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A Model for Using Community-Based Participatory Research to Address the Diabetes Epidemic in East Harlem

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Abstract

Objective—Diabetes prevalence and mortality are increasing, with minority populations disproportionately affected. Despite evidence that weight loss due to improved nutrition and increased physical activity can prevent or control diabetes, there is often a disconnect between this evidence and individuals' lifestyles.

Methods—East Harlem is a predominantly African-American and Latino neighborhood that has the highest rates of diabetes prevalence and mortality in New York City. The East Harlem Diabetes Center of Excellence is a community-centered coalition. To help direct their work, the coalition used their experiences, research, outreach, and literature review to build a conceptual model describing how local factors affect health behaviors and health outcomes such as obesity and diabetes.

Results—This model describes the relationship between the physical environment, the social/medical environment and individual factors including demographic data, food and exercise beliefs and behaviors, and health outcomes. The coalition inserted local data from surveys and focus groups into the model to identify targets for future interventions, research, and activism.

Conclusions—This type of collaboration and the model may be useful tools to help communities identify and address the deficits that prevent their residents from enjoying the health benefits of improved nutrition and increased physical activity, and that also lead to racial and ethnic disparities in health.

Keywords

diabetes; nutrition; physical activity; health disparities; community; African-American; Latino; community-based participatory research

Objective

Diabetes prevalence has reached epidemic levels and continues to rise. Nearly 17 million adults in the United States have been diagnosed with diabetes and millions more remain undiagnosed.^{1,2} The diabetes epidemic is increasing in parallel with the obesity epidemic, with morbidly obese adults at a sevenfold increased risk for diabetes.¹ Close to two-thirds of Americans are overweight or obese, with nearly one-third obese.³ Despite a decrease in all-cause, cancer, and heart disease mortality from 1970 to 2002, the diabetes-specific death rate rose 1.5 times in that period.⁴

Minority populations bear an inequitable share of the national burden of diabetes prevalence and mortality.^{5,6} African-Americans are 1.6 times more likely and Mexican-Americans are 1.9 times more likely to have diabetes than are Whites.⁷ Researchers predict that one out of three children born in 2000 will develop diabetes; the risk for African-Americans and Latinos is nearly one in two.⁸ Diabetes mortality is 1.5 times greater for Latinos and 2.2 times greater for African-Americans than for Whites.⁹

There is no magic bullet to prevent or treat diabetes, but lifestyle modifications can accomplish both. Large randomized controlled trials demonstrate that changes in diet and physical activity that lead to 5–7% weight loss can delay or prevent the onset of diabetes in adults with impaired glucose tolerance, or pre-diabetes.^{10,11} In the Diabetes Prevention Program, lifestyle changes eliminated racial and ethnic disparities in incident diabetes.¹¹ Weight loss can improve diabetes control^{12,13} and decrease mortality.^{14,15} Physical activity can improve diabetes control.¹⁶

Despite evidence that lifestyle modifications can prevent or control diabetes, many barriers thwart patients from making these positive changes. Although clinicians can effectively counsel patients to lose weight with dietary and activity changes,¹⁷ many physicians spend an inadequate amount of time counseling patients about lifestyle changes and do not consistently refer patients to nutritionists when warranted.^{18–20} Interventions by nutritionists can also prevent or control diabetes.^{12,21,22} However, nutritionists are scarce, particularly in low-income communities,²³ and may not be equipped to address the unique needs of non-White patients.^{24,25} Even when nutritionist-based interventions are successful, such programs may not be sustainable once their grant funding ceases.

People may face barriers to positive lifestyle changes. Diabetes is a chronic, slowly progressive illness, and those with diabetes do not always feel sick or have symptoms and therefore may not be motivated to make these changes. Poverty and chaotic home situations may make it difficult for patients to make their own health a priority. Race and culture may affect patients' perceptions of appropriate weight and overweight, consequently impacting patients' willingness to lose weight.²⁶ The importance of food and eating together in many cultures may make it difficult for people to change their diets. People eat foods that they enjoy and therefore may be resistant to compromising on taste to accrue health benefits.²⁷

Paradoxically, the intensive behavioral interventions that show such great promise for combating the diabetes epidemic and the disproportionate toll it takes on people of color appear to present the most challenges to tailor for, and sustain in, minority communities. The factors described above thwart lifestyle interventions from succeeding. We wanted to understand and address the disconnect between the evidence that lifestyle modifications improve health, and the evidence that the rates of obesity and diabetes these modifications are meant to address are rising, particularly in East Harlem and similar communities nationwide. To this end, we created a model describing the interrelatedness of individuals' environments, medical care, beliefs and behaviors, and how these affect nutrition, physical activity, and health outcomes including obesity and diabetes. Such models help illustrate the

remediable barriers to maintaining a healthy diet and physically active lifestyle. By helping to identify these weaknesses, these models may be useful as part of efforts to develop practical, sustainable, economically and culturally appropriate interventions to improve health and quality of life.

