



Perspectives of Non-Hispanic Black and Latino Patients in Boston's Urban Community Health Centers on their Experiences with Diabetes and Hypertension

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BACKGROUND: Racial/ethnic disparities exist in the prevalence and outcomes of diabetes and hypertension in the U.S. A better understanding of the health beliefs and experiences of non-Hispanic Blacks and Latinos with these diseases could help to improve their care outcomes.

METHODS: We conducted eight focus groups stratified by participants' race/ethnicity, with 34 non-Hispanic Blacks and Latinos receiving care for diabetes and/or hypertension in one of 7 community health centers in Boston. Focus groups were designed to determine participants' levels of understanding about their chronic illness, assess their barriers to the management of their illness, and inquire about interventions they considered may help achieve better health outcomes.

RESULTS: Among both groups of participants, nutrition (traditional diets), genetics and environmental stress (e.g. neighborhood crime and poor conditions) were described as primary contributors to diabetes and hypertension. Unhealthy diets were reported as being a major barrier to disease management. Participants also believed that they would benefit from attending groups on management and education for their conditions that include creative ways to adopt healthy foods that complement their ethnic diets, exercise opportunities, and advice on how to prevent disease manifestation among family members.

CONCLUSIONS: Interactive discussion groups focused on lifestyle modification and disease management should be created for patients to learn more about their diseases. Future research evaluating the effectiveness of interactive diabetes and hypertension groups that apply patient racial/ethnic traditions should be considered.

KEY WORDS: diabetes; hypertension; Blacks ; Latinos; racial disparities.

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INTRODUCTION

Numerous studies have documented that non-Hispanic Blacks and Latinos are disproportionately affected by diabetes and hypertension when compared to the non-Hispanic Whites, even after adjustment for socioeconomic status¹⁻⁶. Despite this data, relatively little is known about experiences in management of diabetes and hypertension among these populations, particularly among patients receiving care in low-income communities⁷.

A few studies have reported that minorities feel less equipped to self-manage their disease^{2,3,7}. Oster et al.⁸ examined the differences in self-management behaviors by race and ethnicity and concluded that more research is needed to better understand why minority patients with diabetes are less likely to use preventive services, engage in adequate self-management behaviors, and revealed the need for further research to determine what types of patient and provider interventions can help to enhance the care and preventive services for patients with diabetes and hypertension. More research is also needed to better evaluate the psychosocial issues involved in diabetes self-management, helping to ensure that interventions are tailored to foster long-term behavioral changes⁷.

Due to the documented disparities in clinical outcomes, there have been several ongoing initiatives with a goal of reducing the gaps in rates of chronic disease prevalence between racial/ethnic groups¹. Given that some authors have suggested that prevention and intervention strategies need to be developed that include input from the affected populations, particularly those receiving care in low income communities⁹⁻¹¹, a much broader understanding of the contribution of cultural and environmental differences in patient-based barriers to the adoption of chronic disease self-management principles is required.

To better understand the experiences, knowledge, and needs non-Hispanic Black and Latino patients with diabetes and hypertension receiving care in low-income communities, we conducted eight focus groups at seven urban community health centers in the city of Boston. The goal of this study was to determine the unmet, modifiable needs of these populations in order to enhance their diabetes and hypertension self-management skills and quality of life and to solicit participants' impressions of interventions they considered may help

achieve better health outcomes. The study adds to the body of literature with a deeper investigation about how and what low income African American and Latino participants feel is missing in the care of their diabetes and hypertension to help frame interventions specific to expressed participants' needs.

METHODS

Overview

Between October 2007 and April 2008, we conducted eight focus groups of non-Hispanic Black and Latino patients with diabetes and/or hypertension. All participants reported being from one of seven community health centers (CHCs) located in Boston neighborhoods with large proportions of these ethnic groups (Roxbury, Jamaica Plain, Dorchester, and Mattapan). All activities for the focus groups were discussed and approved by the study's Community Advisory Board (CAB), which consisted of health center providers, community residents, academic researchers, and a partnering community based organization. In addition to developing study aims, the CAB came to agreement on three key methodological issues: (1) to conduct focus groups as opposed to directed interviews to facilitate collecting data in a timely manner and allow for cross-pollination in ideas that would not necessarily be articulated on one-on-one interviews, (2) that each focus group should be conducted within a neutral community based setting geographically located between health centers in each of the four neighborhoods, and (3) that given the relatively low proportion of fluent English-speaking Latinos receiving care in participating CHCs, all Latino focus groups would be conducted in Spanish only to assure appropriate discussion among participants. The study protocol was approved by the Human Subjects Committees of the Harvard Medical School and Partners HealthCare.

