

Grand Rounds

Using Community-Based Participatory Research to Reduce Health Disparities in East and Central Harlem

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Abstract

Objective: It is important to teach community members about the causes, magnitude and effects of health disparities that affect them, and to partner with them to develop, test and disseminate programs that they can sustain to improve health. East and Central Harlem are two underserved, predominantly minority, inner-city communities whose residents have disproportionately high morbidity and mortality from chronic conditions. We developed an approach to educate and work together with Harlem residents to study health disparities, and to use peer-led classes to improve chronic disease management and outcomes.

Methods: Researchers and community leaders formed a community-based research core ("Core") with funds from a large health disparities grant. We then assembled a community advisory board and partnered with them to start a community newsletter to explain the causes of local health disparities and suggest ways to eliminate them. Together, we also began to create a self-sustaining cadre of community-based peer educators to teach culturally acceptable chronic disease self-management skills.

Results: The recruited board consists of 33 leaders of community-based health and social service organizations, religious institutions, and tenant organizations, as well as local activists. We produced and distributed our first educational newsletter to more than 4,000 community leaders, members and community-based organizations. We also adapted an existing chronic disease self-management program for the Harlem population and developed strategies to recruit peer educators and sustain their efforts in the future. To help them attain expertise in teaching chronic disease self-management, the board selected four individuals to become master peer-education trainers. The board then helped recruit more than 60 community members and leaders for our first two peer-education courses.

Conclusions: Researchers, clinicians and community leaders worked together to disseminate knowledge about health disparities and a peer-organized education program to address these disparities. This approach provides a foundation to attain a cadre of community-based experts to inform the community about ways to reduce health disparities. By pooling local and academic expertise and resources, we hope to develop programs that are workable, effective and sustainable without outside control or funding.

Key Words: Health disparities, community, self-management, African-American, Latino, community-based participatory research, chronic disease, grants.

Introduction

RACIAL DISPARITIES in health and health care continue to plague our society (1). Following years of research documenting the existence of such disparities, the focus is now on finding in-

terventions to eliminate these differences. Community-based participatory research (CBPR) offers an opportunity to redress health disparities in communities. CBPR is equitable involvement between researchers and those affected by the issue under study in all aspects of a research process, aiming to improve health, generate knowledge and effect social change, and includes recognizing the social, economic and political systems that shape health behaviors and access to resources needed to maintain health (2). It also includes designing community health programs that address differences in cultures, health beliefs and disease presentations, which may result in substandard care for individuals or groups (3).

Although communities and health care systems often have historical reasons for mistrust and misgivings about each other, both can ben-

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efit from envisioning each other as partners with important expertise and resources (4). Together, researchers and community leaders can develop workable, sustainable programs that target a population's needs, ensure cultural appropriateness, and evaluate and disseminate the results (5). Collaboration in CBPR is a partnership among equals with unique and complementary knowledge or expertise (6). This research begins with a topic of importance to the community, and aims to combine knowledge with action, to improve health outcomes and eliminate disparities. CBPR motivates co-learning and sharing expertise by researchers and community members. It differs from more traditional community-placed research, which favors work conducted in a community setting, but with limited community involvement (6).

East Harlem (also called Spanish Harlem or *el Barrio*) and Central Harlem in New York City have a combined population of approximately 228,500 people, 34% of whom are low-income Hispanics (predominantly Puerto Rican) and 57% African Americans (7). Recent migration changes have seen the growth of new enclaves of immigrants from Mexico and Central America. Harlem has a long history as a cultural center, because of its ethnic diversity and its prominence in American arts and culture. Much of this cultural richness still remains and is now being revitalized, with recent initiatives such as the Federal Empowerment Zone. However, 36% of Harlem residents live in poverty (7). Although East and Central Harlem house two municipal hospitals, one community hospital, one tertiary-care medical center, and many community health clinics, their residents have the highest rates of cerebrovascular deaths, infant mortality, cancer deaths and all-cause mortality in New York City (8). Mortality rates for Central Harlem in 1980 were not only the highest in New York City, but also more than double those of U.S. whites and 50% higher than those of U.S. African Americans. African American men in Harlem at that time were less likely to reach age 65 than were men in Bangladesh (9). Moreover, there are still great disparities between health outcomes in Harlem and in the adjacent Upper East Side, whose population of approximately 216,400 is 91% non-Hispanic white (7). The Upper East Side has the lowest poverty rate (6%) and the lowest death rates for the above conditions in New York City (8).

