

Effectively translating diabetes prevention: a successful model in a historically underserved community

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ABSTRACT

Lifestyle interventions can prevent diabetes through weight loss, but they are rarely translated for use in underserved communities. The aim of this study was to describe how a community–academic partnership formed and developed a program to address local health disparities by developing a low-cost, culturally and economically appropriate, peer-led community-based diabetes prevention program. Using a participatory approach, the partnership chose to focus on diabetes prevention, and co-developed all intervention, recruitment, research, and evaluation strategies. The partnership's philosophy to maintain high clinical and scientific standards paired with their ability to represent and engage the community facilitated the development of a randomized controlled trial that achieved statistically significant and sustained weight loss, and the recruitment of a largely Spanish-speaking, low income, uninsured population. The success of this intervention lies in the partnership's commitment to the community, co-ownership of research, and a careful balance between academic rigor and community engagement and relevance.

KEYWORDS

Diabetes prevention, Lifestyle modification, Weight loss, Community-based participatory research, Underserved communities, East Harlem

INTRODUCTION

As the prevalence of diabetes in the USA rises to epidemic levels, it is crucial not only to identify effective prevention methods but also to successfully and sustainably implement them. Over 10% of American adults have diabetes and nearly two million people are diagnosed yearly [1]. The rise in diabetes parallels the doubling rates of obesity among adults over the past two decades [2]. All-cause mortality in the USA is steadily declining, with declines in cardiovascular disease and cancer deaths, but diabetes mortality rates continue to increase [1, 3, 4].

The burden of diabetes and its associated costs falls disproportionately on Blacks and Latinos, who are more obese and have nearly twice the diabetes prevalence and mortality rates as Whites [5]. Half of

Implications

Research: With the proper tools and information, a community can successfully envision, create, and conduct rigorous scientific research and produce meaningful results that directly impact local health.

Practice: Pre-diabetes is very prevalent in minority communities and local detection and prevention efforts may prove very successful.

Policy: Fostering community-academic partnerships may uncover and address root causes of illness and promote health.

Latinos and nearly half of Blacks born in the year 2000 will develop diabetes if adequate preventive measures are not taken [6].

Pre-diabetes affects an estimated 30% of the US adult population [7]. Adults with pre-diabetes (impaired fasting glucose of 100–125 mg/dl, and/or impaired glucose tolerance of 140–199 mg/dl post-prandial) have a 10% annual progression to diabetes, and 70–100% will ultimately develop diabetes [6, 8]. Pre-diabetes is also independently associated with increased risks of cardiovascular disease and all-cause mortality [9].

The only proven diabetes prevention interventions are weight loss, and to a lesser degree, increased physical activity among overweight adults with pre-diabetes [10]. Fortunately, efficacy studies among pre-diabetics have shown that only a modest amount of weight loss (5–7%) or increased physical activity (i.e., walking 150 min/week) can prevent or delay diabetes by 33% to 68% [3, 8, 9, 11–15]. These lifestyle modifications, which eliminate disparities in incident diabetes between Whites, Blacks, and Latinos, are considered the primary method for diabetes prevention [8, 16]. However, studies generally select only adherent individuals and rely on lengthy, frequent, individualized weight-loss interventions by health professionals [8, 11]. Resources to sustain and scale these proven-effective approaches are out of reach for communities most impacted by pre-diabetes [17].

Currently, only one diabetes prevention program has a community dissemination plan, through selected YMCA sites [18].

East Harlem, a predominantly Black and Latino, low-income community, has the highest diabetes prevalence and mortality in New York City [19, 20]. Community and academic partners joined together in 2005 to form a partnership, and chose a mission to “prevent diabetes through community-based interventions that empower the residents of East Harlem to live healthier, happier, and longer lives.” The partnership employed a Community-Based Participatory Research (CBPR) approach and developed a diabetes prevention strategy that led to significant and sustained weight loss among adults with pre-diabetes [21]. This paper will outline the methods used and steps taken to develop a successful and scientifically rigorous local intervention designed to be inexpensive, conceptually simple, durable, and scalable for similar communities.