Patient Recruitment

Two members of the research team (1 Non-Hispanic Black male; 1 Latina) conducted the recruitment at the seven community health centers (CHCs). The recruiters met with a designated "champion" selected by each health center director to work as a liaison with the study. Flyers were developed in both English and Spanish and were placed in agreed-upon locations in each participating health center.

Site recruiters utilized various methods to optimize participant recruitment at the respective CHCs, such as setting up tables in the health center's lobby area, attending existing health center patient groups, and meeting directly with diabetic case managers and health care providers. During on-site recruitment, 94 patients approached study staff about the project, from these, 78 patients agreed to participate and were scheduled for a follow-up telephone call to further explain the study and to schedule participation in the focus group. Each potential participant received at least two telephone calls for screening into the study, to find out the best time of the day for them to attend a group. Participants were eligible to take part in the focus groups if they had diabetes, hypertension or both. Additional eligibility requirements included that participants had to be receiving health care services from one of the seven participating health centers, and was least 18 years of age.

Participants who required transportation to and from the sessions were provided with taxi vouchers. Focus group sessions were held in non-CHC community sites in each of the four neighborhoods in Boston.

Focus Group Sessions

Eight separate focus groups were held: four groups in English with non-Hispanic Blacks patients and four groups in Spanish with Latino patients. All project documents were available in English and Spanish. Each focus group session varied between 1½ to 2 hours in duration and included between 3–8 participants. Each focus group had both a facilitator (English or Spanish-speaking) and one observer (English or Spanish-speaking) who subsequently reviewed notes from each group transcripts to assure they were complete. Before starting each focus group session, facilitators introduced themselves and reviewed the IRB approved study consent forms with participants to address any questions or concerns.

For each group, facilitators reviewed the ground rules and reminded participants that the session would be tape-recorded. Utilizing an approved structured focus group questionnaire, facilitators asked participants general questions about diabetes and hypertension that addressed their knowledge of the etiology of these conditions and their experiences with the management of diabetes and/or hypertension. They were also asked about their experiences with care at their community health center; whether resources for their diabetes and hypertension existed in their community, and what forms of support they would they need to better manage their condition(s).

Focus Group Moderators

Four English-speaking focus groups were facilitated by an experienced non-Hispanic Black facilitator from the Center for Community Health Education Research and Service (CCHERS) which was our community-based partner in the project. The four focus groups for Latino participants were conducted by paid consultants from the Latino Health Institute (LHI), a community-based organization in Boston that has a history of conducting focus groups utilizing expert Spanish-speaking facilitators and transcribing Spanish language transcripts.

Qualitative Analyses

After each participant was consented, responses were audio taped during the focus groups to assure accuracy of analysis. Focus groups conducted in Spanish were transcribed in Spanish via the LHI staff and the English-speaking groups were transcribed in English by a contracted transcriber that was not connected to the project.

We conducted a simple thematic analysis of data obtained from each focus group. The transcripts were analyzed using the qualitative analytical software NVivo 7 (QSR International). Spanish-speaking transcripts were analyzed in the original language. The participant responses were placed into categories, or nodes, of participant's experiences, knowledge, and management of diabetes and/or hypertension that stemmed from the questionnaire. The number of such coded references at the node and the coverage, or percentage of each focus

group transcript, that covers a node topic was obtained with NVivo. After an initial sample of English-to-Spanish and Spanish-to-English language translations of study promotional materials and research-related reports done by our Spanish-speaking observer were reviewed by an independent translator affiliated with the Harvard Medical School to assure accuracy of her translations, Spanish-language transcripts were translated into English by the Spanish-speaking observer. Themes only emerged when coded transcript data and quotations from both groups referred to the same concept. This resulted in having three themes that encompassed all those topics that emerged from participant responses. Afterwards, representative quotes in the topics and themes were selected (and translated into English if they were originally in Spanish) to correspond and convey the theme.

RESULTS

Participant Characteristics

Of the 78 eligible patients who agreed to a follow-up phone call, we successfully recruited 34 patients who attended their scheduled focus groups. The 34 participating patients were similar to those that consented but did not show among Latinos; however, participating non-Hispanic Black men were significantly underrepresented compared those who did not show (12% of non-Hispanic Black participants were men compared to 24% of non-Hispanic Blacks who consented but did not show). Overall, 85% of participants were female. The mean age was 58 years (range 42 to 90 years). Among Latinos, 32% had hypertension, 45% had diabetes, and 23% had both. Among non-Hispanic Blacks, 47% had hypertension, 26% had diabetes, and 26% had both. Table 1 provides a detailed description of the focus group participants by race and ethnicity, gender, and neighborhood.