Methods

Focus on East Harlem

We chose to focus on East Harlem, because this neighborhood has the highest prevalence of diabetes and the poorest diabetes-related health outcomes in New York City. Typical of minority communities across the nation, her residents struggle with limited resources while bearing a great chronic disease burden (Table 1). East Harlem residents are 50% Latino and 40% Black, compared to her immediate neighbor to the south, the Upper East Side, which is 6% non-White.²⁸ East Harlem is the poorest neighborhood in Manhattan, and the Upper East Side is the wealthiest. East Harlem has the city's highest rates of obesity and diabetes, and the Upper East Side has the lowest rates.²⁹ Although East Harlem has five major health care sites, residents have the city's highest rates of hospital admissions that are preventable with outpatient care, greater than expected rates of serious diabetes complications, and the highest rates of diabetes and all-cause mortality.^{30,31}

The East Harlem Diabetes Center of Excellence

In 1997, a group of clinicians, outreach workers, community leaders and researchers joined together to form a coalition, the East Harlem Diabetes Center of Excellence. The aim was to respond to the diabetes epidemic in East Harlem through novel, low-cost, practical, and culturally appropriate interventions that take advantage of the assets and expertise that exist in this vibrant community. The coalition was founded on the principles of community-based participatory research, outreach and action. This collaborative approach to research recognizes the unique strengths of all partners, whether drawn from the community, research, health, or the public health sector, and equitably involves all partners in all aspects of the research and educational process. Partners work together to improve health, generate knowledge, educate, act, and effect social change.^{32,33}

The coalition has a community focus and a commitment to improve communication and understanding between clinicians and community members, develop practical and feasible programs based on community realities, and discover and work with assets in the community.³⁴ Initially, we built trust through outreach and community events. The coalition then turned to research. After numerous community events and meetings, it became clear to coalition members that residents with diabetes were frustrated by the obstacles they faced to eating healthy and staying physically active and were interested in addressing these obstacles. Therefore, the coalition narrowed its focus to helping East Harlem adults tackle these challenges.

With the purpose of developing a shared vision for future community research, interventions, and activism, the coalition designed a conceptual model to help organize our inquiries and focus our efforts to describe the relationships between health behaviors, health outcomes, and the environment. The coalition built this model based on a literature review and the local experiences of its members. We hypothesized that this model would be a tool to help us identify areas for more intensive research and offer a practical guide for future interventions. We then applied this conceptual model to East Harlem, using data we collected from surveys and focus groups of East Harlem residents with diabetes, and a food availability study.³⁵ Our application of the model to East Harlem was also guided by other coalition activities, including a local Nutrition Summit with over 60 community leaders,

Town Hall meetings about diabetes, a healthy food festival, numerous local diabetes awareness and educational events at venues such as churches and senior centers, and quarterly coalition meetings. More recently, a new group, the East Harlem Partnership for Diabetes Prevention, extended and expanded the work of the Center and is employing community-based participatory research to develop and implement a community-based diabetes prevention program.

Results

Our Model: Conceptual Framework

We created a conceptual model to describe the relationship between individuals' environments, medical care, and beliefs and behaviors, and how all of these elements affect nutrition, physical activity, and health outcomes including obesity and diabetes (Fig. 1). The model illustrates that the physical environment dictates the availability and quality of foods and exercise programs that individuals in a community can access. The social/medical environment determines individuals' access to actionable information about nutrition and physical activity, including access to clinicians, education, family and community support, and economic factors. Individual factors dictate the relationship between individuals' sociocultural backgrounds, their food and physical activity beliefs and behaviors, and their health outcomes. In turn, individuals also impact their environments.