METHODS

Community action board formation

In 2005, community and academic leaders experienced with various health coalitions and studies in East Harlem jointly wrote a grant to the National Institute on Minority Health and Health Disparities of the National Institutes of Health (NIH). The funder requested proposals, in which a partnership would form, choose a specific health condition, assess related health disparities, and develop and pilot an intervention. Thus, the partnership began with no specific topic but proposed using CBPR to meet these goals. Upon funding, community and academic co-investigators formed a Community Action Board (“Board”) and recruited members with diverse interests, as they chose no research topic in advance. Co-investigators selected East Harlem community members and leaders with reputations as doers and consensus builders who reflected important local social networks, sectors, and organizations (i.e., faith-based, business, grass-

roots, social service, and clinical), representing local demographic groups and committed to addressing health disparities [22].

Once formed, the 20-member Board aimed to conduct assessments, choose a health condition, develop a community-based, culturally appropriate, sustainable, research-sound intervention, and begin to pilot it—all in the span of 2 years. After reviewing the prevalence and burden of common local health problems, Board members decided to choose a general disease topic—diabetes—to focus on and narrowed the topic further to diabetes prevention, because preliminary research revealed that prevention efforts in communities were nearly absent. The community was also interested in maintaining local health, rather than focusing on disease. While academics participated in all discussions, they did not vote on this and other early key decisions, as the Board chose to make the first major decisions independently, with a singular community focus.

At meetings, the group used several techniques to develop trust, solidarity, a sense of group purpose, and a shared knowledge base to address the earned skepticism community members have regarding academics. These included icebreakers, mini-retreats, and having times for the Board to meet without investigators and articulate concerns. The Board also asked academics to present on topics relevant to diabetes prevention and research development (such as survey writing and types of study designs) so they could make fully informed decisions that would maximize the benefit of their research in the community. Board members used parliamentary procedures, voting on decisions after discussion. A full-time community project manager and community coordinator regularly met with, supported, and advised Board members. Table 1 provides a timeline for the Board's work.

Community assessments

The Board accomplished its work through subcommittees. Here, and in Table 2, we review their

Table 1 | Project timeline and milestones

Date	Accomplishment
February 2005	Community/academic partners wrote grant proposal
September 2005	Grant funded
October–December 2005	Community action board formed
January–September 2006	Community-based assessments conducted
January–March 2006	Selected pre-diabetes
April–October 2006	Formed intervention, evaluation, recruitment subcommittees
November–March 2007	Pilot intervention chosen and developed
April–July 2007	Participants Recruited, Enrolled, Randomized
July 2007–July 2008	Pilot conducted
November 2007	Submitted grant for 5-year expansion
February 2008	Funding began for 5-year expansion
August 2008	Pilot study completed
March 2009	5-year expansion recruitment began

Table 2 | Results of community assessment surveys

Assessment	Goal	Result	Recommendation
Local community organization survey (n=63, response 78%)	Determine availability of local services for pre-diabetes	Familiar with pre-diabetes 65% Offer services for pre-diabetes/diabetes 8% Have process to refer pre-diabetes/diabetes 43% Participate in health screenings 33%	Organizational outreach to improve local awareness of pre-diabetes
Emergency food provider survey (n=26, response 81%)	Determine if provide fresh produce and nutrition information	Provide fruit/vegetables at least weekly 77% Provide info/services on pre-diabetes/diabetes 14% Provide nutrition information 33%	Need to educate individuals about finding healthy, affordable foods.
Community member survey (n=183, response 83%)	Explore diet, exercise, knowledge of diabetes	Worry about getting diabetes 53% Think will get diabetes 35% Advised to eat healthy/exercise by MD 40% Walk for exercise 31% Exercise barriers Time 30% Too much effort 32% Too tired 46% Cost 19% Safety 19% Eat fruit or vegetables daily 42% Diet barriers Raised to finish all food on plate 66% Taste 64% Cost 48% Access 55%	Focus on motivating people to change lifestyles.
Clinician survey (n=229, response 96%)	Test recognition of pre-diabetes criteria	Accurately specify pre-diabetes range glucoses 9%	Need clinician education before diagnosing pre-diabetes in community

accomplishments in intervention choice, conduct, and evaluation. All Board members were required to participate in at least one subcommittee consisting of at least three community members, one academic partner, and one staff member. Subcommittees would make recommendations that the entire Board would discuss and vote on. The Board also held a full-day retreat to synthesize subcommittee recommendations and make decisions about the intervention.

