing that comes to your mind?
Probe Questions	What is diabetes? What does diabetes mean to you?
Key Questions	In your opinion what causes diabetes? How does a person get diabetes?
Key Questions	How does a person know if they have diabetes?
Probe Questions	How did you learn you had diabetes? How did you react? What about your family?
Key Questions	What things can you do to control your diabetes? How do you treat your diabetes?
Probe Questions	How is diabetes treated? What are ways to treat diabetes? What else can you do? What does your doctor say you do?
Key Questions	What is the purpose of these treatments (mention the treatments participants talked about? How do they help your diabetes? What are the benefits of these treatments?
Probe Questions	What things do you not do that you know you should? What keeps you from doing them? Of the things you do what is the hardest to do and how is it harder? Of the things you do what is the easiest to do and how is it easier?
Key Questions	How important is the treatment of your diabetes to you? Why?
Key Questions	What makes it difficult to follow your diabetes treatment? What helps you maintain your treatment regimen? Who helps you?
Probe Questions	Social support system. Monies to purchase medications. Equipment (i.e. glucometer, strips).
Key Questions	How has diabetes affected your life?
Probe Questions	Are there any positive things that have occurred, indirectly as a result of having diabetes? Improved overall health? Better diet? Weight loss? Better relationship with your doctor? Improved family relationships?
Key Questions	How often do you go to the doctor for your diabetes? When do you go to the doctor for your diabetes?
Probe Questions	Do you go for regular check-ups?
Key Questions	What do you think prevents people from getting treatment for diabetes?
Key Questions	Where do you go for information about diabetes?
Key Questions	Whom do you trust most to give you advice about your diabetes treatment? Why?
Key Questions	Imagine you had a friend who just was diagnosed with diabetes. What advice would you give them?
Key Questions	Imagine you were part of a committee for your community to help those individuals with diabetes manage and treat their diabetes, what would you do?
Probe Questions	Who would you reach out to in your community? How would you reach your community members? How would you convince them to be active in their diabetes treatment?
Closing Question	When you think back to all the things discussed today, what do you feel were the most important for you?