Utilizing the principles of community-based participatory research, we aimed to reduce such disparities by addressing the specific

challenges of the Harlem community with practical, sustainable, culturally appropriate solutions that utilize the community's strengths, and whose effectiveness can be tested by rigorous research methods. The Harlems (typical of many minority communities) have lacked adequate research expertise, funding, and active community input devoted to providing better care for people with the typical health care problems in these communities. We therefore applied for and received a federally funded EXPORT (**EX**cellence in **P**artnering for **C**ommunity **O**utreach **R**esearch on Health Disparities and **T**raining) center grant to establish a center where researchers, community residents, policymakers and clinicians could put their combined strengths to use in eliminating health disparities. Over time, we expect these efforts to generate innovative programs and collaborations with clear results, and inspire a new generation of community leaders and researchers to help eliminate health disparities and develop community-based programs to do so. We also aim to devise ways of maintaining successful activities after funding has been terminated.

We actively involve community members in efforts to educate the community about the prevalence and causes of racial and ethnic health disparities, and potential strategies to eliminate them. Specifically, we partner with Harlem leaders to recruit and teach local individuals with chronic diseases to become peer educators who can then teach other community members self-management skills for their chronic illnesses. These skills have been adapted to the ethnic, cultural, and social environment in Harlem. Self-management education is a critical ingredient of appropriate health services, especially for the African-American and Latino populations. That is because these groups, in addition to carrying a heavy burden of illnesses, encounter limited access to health care and to health education due to economic, language and cultural barriers (10). The "Chronic Disease Self-Management Program" is a peer-led self-management program utilizing groups that include patients with different chronic diseases. The program improves patients' self-management skills, increases their perceived ability to manage their conditions and the demands of everyday life, improves their health status, and facilitates their more effective use of health care services (11).

Through six 2¹/₂-hour-long classes, the program teaches patients how to take the initiative for their own health care and their dealings with

health personnel, clarifies the use of family and community support systems, and builds on patients' relationships with providers and institutions. The program has been proven effective in reducing patients' symptoms, emergency visits and costs, and in improving ability to function, among people with symptomatic chronic diseases (12). Our goals were to adapt this program to the populations of Harlem, base it in the community rather than in health institutions, and identify community members to be trained as peer self-management educators. The peer-education classes will be tested through research and made available throughout the community as a service. Using this strategy, we aim to create a self-sustaining cadre of community-based experts in chronic disease self-management techniques and training. In this paper, we will describe our approach, thereby providing a concrete example that can be used by other clinicians and researchers, as a way to begin partnering and actively working with community members to improve local health.

Methods

To address health disparities in Harlem, we formed a community outreach and information dissemination core ("Core") as part of the EXPORT Center grant. The Core's goals were to establish and maintain meaningful community partnership and expertise, with a focus on improving the delivery of effective health care to residents of Harlem. We carefully selected an interdisciplinary leadership team to build on the strengths and experiences of community leaders, clinicians and researchers. All members have extensive experience working in Harlem and building academic-community collaborations (13).

Grant-proposal-writing itself was used as a method to build partnerships and trust, and to share ideas. Through a series of meetings, Core leaders agreed on a set of objectives, and methods to accomplish these goals. We also wrote a detailed education plan to involve the community in building, leading and sustaining peer-led self-management classes. Our planned dissemination strategy included developing both a community newsletter and a series of community lectures and discussions. We used grant proposal "letters of support" to begin dialogues with community leaders about our shared aims, thereby garnering wider community commitment from the outset. These letters became statements of mutual commitment—for the

Core team to involve supporters, and for supporters to actively work with us, if the grant were funded.

Once funding began, we informed all persons who wrote support letters that we were ready to begin our work, and gave them a summary of what we planned to accomplish. First, the Core co-directors (a white clinician and researcher, and an African-American health activist), began to form an EXPORT community advisory board ("Board"). We sought persons who had extensive experience in Harlem, could communicate easily with community and health leaders, and possessed an intimate understanding of the community's social networks and assets. All the individuals from community-based organizations, churches, tenant associations, health centers and local businesses, as well as the community activists who were invited, agreed to join the Board. Recruiting such persons is the cornerstone of community health advisor programs that aim to improve the health status of underserved communities and increase their access to health care and social services (14, 15).

The Board meets on a quarterly basis to deepen their involvement in the EXPORT Center. We "assigned" each Board member to one of the Core leaders, so that the leaders would regularly stay in contact with them between quarterly Board meetings. During Board meetings, Center researchers and clinicians update the Board about the Center's recent activities, and elicit their advice and feedback. Community leaders present ideas for projects to help reduce health disparities among people in Harlem. The Board has formed a peer-education subcommittee and a newsletter subcommittee. Through these two subcommittees, the Board works to implement its education and dissemination strategies.