The Evaluation Subcommittee was charged with conducting assessments to better understand factors that affect people with or at risk for diabetes. The goal was to narrow intervention possibilities by excluding those already in place and identifying

obstacles that could make some interventions more challenging to implement than others. They also were responsible for developing all evaluation tools. First, they reviewed local data and determined that there was no information on whether community organizations had services related to pre-diabetes. They therefore wrote and administered a survey to 63 local health, religious, social, and senior service organizations. Most had heard of pre-diabetes, but almost none offered any services for people with pre-diabetes, and under half had a process in place to refer pre-diabetics to clinical or community services. They decided to recommend that the Board improve local awareness of pre-diabetes to benefit residents and to recruit participants, and that

the Board form an additional outreach subcommittee that would be charged with this task.

They next evaluated shortages of affordable healthy foods, supplementing results from previous studies with a new survey of food availability, corroborating earlier findings that a major problem was bypassing many local stores that do not carry healthy foods, to find the local stores that do exist that carry these foods [23]. They then explored diabetes awareness among emergency food providers (food pantries and soup kitchens) [24]. Of the 21 (of 26) pantries that responded, the majority provided fresh vegetables and fruits at least some of the time, but very few provided information or services for pre-diabetics or diabetics, or nutrition information (Table 2). The group decided to recommend developing an intervention to educate individuals about which foods were healthy, where to find them and how to affordably include them in their diets, rather than focusing on changing the food environment.

The subcommittee also surveyed community members to investigate the environmental, social, and individual factors that could influence the development of diabetes among those with pre-diabetes. They listed domains of interest, and asked study staff to supply validated scales to explore these domains. They piloted scales and items in their community, revised the survey accordingly and wrote supplemental questions as needed. The survey was translated into Spanish and written for a fourth-grade reading level. Trained community members surveyed 183 East Harlem adults without known diabetes, at multiple community locations. Half had a family history of diabetes, less than a third walked for exercise in the past month, and less than half ate any fruits or vegetables daily. Most understood that diabetes is a serious illness and one third thought they would develop diabetes at some point. The most common barrier to eating healthy was being raised to finish everything on one's plate, a question the Board asked to be added to the survey that was not found in the literature (Table 2). Fatigue, lack of time and effort were common barriers to exercise, but cost and safety were not. Barriers to healthy eating included taste, access, and cost. Based on these assessments, the subcommittee chose to recommend focusing on motivation and education rather than access.

The Clinician Education Subcommittee. Two overweight Board members recognized that their fasting sugars were in the pre-diabetes range; however, their clinicians (doctors or nurses) told them that they were fine. Their experiences prompted the Board to develop a survey to assess clinician's preparedness to identify and treat people with pre-diabetes. Of the 229 clinicians caring for adult general medicine outpatients at two hospitals and two local health centers who completed the survey, only one in ten could accurately specify pre-diabetes level fasting and postprandial glucose levels

(Table 2). The Board thus formed a clinician education subcommittee who recommended the Board educate clinicians about pre-diabetes, but that this be done prior to the study (so that clinicians would appropriately care for people the Board identified as pre-diabetic), and not as part of the intervention itself.

The Intervention Subcommittee researched types of interventions, both environmental and behavioral, that could be appropriate for diabetes prevention. They would later be charged with overseeing intervention development.

A Latino Education Subcommittee, consisting of native Spanish speakers from the regions of origin most common in East Harlem (Puerto Rico, Mexico, the Dominican Republic, and Cuba) worked together so that all project materials were accurately and appropriately translated into Spanish that would be universally understood, despite linguistic and cultural differences [25].

The Community Engagement Subcommittee developed strategies to educate the community about pre-diabetes. They would later be charged with determining how to most simply and accurately find people who have pre-diabetes, defining who would be eligible, and how to recruit them in a sensitive, effective, and non-coercive manner.