Comprehension of Conditions and Prevention

Participants in each of the eight English and Spanish speaking focus groups discussed their perceptions of the causes, their knowledge, and preconceptions of diabetes and hypertension. Participants mentioned that they did not fully understand their disease etiology and progression. One non-Hispanic Black participant stated the following about diabetes: "I kind of think it's a disease like hypertension just over blown...It's just kind of the result of hypertension that has just gotten worse to a higher point." Furthermore, a Spanish-speaking

Latina stated that, "In reality, we don't have all the information that Latinos need to know in order to avoid the disease."

Spanish-speaking participants often asked for clarification of the term "hypertension" and whether the term had the same meaning as "high blood pressure." Participants suggested that they would benefit from clarifications of the type of diabetes they have, what hypertension and diabetes actually are, what they affect, and the expected long-term effects. Groups of both race/ethnic backgrounds suggested that receiving more education and preventive information about these chronic diseases would be beneficial and non-Hispanic Black participants concurred that the medical community could better explain the pathology behind disease. Similar responses were made by both groups and are presented in Table 2.

Symptoms of diabetes were referenced 28 times among the eight focus groups. Participants reported difficulty distinguishing between symptoms of having high or low blood pressure or high or low blood glucose, respectively. One participant shared that, "The other day I had [symptoms including] shaking, sweating, all nervous and thought that I had it high because I suffer from high [blood pressure] but when I checked I had it low... So one never knows exactly when it is high and when it is low."

Factors Affecting Health Conditions and Daily Management

Participants said that several factors play a role in the care and daily life of a person with diabetes and/or hypertension. For example, stress was commonly mentioned in both groups as a factor affecting a person living with diabetes and/or hypertension. Stressors mentioned included family and financial issues, which sometimes included difficulties paying for medications. Participants in three of four English and three of four Spanish speaking focus groups discussed payment and/or insurance issues as a stressor and problems obtaining medications were also referenced more often in Latino groups compared to non-Hispanic Blacks (23 and 5 references, respectively).

Living environments were discussed as a factor affecting health by participants in three of four English and all four Spanish speaking focus groups. For example, a non-Hispanic Black female commented, "... we can't let it [stress] bother you like that because that will bring up your blood pressure just sitting and worrying about every little thing... I got a couple of my grandkids to raise and the first year I was always screaming and hollering at them, raising my blood pressure. A Spanish-speaking Latina commented that, "I don't know if it is that there is a lot of stress [in this country], that one gets a lot of things like diabetes, which I have noticed that in my home country are much better."

Participants in one Spanish-speaking group mentioned that in their experience, depression was common after being diagnosed with diabetes. They mentioned that depression may have been due to several factors and may have arisen once participants needed to manage their condition. As an example, one Latina participant who dealt with depression shared that she ended up with problems with her medical insurance. Furthermore, participants expressed that such experiences can lead to becoming fearful of the consequences of unmanaged diabetes and/or hypertension. One Latina patient recounted

Table 1. Focus Group Participants' Characteristics by Race/Ethnicity

Characteristics	Non-Hispanic Black (N=16)	Hispanic (N=18)	Total N
Sex N (%)			
Male	2 (40)	3 (60)	5
Female	14 (48)	15 (52)	29
Massachusetts Neighborhood N (%)			
Roxbury	6 (67)	3 (33)	9
Dorchester	6 (67)	3 (33)	9
Mattapan	4 (100)	0 (0)	4
Jamaica Plain	0 (0)	12 (100)	12

Table 2. Summary of Non-Hispanic Blacks and Latino Participants with Diabetes and/or Hypertension Regarding the Understanding of Their Health Conditions