The newsletter, ECHHO (East and Central Harlem Health Outcomes), co-written by researchers and community leaders, contains articles that focus on health disparities and programs in Harlem that address them. The newsletter subcommittee of the Board became the editorial board, and appointed two co-editors, a researcher and a community leader. The newsletter contains articles that are co-written by a researcher and community leader, to foster sharing of expertise, communication, understanding, respect and trust. Through collaborations, the subcommittee aimed to bridge the gap between members of academia and members of the community. The newsletters, distributed to

more than 4,000 community leaders and community members, help keep the community informed of and involved in the Center's plans and activities. The results below will highlight the strategy we employed to build partnerships that lead to a sustainable program in which local residents are expert peer educators and teach skills to improve the self-management of chronic diseases.

Results

We identified and recruited 33 leaders of community-based health and social service organizations, religious institutions, and seniors' and tenants' organizations, as well as local activists, to form our community advisory board. Through quarterly meetings, and frequent subcommittee meetings, the predominantly white researchers and predominantly non-white community leaders began to understand and respect each other's expertise and perspectives. Community leaders, some of whom joined the board as a favor rather than an opportunity, came to appreciate the complexity of planning and implementing a large-scale research project. They also appreciated the commitment researchers had to working with them in their community on a long-term basis. In addition, they stayed actively involved because they had subcommittee responsibilities and were therefore essential team members, not bystanders. Researchers, some of whom viewed the Board as an obligation rather than an opportunity, learned the depth and breadth of existing local programs to target racial and ethnic disparities, and the extent of Board members' expertise in issues relating to the local community's health.

As we learned to work smoothly with the Board, we tailored the peer-education program to the predominantly African-American and Latino adults who reside in Harlem. For example, community leaders strongly recommended that the program acknowledge and provide opportunities to discuss the effects of poverty, racism, and perceived substandard health care and housing on residents' health and well-being (16). We therefore worked with the developers of the program to modify the program to allow for discussions of these and other local issues. Next, we chose four persons from the community to undergo a one-week-long training course to become "master trainers" who could lead programs and train community members to lead the programs.

We then needed to train community members to conduct peer-education groups. To do this, we chose to identify community members with chronic diseases to attend peer-education groups and invite them to become peer leaders. The Board's peer education subcommittee worked with Core leaders to build a recruitment strategy. Core leaders contacted their "assigned" Board members, each an emissary of a community-based organization, and asked them to nominate one or two of their constituents (or themselves) who had chronic diseases and wished to learn self-management skills, to attend one of two classes. We also contacted others who had sent us letters of support, to "keep our promise" that we would work with them to accomplish the aims they had agreed to support. In this way, we sought both to garner community support and to firmly establish the peer-education program in the community from its outset.

The process of identifying peer-group members and potential leaders was delayed, as community leaders learned first hand about the necessity of receiving Institutional Review Board approval and obtaining informed consent from the group members, who were also potential research subjects. Core community members also worked intensely with researchers, who were concerned that community recruitment would compromise an impending randomized trial to test the effectiveness of the program. Community members expressed their concern that the narrow parameters for inclusion in the randomized trial would exclude many community members, thereby deepening local cynicism and mistrust of the program and damaging potential to disseminate and sustain the program in the future. They were also concerned that researchers planned to hold two community classes and that all remaining courses would only include research. Based on these concerns, researchers agreed to allow community partners to host the classes at their sites, and have research subjects join community classes. Core leaders and researchers successfully wrote a document that outlined a compromise that all were comfortable with, and used this to communicate with other researchers and members of the Board. Researchers were pleased they decided to adopt community leaders' recommendations when these leaders moved from being reluctant to recommend potential participants to enthusiastically offering to hold classes and recruit participants.

To date, 78 participants attended the first 6 classes and 11 organizations have agreed to host

classes. A major goal of these first classes is to identify individuals who wish to become lay leaders and teach their own classes. Therefore, those who complete these courses and are considered potential peer-education leaders will be invited to a 4-day peer-leader training course. They will be paid for their time to take this course, and for their future work if they lead sessions that are part of the randomized-trial research study of the peer groups. By “embedding” these leaders in the community, the Board is creating an ongoing, sustainable resource.

Discussion

By bringing together a diverse group of community-based organizations and activists to write a grant proposal to eliminate racial health disparities in their communities, we established the foundations of an ongoing relationship dedicated to educating and disseminating information about ways to reduce health disparities in Harlem. Together, individuals from health and social services, community-based religious institutions and seniors’ and tenants’ organizations, as well as local activists and researchers joined to educate members of the community about chronic disease self-management skills. Several Board members plan to be trained as peer-education group leaders, so that they can bring this service back to their constituencies and become an integral part of this sustainable service. They are thereby developing a potentially sustainable community resource of individuals skilled to train additional community residents in the future. By using a community-based participatory approach, we have been able to develop and strengthen the trust between groups of individuals who historically have reasons for mistrust. We have also built on the momentum developed during the grant writing and on the positive relationships between researchers and community members, to engage our community advisory board, and enroll community residents for peer-education training and contributions to our newsletter.