A Membership Committee solicited applications for new Board members and recommended the amount of yearly stipends members would receive and the minimum amount of participation that would qualify receipt of the stipends. Failure to attend three or more meetings per year would result in demotion to the advisory council, a group of community members invited to regularly attend meetings but without voting rights.

Intervention development

Ultimately, the Board decided to develop and pilot a peer-led, group education workshop to promote weight loss among overweight East Harlem adults with pre-diabetes. In a community hesitant to participate in research, they viewed group education as non-threatening, cost-effective, scalable, and a vehicle for people to share challenges and solutions and motivate each other. Peer leaders were viewed as a more approachable and culturally appropriate alternative to trained health professionals and as uniquely positioned to understand and support their neighbors in making difficult lifestyle changes.

After discussing pros and cons of various intervention designs, the Board chose to conduct a randomized control trial (RCT) to ensure that findings would stand up to the scrutiny of scientists so they would influence policy and be of a quality that would increase the likelihood of further funding [26]. Board members decided to address likely concerns that a control group would receive "nothing" by offering a delayed intervention in 1 year, so every participant would eventually have access to

the workshop. By acting as the face of the project, publicizing that the project was designed for the community by the community, and explaining that they could only know if the intervention was truly helping people by examining its outcomes, they believed individuals would overcome any initial distrust of the project. The Board named the intervention “Project HEED” (Help Educate to Eliminate Diabetes) and in Spanish, *Ayuda a Educar Para Eliminar la Diabetes*. To accommodate participant schedules, English and Spanish workshops would be held during daytime, evening, and weekend hours in convenient community locations.

After outlining the intervention design, the Board assigned project work to subcommittees. The Evaluation Subcommittee reviewed and revised the initial community survey. Guided by a scientific advisory board and survey experts, they chose clinical measures and implemented survey items detailed elsewhere [21]. Follow-up data collection (repeating all baseline measures on subjects at 3, 6, and 12 months) would take place at convenient local sites. To increase accuracy and user-friendliness of the survey, the subcommittee constructed a tray with sample portions to capture portion size for the food frequency questionnaire and was granted permission from developers of the physical activity questionnaire to include pictures of people doing physical activity more locally relevant to help choose their activity levels. The resulting 30-min survey was translated, reviewed, piloted, and revised [27–29].

For clinical measures, the group chose height, weight, waist circumference (an average of two readings), blood pressure (an average of three readings with a BpTRU digital device™), serum lipids, and hemoglobin A1c (HbA1c). To choose among various strategies to identify people with likely pre-diabetes, they prioritized accuracy over convenience. Given concerns that East Harlem residents did not always have access to high quality or any medical care, they wanted to offer the highest quality testing and minimize false-positives and negatives. Also, as CBPR has, at times, been viewed as less scientific than other kinds of research, they wanted to ensure that their work would not be discounted by the scientific community because the patient identification strategy was not rigorous enough. In concert with a scientific advisory board of national experts in diabetes prevention, they decided to conduct oral glucose tolerance tests (OGTT). Performing only fasting glucose tests for simplicity and convenience for community members would wrongly exclude people with pre-diabetes who have normal fasting glucoses but impaired glucose tolerance [30]. Hemoglobin A1c testing was not an accepted method for diagnosis at the time. And, as fingerstick A1c machines do not yet provide reliable readings, A1c diagnosis would require phlebotomy and re-contact for results, which was not deemed to be practical, sustainable, or

community-centered. They viewed confirmatory OGTT testing on a separate occasion as unnecessary if only lifestyle modification is planned [4], recognizing that this burden would thwart efforts to ensure that procedures could be reproduced and disseminated in the future.

The subcommittee chose inclusion criteria: (1) age ≥ 18 ; (2) $BMI \geq 25$; (3) East Harlem residents with no plans to relocate from the NYC area in the next year; (4) pre-diabetes, defined by OGTT; (5) able to communicate verbally; (6) English- or Spanish-speaking; (7) no self-reported diabetes; (8) not currently pregnant; (9) not taking medications that raise or lower blood sugar; (8) No cognitive or physical impairment that would preclude comprehension and communicating in a group; (9) no self-reported contraindications to losing weight.