Dimensions of Experiences with Diabetes and Hypertension	Views of both Non-Hispanic Black and Latino Participants
I. Prevention and understanding of conditions:	
Perceptions	Initial thoughts from both groups about the word “hypertension” were suggestive of their observations that hypertension may be hereditary and is not always related to weight
Experience and existing knowledge	Both groups mentioned having other relatives with these conditions
Perception of prevalence	Both groups perceive diabetes as being very common and as presenting itself over time
Perception of cause	Both groups commonly attributed food, genetics and stress as being causes. They also mentioned traditional diets as being related and as contributors
Symptoms	Both groups viewed hypertension as not often having symptoms, yet some included double vision, headaches, and fatigue. Common diabetes symptoms thought to be thirst, blurry vision, and frequent urination
Perception of health center care	They liked the care they received at the health centers and would have liked to have had care focused on prevention of diabetes and hypertension
II. Factors affecting health condition and lifestyle:	
Ethnicity	Major barriers in management of care included the custom of eating unhealthy food common in their community
Stress	A strong factor that affects their condition and lifestyle
Depression	Affects the ability to manage their conditions
Environment	There are no [external] barriers. An [internal] barrier often mentioned was that the person him/herself might be a hindrance to improving their health since they struggle to sustain health maintenance changes. Environmental stress due to safety, crime and poor conditions of neighborhoods. The fast pace of daily life also negatively affect their health
Race & language	Not a barrier for care in their health centers. There are bilingual services
Management Methods	Taking medication, eating healthy, exercise and drinking water often
Medication & Insurance	Majority had no problems receiving or paying for prescriptions
Resources & Services	Community health centers (nutritionists, podiatrists, mental health counseling, and some dental services), gym or and local pharmacies are available
III. Diet and Exercise	
Diet	Attempts in changing diets to manage conditions was a major challenge
Exercise	A major challenge for participants

some experiences of her mother dying from complications of diabetes: “Sometimes I get like that [depressed]...but I have blamed it on the death of my mother...seeing how my mother suffered and I do not want to go through that.”

Diet and Exercise

Participants in three of four English and all four Spanish speaking focus groups revealed that attempting to change their diet in order to manage their condition was a major challenge. They suggested that the difficulty in changing was due to being accustomed to eating traditional foods that may not always be healthy. For example, a non-Hispanic Black woman shared that “[by eating] the same old stuff, potato salad, sweet potatoes, baked macaroni and cheese, you’re going to gain [weight].” Similarly, a female non-Hispanic Black participant stated that unhealthy food remains part of their diet meaning foods that are recommended by nutritionists-“we just keep it the same way all the time instead of trying this stuff.” A Spanish-speaking Latina mentioned, “In general, among us Latinos [hypertension and diabetes are] very common because... foods that we eat since we are young helps us [acquire these diseases]. Plus we are dragging it in our family.”

The majority of participants agreed that they have consulted with nutritionists or dieticians generally available at their health centers. When questioned about how Boston’s environ-

ment affected or interfered with the management of hypertension or diabetes, many non-Hispanic Black participants mentioned that they cannot buy the healthier foods suggested to them by nutritionists at an affordable price: “The healthier foods, the foods that are supposed to give you the longevity and extend your life are in places [stores] that you can’t afford.”

Exercise was discussed as a challenge for participants in three of four English-and two of four Spanish-speaking focus groups. One Latina participant in particular mentioned, “We don’t really like to exercise,” and several other participants in that focus group concurred.

Participant Recommendations

Recommendations for health care centers were provided by participants in three of the four focus groups for both English-speaking and Spanish-speaking participants. Participants suggested that they would benefit as patients if their community health center began to hold interactive discussion groups in order to learn about their disease and the management of their condition with and from other patients and believed that it may be beneficial to have ongoing groups for management education and support for their conditions. Participants from both groups suggested that the researchers in this study and the participating health centers can help by giving education and increasing awareness about diabetes and hypertension. They recommended holding meetings or groups to give more

information about these conditions and making more pamphlets or other literature available to them in their language.

Participants suggested that they would like more opportunities to exercise and said they may benefit from exercise groups as well. One Spanish-speaking Latina participant said her ideal place would be:

a center where the people, the diabetics, can go to share ideas, have a place to do exercise, a place where one, perhaps, could buy foods that are healthy. All that in the same center.

Additional suggestions included that health centers provide transportation assistance, such as vans or cab vouchers. One Spanish-speaking focus group participant mentioned that her clinic occasionally provided transportation, but other participants in that group were not aware of such a service. Participants in a non-Hispanic Black group mentioned that the transportation provided by Medicare/Medicaid takes several hours to arrive and is therefore not very helpful. A participant in this same group said, "I would love for them to have vouchers but sometimes I don't even want to bother them."

DISCUSSION

This study addresses limitations of the current literature by providing deeper investigation about how and what low income African American and Latino participants feel is missing in the care of their diabetes and hypertension to help frame interventions specific to expressed participants' needs. Results of these focus groups established overlying themes that are common among the experiences of non-Hispanic Black and Latino participants. We found 1) gaps in participants' knowledge and understanding of the nature of diabetes and hypertension; 2) that stress was a factor that strongly affected the condition, self management, and lifestyle of participants; 3) participants were challenged by a need to change their traditional eating and exercise habits; 4) that many participants reported they could not buy the healthier foods suggested to them by nutritionists at an affordable price; 5) exercise was a challenging factor, especially for participants in the Latino groups; and 6) participants suggested that implementing group education and exercise classes and assisting with transportation to their health center may be helpful strategies to improve care and outcomes from their disease.