The Physical Environment—Individuals can only eat foods that are available to them. For poor, minority populations, healthy foods are often difficult to obtain. Urban dwellers, especially low-income, non-White individuals, are less likely to live near supermarkets, which is associated with decreased consumption of fruits and vegetables and increased fat consumption.³⁶ Convenience is the most important factor for low-income, non-White adults when making food choices.²⁷ Although small stores have convenient hours and locations, they often offer a limited selection of food at higher prices. Fast food can also be convenient, but is high in calories and fat.³⁷ The consumption of fast food in the United States has increased from 4% of total sales of food away from home in 1953 to 34% in 1997,³⁸ and lower income, non-White, obese individuals are more likely to consume fast food.³⁹

Individuals are more likely to exercise when free public spaces are available to them. Those with access to more public places, such as gyms, parks, and recreation centers, are more likely to report higher levels of leisure time physical activity.^{40–42} Neighborhood characteristics, including the presence of sidewalks, enjoyable scenery, and hills, are positively associated with physical activity.⁴² Ironically, residents of poorer neighborhoods are less likely to have access to free spaces to exercise. Lower socioeconomic status neighborhoods have fewer free physical activity resources than high socioeconomic status neighborhoods.⁴³ Residents of low socioeconomic status neighborhoods are also more likely to report higher crime rates, unattended dogs, and untrustworthy neighbors as deterrents to physical activity.⁴⁴

Social/Medical Environment—People will more deliberately purchase and consume healthier foods and engage in physical activity if they understand that these behaviors are beneficial to them and if these behaviors are consistent with their social and cultural backgrounds. Although patient education is critical to facilitating behavior change, clinicians often miss the opportunity to counsel their patients. In one study of obese patients, only 42% were advised by their physicians to lose weight.²⁰ Patients who receive weight loss counseling are three times more likely to attempt to lose weight, but even among those who were counseled and were trying to lose weight, only half were engaged in both dieting

and physical activity.²⁰ Physicians are less likely to counsel less educated^{19,20} or lower income¹⁹ patients.

Social factors can also impact whether individuals act on the nutrition and physical activity information they receive. Family and community support for healthy eating increases the likelihood that a person will eat a healthy diet.⁴⁵ Physical activity interventions that create or enhance social networks more effectively promote activity.⁴¹ Social factors that are associated with physical activity include surroundings in which others are exercising, friends who encourage exercise, and having at least one friend with whom to exercise.⁴³

Economic factors such as cost of food impact individuals' decisions to eat healthier. Even when healthy foods are available in low-income neighborhoods, they tend to cost more, and beneficiaries of public assistance often cannot purchase foods that meet their nutritional needs.⁴⁶ Americans cite cost as more important than nutritional value when purchasing food.^{37,47} Food insufficient individuals, people who skip meals or eat less than they feel they should because of money, choose less costly and less healthy diets, leading to more obesity and greater health care utilization.⁴⁸

Racism and discrimination affect health directly, in addition to effects on socioeconomic status, which also impacts health.^{49,50} Minority populations are less likely to receive the same procedures for the same medical conditions as Whites.⁴⁹ Perceptions of discrimination lead to stress that may also exacerbate medical conditions.⁴⁹

Advertisements for food impact food knowledge and behaviors. The types of foods advertised during television shows that have predominantly African-American viewers are more likely to include fast food, candy, and soda versus general market programs.⁵¹ Food marketing has been shown to impact food knowledge and behaviors, specifically to increase consumption of unhealthy foods that are familiar from television marketing.⁵²

Individual Factors—People's sociocultural backgrounds impact their food choices. Specific demographic characteristics are associated with food behaviors: consumption of more fruits and vegetables is associated with more education and higher income⁵³ and lower body mass index.⁵⁴ African-Americans and Latinos eat fewer fruits and vegetables than Whites, and Latinos eat more high fat foods than Whites.⁵⁵ Many factors may lead African-Americans and Latinos to make different food choices, including racial and ethnic culture and history.⁵⁶

Nutrition knowledge affects food purchasing, and so lack of understanding of the nutritional value of produce leads to the purchase of fewer fruits and vegetables.⁴⁷ In order to change food behaviors, education must be appropriate for individuals' culture⁵⁷ and literacy level.⁵⁸

Poor health outcomes including obesity and diseases result from the intake of high fat foods and the lack of intake of healthier foods, such as fruits or vegetables, and an inadequate amount of physical activity. To combat obesity, it may be necessary to change individuals' food and exercise beliefs and behaviors, specifically those beliefs and behaviors that encourage overeating and a sedentary lifestyle.⁵⁹ This may require changes at all levels of the model: increasing availability of healthy foods, education programs to promote healthy eating and active lifestyles, and ultimately working to change tastes and preferences so people are interested in engaging in healthier behaviors.