The Community Engagement Subcommittee chose to study and evaluate several different recruitment and enrollment strategies to engage East Harlem residents with pre-diabetes in the intervention. They worked with a graphic designer to develop a logo and colorful marketing materials, and made recruitment packages and trained Board and community members in their use. Screenings would be conducted at local community venues with weekday and weekend hours. Participants with diabetes-level sugars would receive information about diabetes and referral numbers for local clinicians, including places providing care to the uninsured. They would be offered enrollment in community-based diabetes management classes, and project staff would follow up with them within the week. Individuals with normal sugar levels would be counseled on weight loss.

Finally, the Board piloted recruitment tools with each other or family members and revised them. Interested Board members, project staff, community members, and students were trained in human subjects protection to conduct recruitment, survey, and collect some clinical data. Staff used procedures that proved effective in recruiting minority patients [31–35], employing bilingual individuals familiar with the community, whom were trained to give simple, clear information, and to understand and address common reasons for research resistance. Participants were offered no financial incentive for participating in the intervention (as payment is an intervention in itself) [36], but subjects received a gift card for each assessment to thank them for allowing staff to conduct evaluations [21]. The study was approved by the academic partner's institutional review board. No community review board existed at this time, but community partners reviewed all submission materials. They also developed an incentive strategy for participants at each stage of the recruitment process, including gift cards and healthy lunches for attending screenings, and T-shirts for participants randomized into the study. Board members received gift cards equivalent to US \$10/h when assisting with events.

The Intervention Subcommittee aimed to develop an intervention that would help participants lose at least 5% of their initial weight and engage in 150 min of physical activity per week. Information was culturally sensitive, at a low-literacy level and designed to empower individuals to make lifestyle changes through simple, actionable messages easily taught by lay individuals. The Board reasoned that if simple and inexpensive to provide, the intervention could be sustained and disseminated long after grant funding ceased. After studying various intervention strategies, they chose to modify a program with a theoretical background and promising results: Project HEAL. This was a weight loss program developed by community-academic partners in East Harlem that incorporated expertise from local clinicians, educators and community members, and whose participants achieved significant weight loss [37]. HEAL and the proposed diabetes prevention curricula are derivatives of the Stanford Chronic Disease Self-Management Program. Stanford's program is a proven-effective peer-led group workshop based on principles of self-efficacy to help participants form action plans to take steps to accomplish their health-related goals [38–40]. To develop the new curriculum, the intervention subcommittee met with subject matter experts and overweight East Harlem adults, as well as participants in the HEAL pilot, and reviewed the analysis of the pilot and the entire curriculum. They listed the topics they wanted to add to the curriculum, such as facts about pre-diabetes and diabetes prevention, information about eating healthy on a budget, finding affordable, healthy foods in the neighborhood, and culturally appropriate exercises (such as dancing), and developed messages to be delivered as short lectures, brainstorming, and problems to solve. They excluded elements that could not be inexpensively and easily sustained by peers, such as weighing participants at each class, giving cooking demonstrations, or having guest speakers. Stanford developers reviewed and revised the entire course, and the subcommittee then discussed and ratified changes.

Pairs of peer leaders from local communities were trained to conduct workshops consisting of eight, 90-min classes (six weekly, then two biweekly) with 8–20 participants each. The biweekly classes were designed to allow extra time for participants to practice and reflect on what they had learned.

The Clinician Subcommittee worked to ensure that local clinicians recognize pre-diabetes, so they support patients identified as pre-diabetic in the study, and they refer patients to the study. The subcommittee created a clinician tool kit with educational materials about pre-diabetes, a laminated card that indicated fasting and postprandial pre-diabetes and diabetes levels, and a form to refer their patients to the project. Members of the subcommittee disseminated this information by mail and through presentations to clinicians at all major sites of care in East Harlem.

RESULTS

As detailed elsewhere, after 3 months of recruitment, the partnership conducted 555 eligibility screenings, obtained consent from 249 individuals, and screened 178 for pre-diabetes [21]. Of those tested, 99 (56%) had glucoses in the pre-diabetes range, 15% had diabetes they were previously unaware of, and only 29% had normal glucoses [21]. Recruitment led by community partners and Board members at their respective organizations and sites was the most effective strategy to identify and enroll participants (67% of participants were enrolled through this method) [41]. Two early enrollment sites (a Latino church and a multi-service agency serving predominantly uninsured, undocumented, Mexican women) pioneered this approach and contributed the majority of patients to the pilot. Although clinicians provided positive feedback regarding the toolkits, no patients were recruited through clinician referral.