We have taken steps to demystify the research process among community members. Community members have become advisors or collaborators in ongoing, funded research projects, enhancing the cultural competency of the research, adding new strategies, assisting in patient recruitment and retention, and developing culturally sensitive information for community members. They also sharpen their presentation skills for clinical, scientific and public health

and policy audiences by presenting at committee meetings and local governmental hearings, co-presenting with researchers at local and regional meetings, and writing articles in the newsletter. In fact, the writing of this paper is an integral part of CBPR.

We have also taken steps to encourage researchers to incorporate CBPR principles and practices into their research projects. By actively participating in the Board’s activities and in working groups with community leaders, researchers have also gained a better understanding of the communities’ perspectives on research, disparities and factors relating to disparities. Researchers now regularly rely on Board members’ advice to develop and conduct research implementation strategies. Through community presentations and writing for the newsletter, researchers are becoming more adept at communicating with residents of Harlem. These skills will help researchers disseminate their new knowledge to the community as well as to other researchers and clinicians. As we work together to write articles and give joint presentations of this work, each group becomes more sensitive to the other’s perspective, and more able to portray that perspective to audiences.

Most programs to improve health in minority communities such as Harlem are developed by persons from outside the target communities, without direct input from members of these communities (17, 18). Interventions created solely by outsiders may perpetuate the inequalities that well-meaning researchers aim to address, create an atmosphere that discourages community experts from sharing invaluable perspectives and ideas, and thwart the entry of researchers and their projects into the communities. By contrast, we built strong relationships with many community leaders, who have helped ensure that our project goals and the means of accomplishing them are relevant and sensible for the targeted Harlem population (19), and that the work conducted under the auspices of the grant will continue beyond the grant-funded cycle. Through mutually respectful relationships, with shared responsibilities, communities and researchers can increase the community’s capacity to identify and solve its own problems (20). Through their experiences, the leaders of this community Core have learned how to successfully engage communities in research endeavors, and communicate with community members in a culturally sensitive manner. We hope these partnerships will be

sustained and expanded in other research and community endeavors.

Researchers usually have ad-hoc relationships with community members that last only for the duration of the projects. Only sustained involvement during the project can equip community members with the knowledge and skills they need to meaningfully participate in studies as more than research subjects. Lack of involvement, on the other hand, can increase community mistrust of research and researchers, and thwart future collaborative efforts (21, 22). Equally important, it can cause researchers to lose an invaluable opportunity to partner with community experts to make their research more relevant, practical, focused and sustainable. We hope that through our dissemination strategies, we will help other researchers solidify relationships with communities and community leaders.

Like other collaborative research teams, we have faced challenges. Successful academic-community partnerships build trusting relationships over time (23). Our partners have different perspectives on the relative importance of processes vs. outcomes, research vs. service, and the need for rigorous evaluation. They also have different styles of communication and decision making, and different opinions of who may legitimately represent the community (24). By establishing common goals and ground rules that promote understanding, communication and respect, and outlining how decisions will be made, our coalition is thriving despite these tensions (25). The message and mission of the coalition is strengthened through active participation, listening and responding to the needs of coalition partners, and capitalizing on strengths rather than focusing on deficiencies of the community. Through this process, we have begun to gain credibility in both the community and academic institutions (26). By establishing a Board and fostering peer-recruitment activities, we are building on existing working relationships and trust to allow us to rapidly mobilize resources and move from planning to implementation (27). We began by explicitly acknowledging the community's mistrust or "healthy paranoia" of researchers and outside organizations, given the history of racism, marginalization of minority communities by health care systems, and past experiences of having researchers enter communities or health centers, collect data, provide no direct benefits, and leave without giving feedback or taking noticeable actions (21, 22, 28).

Our project is still in its early phases. It is too soon to determine whether we have been successful in creating a sustainable cadre of community-based expert teachers of chronic disease self-management. We are working to sustain the peer-educator program in two ways. First, as part of community faculty development, Center personnel will mentor community leaders to write grant proposals to governmental or private organizations that could fund a peer-group coordinator, peer educators, or peer-education. Second, faculty will work with individual agencies to continue conducting groups. We believe that through simple steps, including involving community leaders in a project from its outset, having an active community-advisory board, providing opportunities for health and community experts to openly communicate and respectfully share expertise and responsibilities, and creating and following a plan to sustain promising programs after grant funding has ended, researchers and clinicians can deepen the meaning and effectiveness of their efforts to eliminate health disparities.

Conclusion

Community-based participatory research optimally takes place through a collaborative process, from grant-proposal-writing through the conduction and planning of research. Through these efforts, we discover the needs and goals of the community, clarify what can and cannot be accomplished, and build mutual trust and respect among researchers and community leaders. This process can further empower communities by using research funding to train community members to utilize effective methods to improve their health, thereby bringing an important, sustainable service to the community.

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