Our findings on the role nutrition and exercise play in patients' experience with disease are supported by existing literature^{7,10,12,14}. For example, Hatcher et al. reviewed¹⁵ research reports on Hispanic adults' beliefs and found that many Hispanics reported having difficulty following prescribed diets within their traditional diets and that the high cost of health foods was a barrier¹². Burns et al. conducted interviews with diabetic study participants and found that an effort to eat right was a daily challenge and that the cost and availability of desired foods hindered appropriate self-management.⁷ Cost is not only higher for healthier foods, but frequently healthier foods are absent from grocery stores in lower socioeconomic neighborhoods^{7,9,13,17}. Among our study population, one major barrier expressed by participants was difficulty breaking

the habit of eating unhealthy foods that are commonly found within their community and in traditional ethnic foods. Similarly, other studies have demonstrated that many individuals in the Latino population do not embrace the idea of exercise^{7,12}. For example, one study found that for some Latinos, the amount and intensity of needed exercise varied with some believing that housework was sufficient exercise.¹²

The origins of stress that were highlighted in our focus group discussions were often cited to be due to the environment, specifically neighborhood safety, crime and poor conditions in the neighborhoods, as well as the fast pace of daily lives⁹. Depression was also a reoccurring theme that affected the ability of patients to manage their conditions^{7,9-11,16}. Our findings suggest, however, that under-treated depression complicates patients' ability to self-manage their disease although no formal diagnoses of depression was verified by a medical provider.

Our focus group participants identified several possible areas and recommendations for interventions. First, participants suggested improving physician counseling regarding the mechanisms behind these chronic diseases including recommending care that focuses on preventing diabetes and hypertension. Participants suggested this could be accomplished by being provided with varied pamphlets or other literature in their language and having longer physician visits or through the creation of interactive discussion groups in order to learn about their disease. Additionally, participants suggested establishing interactive discussion groups for community members with diabetes and hypertension focused on lifestyle modification to prevent complications from these diseases. Such groups would be composed of patients with similar illnesses to listen and share information. Important topics of discussion would include clarification of the type of diabetes they have, explanations of what diabetes and hypertension actually are, what they affect, the long-term effects that may be expected (etiology, prognosis, and progression), and management techniques^{7,8}.

There are several potential limitations of our study. Although focus group research is a valuable and effective method for exploring health-related needs and perceptions of the health care system, they may include a self-selected group of individuals who are more articulate about the opinions than non-participants, may limit the discussion from participants who are concerned about disclosure of sensitive information to the remainder of the group, and/or may include participants who have had more extremely negative or positive experiences than the norm, potentially leading to biased results. For example, in a prior study utilizing site visits to each of the participating health centers we found that each center attempted to have language concordant materials about diabetes available¹⁸, however participants in our groups stated this type of material is often not given to them. This finding may signal that the presence of language concordant educational materials isn't sufficient alone in communicating health information, or instead, participants in our focus groups may have been disproportionately unaware of services available within their center compared to non-participants.

We did not have information on those who refused to participate, however, non-Hispanic Black men were under-represented in the focus groups when compared to those who agreed to a follow-up phone call and as a result, if there are differences in experiences and recommendations that differ by race and gender, those of non-Hispanic Black men may be inadequately represented. The study may also be biased

toward women as most of the responders were female. The overall number of persons who participated in the focus group may not be representative of the larger population and thus the findings may not be generalizable. Results of our study did capture the beliefs and challenges faced by non-Hispanic Black and Latino patients with diabetes and hypertension in an urban setting. The study also presents suggestions from patients to health care providers with regard to effective preventive interventions that would enhance patient knowledge base and self-management skills.

Our findings support results from other studies and concur that interventions for prevention need to be developed with input directly from affected population groups^{7,9-11,17}. Participants of this study stated that they would benefit from ongoing interactive discussion groups to gain management skills, education, and support for their conditions, which would increase awareness about diabetes and hypertension. Such ongoing groups need to provide support for patients in creative ways, including assistance in the adoption of healthy nutrition plans that complement their ethnic diets. Furthermore, groups need to allow for exercise opportunities and provide coaching on methods to prevent or minimize disease manifestation within their families of the participants. Further studies are necessary in order to evaluate the effectiveness of interactive diabetes and hypertension groups that are both patient-based and apply patient racial and ethnic traditions.

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