The 99 participants enrolled were predominantly female (85%), Latino (87%), Spanish-speaking (77%), uninsured (49%), undereducated (58% did not complete high school), and unemployed (70%). One quarter was food insufficient [21]. The primary outcome was weight loss. Using intention to treat analyses, we assessed changes in participants' weights and behaviors between baseline and 12 months with paired *t* tests. Those randomized to the intervention lost a mean 7.2 lbs (4.3% of their baseline weight) versus 2.4 lbs (1.5% of their baseline weight) in the delayed intervention group at 12 months ($P=0.01$) [21].

After completion of the pilot, a trained outsider interviewed study participants in small groups or individually, using a moderator guide developed by the evaluation subcommittee to explore study impact. The subcommittee analyzed transcripts of the audiotaped interviews. All enrolled participants were invited to take part in the interviews, and 36 agreed to participate (16 intervention, 20 control). The participants did not differ statistically from the overall study group in age, education, marital, employment, or insurance status; however, significantly more were born outside of the USA [21]. Participants were asked to discuss their motivation for joining and remaining in the study, their perception of the workshop, and to suggest future changes. Those control participants who had been able to participate in a workshop at the time of the interview were invited to comment on their experience, while those control participants who had not yet attended a workshop were asked to identify their reasons for staying involved in the study. Participants reported joining the study primarily because of health concerns (motivated by pre-diabetes level glucoses), positive encouragement from a trusted person or organization, and to help their community. Participants highlighted the importance of workshop themes such as group support and empowerment in helping them reach their goals and cited that

lack of childcare was the principal factor for missing a workshop session.

DISCUSSION

In just 2 years, a group of community and academic leaders chose a health priority (diabetes prevention among adults with pre-diabetes), conducted assessments, and developed a pilot, community-based intervention that proved successful. The partnership's philosophy to maintain high clinical and scientific standards, paired with their ability to represent and engage the community, enabled the successful development and translation of a diabetes prevention lifestyle intervention to the East Harlem community.

Atypical of most grants, community and academic partners began with merely a commitment to come together and address a health condition. While academics provided the board with relevant information and research, community partners ultimately chose the topic, intervention design (i.e., RCT versus pre-post), and intervention type (i.e., peer-led education versus an environmental target) that they deemed most appropriate for East Harlem. This allowed for a nearly ideal implementation of CBPR; the community had full ownership of the research project, in both its creation and content. Rather than voting on or approving steps that would then be taken by their academic partners and supporting staff, the Board organized and oversaw intervention choice, development, conduct, and evaluation with staff and researchers responding to requests, and providing guidance as needed.

Throughout the project's development and implementation, the partnership maintained a strong and sustained commitment not only to CBP (participation—the relevance) but also R (research—the rigor). To date, few CBPR studies have successfully conducted rigorous interventions such as randomized controlled trials [42–45]. This may be due to challenges associated with CBPR (i.e., difficulties engaging and maintaining local involvement, sharing responsibilities, confronting and overcoming conflict, and maintaining continuity of leadership) that can hinder successful intervention implementation [44, 46, 47]. The partnership worked to overcome these challenges by participating in activities that cultivated attitudes of openness and collaboration. Though a path of lesser resistance could have been inaction due to frustration with a tight timeline and limited budgets, the Board chose action as, “you can't wring your hands and roll up your sleeves at the same time” [48].

The partnership was able to screen and enroll participants with pre-diabetes level glucoses into a trial that resulted in significant and sustained weight loss. Recruitment was swift due to implementation of the partner-led approach, in which community representatives or Board members organized and

led outreach and recruitment. Participants cited being encouraged by individuals that they knew and trusted as principal reasons for joining the study, demonstrating that community involvement is as critical for project implementation as it is for project development. Community partners acted as liaisons between researchers and the community and enabled individuals to better understand the project and its purpose [47]. Through their successful recruitment techniques, the partnership reached a vulnerable population typically hesitant to participate in research, consisting principally of undereducated, underemployed, non-English-speaking, recent Latino immigrants. These individuals received diabetes screenings held to the highest standards of clinical care and a lifestyle intervention that helped them to lose weight to help lower their risk of developing diabetes.