The Conceptual Model and Local Data

The model in Fig. 1 helped us to identify data that explores relationships between deficits in physical environment and social/medical environments, unhealthy diets and inadequate

physical activity, and poor health outcomes, including obesity and diabetes. After developing this model, we collected and utilized local data from coalition research projects and events in East Harlem to understand and address the barriers to healthy behaviors and to find and make use of the opportunities to positively impact the health of the community. The data came from two telephone surveys with a total of 1,340 adults with diabetes who live and receive care in East Harlem, four focus groups with a total of 37 East Harlem adults with diabetes, and a food availability study that surveyed all food stores in East Harlem and the Upper East Side.³⁵ We then inserted local data into the model (Fig. 2). The model helped us to more clearly identify potential targets for interventions, highlight important problems and potential solutions to inform policy, and to empower the community to attract resources and develop solutions to the local diabetes and obesity epidemics.

Physical Environment—Our research revealed several deficits in the physical environment in East Harlem. In our food availability study, Upper East Side stores were 3.2 times more likely than East Harlem stores to carry items from five representative healthy food categories. Only 18% of East Harlem stores carried all five recommended food items compared with 58% of Upper East Side stores. East Harlem residents were also more than twice as likely to live on a block with stores that did not carry all five healthy food items.³⁵ From our surveys, we found that residents shop at bodegas because of convenience (96%) and familiarity (90%).

Social/Medical Environment—Our research showed that the social/medical environment was not conducive to helping adults in East Harlem eat healthier and be more physically active. In our surveys, more than half of East Harlem adults with diabetes never saw a nutritionist.³⁴ We also found deficits in the availability of nutritionists in East Harlem. In an additional survey conducted in 2005 of the three large adult medical practices within the three East Harlem hospitals, serving over 100,000 adults yearly, one had a bilingual nutritionist available one 1/2 day per week, one had an English-speaking nutritionist available 1 day per week, and one had no nutritionist available. The scarcity of nutritionists is particularly unfortunate because our research showed that patients who had seen a nutritionist were more knowledgeable about diabetes-healthy behaviors such as nutrition and physical activity.³⁴

Social factors interfered with healthy eating. In our focus groups, adults with diabetes described how family pressure prevented them from cooking and eating healthier foods. In our surveys and focus groups, economic barriers affected dietary choices. Cost concerns caused 28% to skip meals and prevented 40% from keeping a healthy diet.³⁴ In our focus groups, participants described how racism and discrimination prevented healthier behaviors. They described how racist food store practices prevented fresh, healthy foods from being sold in East Harlem.

Coalition members described how advertising for unhealthy foods in East Harlem is so pervasive that residents are bombarded with these messages multiple times a day. They described how billboards on buildings and posters at bus stations and in fast-food store windows present a constant temptation to local residents.

Individual Factors—The individuals who were surveyed and who participated in focus groups were representative of East Harlem. They were predominantly African-American or Latino with a low education level and low income.^{34,35} In our surveys, demographic data affected knowledge: patients with more education and those with insurance were more knowledgeable about diabetes-healthy behaviors such as nutrition and physical activity.³⁴

Our research demonstrated deficits in beliefs and behaviors related to food and exercise. In our surveys, over half of respondents saw no need to change their diets.³⁴ Focus group sessions illustrated the difficulties in sustaining healthy food behaviors, which often involved choosing between cost and quality; between familiarity, comfort, and convenience versus health; and between eating healthy foods alone versus eating unhealthy foods together with loved ones. Gaps in knowledge included the importance of exercise (23%), how to control weight (19%), how much to eat and drink (25%), how to shop for and cook healthy meals (39%).³⁴ More than half of the adults surveyed did not reach the nationally recommended level for physical activity. These food and exercise beliefs and behaviors also affected health outcomes. On the basis of respondents' self-reported heights and weights, 74% are overweight or obese, and over 50% identify their own health status as "fair" or "poor."³⁴ Those patients with better health status were more knowledgeable about these diabetes-healthy behaviors.³⁴

The effects of the social/medical environment on knowledge and health outcomes were apparent in our surveys. Patients who had received nutritionist education were more knowledgeable about nutrition and physical activity.³⁴ Individuals who were forced to make unhealthy choices due to economic factors had poorer health status.³⁴

Discussion

Diabetes is a highly prevalent disease with significant morbidity and mortality in the United States. Minority populations are disproportionately affected by the diabetes burden. However, racial and ethnic disparities in developing diabetes disappeared with lifestyle modifications.¹¹ Unfortunately, there is a disconnect between what clinicians know about nutrition and physical activity and what people with diabetes know and do.