Several recent studies have translated diabetes prevention lifestyle interventions into underserved and/or minority community settings, some of which employed CBPR. To the authors' knowledge, however, this study is the only CBPR diabetes prevention intervention designed to be led by local peer leaders [49–54]. Peer leaders share similar backgrounds with community members, can impart information that may not be accepted from outsiders such as health professionals, and have been shown to be effective in health-related interventions designed for minority communities [55–57]. Peer leaders may be more cost-effective than health professionals. The workshop curriculum was kept simple, concise, and culturally appropriate not only to facilitate its adaptation among principally underserved and undereducated populations, but also to ensure that laypeople from the community with only a high school education could easily master and deliver material.

The success of Project HEED demonstrates that significant weight loss can be achieved among individuals with pre-diabetes using a community-driven approach and a curriculum that is simpler both in length and design than typical diabetes prevention interventions, does not include one-on-one counseling or home visits, and does not require trained professionals. It therefore may be possible to sustain this type of simple program and replicate it in the communities hardest hit by diabetes and its consequences.

After completion of the pilot, the Board began discussing the importance of disseminating results of the pilot study to the local community, aiming to further increase community trust in the research process and to break the stereotype that researchers enter an underserved community, conduct research, and leave with no noticeable improvement and having given no indication of the fruits of their efforts [58, 59]. They insisted that subjects who participated in the pilot receive a comprehensive summary of the results of the trial and suggested that they be invited to help with recruitment by sharing

personal stories and successes. Furthermore, the Board and researchers presented the pilot's results at local community and academic venues, national and international meetings, submitted manuscripts to peer-reviewed journals, and prepared press releases for the media. All presentations and publications are fruits of community and academic collaboration so that audiences benefit from both perspectives and partners learn from each other and build capacity to write, present, and act.

Future steps

The Board chose to adhere to a very stringent timeline in order to have pilot data for a 5-year grant to expand the study. Upon funding, the Board voted to include obese individuals with normal glucoses, as they have a high risk of developing diabetes [60]. This would allow for comparison of motivation for and response to the weight loss intervention between people with and without pre-diabetes, and would create an opportunity to engage and potentially benefit a larger proportion of the community at risk for diabetes.

Challenges

This work was not without challenges. Some remained skeptical of the need for such rigorous research and did not want to adhere to timelines inherent in NIH grants. When community partners asked to spearhead recruitment, it was at first difficult for academics to let go of control of early data collection, and this was appropriately infuriating to the Board. Some remained frustrated that stringent inclusion criteria for the study were retained, wishing to reach a far greater population more rapidly. At times, staff members were too helpful, i.e., developing study-related tools that the Board wanted to create on their own. Yet, partners chose to stay and work out differences, and through these struggles, better understand each other's perspectives. In the end, many described the partnership as functioning like a family, whose bonds strengthen over time.

The Board also faced challenges in accurately representing the East Harlem community in the Pilot, ultimately over-representing Latina females and under-representing Blacks and males. This can primarily be attributed to the unprecedented success in recruiting participants at the first several organizations the Board approached—a Latino church and a multi-service agency for Latina women [41]. The Board originally partnered with these organizations because they represented populations typically underrepresented in research; however, the sample size was met so quickly that it limited the need for recruitment elsewhere. In the future study with a sample size of 400 participants, the Board will aim to expand recruitment to more accurately reflect the entirety of the East Harlem population.

CONCLUSION

Over 2 years, the Board transformed from a new and unfamiliar group of community members coming together to address health disparities in East Harlem into a cohesive, collaborative partnership, capable of developing an intervention with clear objectives and measurable outcomes. Through this experience, community members expanded their capacity to conduct research and disseminate its results, while academics learned to partner and relinquish typical research responsibilities and decisions to community members. The positive results of Project HEED demonstrated that with the proper tools and information, a community can successfully envision, create, and conduct rigorous scientific research and produce meaningful results that directly impact local health.

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