Our coalition represents a community-based effort to improve diabetes prevention and control in East Harlem. The conceptual model that guides the coalition's work integrates research, outreach, and insights and experiences of coalition members. This model describes the effects of environmental factors, medical care, and education on nutrition, physical activity, and health outcomes including diabetes and obesity. As the model illustrates, individuals are constrained by the availability of foods and exercise resources in the physical environment and by the actionable information they acquire in the social/medical environment. These factors inform their food and exercise beliefs and behaviors and ultimately affect their health outcomes. East Harlem residents with diabetes report inadequate knowledge of what they should be eating and why they should be exercising. Many are unable to shop in stores that offer healthy alternatives due to geographic, financial, or time constraints. Yet, East Harlem residents are aware that their health could be improved and are striving for better health.

The model also draws attention to deficiencies in our knowledge base. Studies to date often reveal relationships between some environmental, social and individual factors and physical activity, nutrition, weight and diabetes. However, studies often conflict, and relationships between these factors and outcomes (weight and diabetes) are not as strong as relationships between these factors and processes (diet and exercise). Thus, it can be difficult to develop interventions based on studies found in the literature. Ongoing research will continue to explore these associations, but interventions to prevent and control diabetes must proceed with the information at hand, which very clearly demonstrates the relationship between weight loss through lifestyle change, and diabetes prevention and control.

We have begun to use the model to develop interventions to impact knowledge and spur action in East Harlem. We used local events to address the physical environment (see Fig. 2,

small boxes). For example, at a local healthy food festival, the coalition invited local restaurants to serve healthier versions of their recipes. This experience demonstrated to consumers that healthy foods could be enjoyable and also showed store owners that local residents enjoy healthy selections.

Having been newly designated as a CDC-funded REACH Center of Excellence for Eliminating Disparities for Blacks and Latinos with or at risk for diabetes, our coalition now has resources to holistically improve diabetes prevention and management, using community-based approaches to take a multipronged approach in a small sector in East Harlem, and award local and regional grants to continue this work. We will, for example, work with local storeowners and chefs who provide emergency and subsidized meals to improve their ability to prepare healthier foods, and build indoor walking trails for safe, year-round physical activity.

To address both the scarcity of nutritionists in the social/medical environment and the gaps in individuals' food and exercise knowledge and behavior, we developed a peer nutrition and physical activity education program for adults in East Harlem with or at risk for diabetes. This program responds to the unique needs of a low-income, low-literacy, and undereducated minority community, can be sustained within the community, and will initiate a chain of leadership training that will empower residents and provide them with the self-efficacy to make healthier choices. A pilot of the HEAL (Health Eating, Active Lifestyles) program revealed that participants lost weight and maintained a 5% mean weight loss at 1 year follow-up.⁶⁰ We are also working to bring about changes in policy by utilizing community and academic leaders and the media to educate policymakers about the need and the opportunities for change.⁶¹

This model can be applied to other communities with low-income and low-literacy minority populations. After adding local data to the model, researchers and community advocates can identify and develop appropriate interventions, and can empower community members to garner resources and create solutions to improve the health of their community.

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Fig 1.
Conceptual model of factors that affect nutrition, physical activity, and health outcomes.

Fig 2. Conceptual model with local data from surveys and focus groups. A selection of interventions are shown in the small boxes on the right.

Table 1Demographic and Health Disparities: East Harlem versus the Upper East Side of New York City²⁹⁻³¹.

	East Harlem	Upper East Side
White (non-Latino)	6	90
Median Income (\$)	21,000	74,000
Less than High School Education (%)	46	5
Obese Adults (%)	31	7
Adults with Diabetes (%)	15	2
Rate Health Fair/ Poor (%)	30	10
Preventable Hospitalizations (per 1000)	45	7
Diabetes Death Rate (per 1000)	54	10
All Cause Mortality (per 100,000)	1064	511