

Giving Voice to Underserved and Culturally Diverse Groups Using Community-Based Participatory Research

Kathleen A. Burklow* and Lisa C. Mills

Harmony Garden, Inc. Cincinnati, Ohio, USA

Abstract: The purpose of this article is to present a community-based participatory research (CBPR) strategy reflecting a partnership between researchers from an independent community-based research organization and a team of five female residents living in an economically disadvantaged, medically underserved community. Using a CBPR approach, we partnered at a grass-roots level with these women to share our research knowledge and technical skills to gain a better understanding of the cultural attitudes, beliefs and behaviors underlying several health disparities affecting their community. We present the methodology and process by which we established our partnership and how our relationship with the team has strengthened our research efforts and resulted in the team taking action steps in their community to promote health. We conclude with a discussion of factors for medical students, residents, fellows and faculty to consider when adopting CBPR strategies to partner more effectively with culturally diverse populations.

Keywords: Community based participatory research, medically underserved, culturally diverse.

INTRODUCTION

Members of medically underserved, culturally diverse communities have much to offer in terms of social and cultural capital, yet they are often disconnected from and have little control over the clinical care, research, and intervention efforts that affect them directly. Traditional medical research has generated the significant health-related information needed to improve health, however, the gap between research knowledge acquisition and translation of this knowledge to clinical practice persists [1]. The consequences of this knowledge gap are perhaps most apparent within medically underserved and culturally diverse communities where health disparities are extensive and widespread [2].

When working with communities with significant health disparities, health professionals may need to integrate alternative or complementary methods into their approach to understand and appreciate better the culturally rich attitudes, beliefs and behaviors that individuals from these communities bring to their health-care experiences. Community-based participatory research (CBPR) is one primary methodological option that ensures input from individuals within the targeted population and empowers them to be change agents for social action to ultimately improve social conditions necessary to prevent health disparities [3].

CBPR has an extensive history in community health research and the social sciences [4-6]. Knowledge generated from CBPR is culturally relevant, connected to people's lived experiences, and, thus, is more readily translated into action than is knowledge that is disconnected from familiar contexts and practices [7]. CBPR acknowledges that

communities already have local knowledge that is crucial to understanding and addressing its own social problems. Community residents not only identify and respond to specific needs of their community but become better connected with their community and provide a "voice" for an otherwise marginalized population. By understanding local knowledge and linking it to scientific knowledge, health professionals using CBPR methods in their clinical care, research and education efforts create the strongest potential for improving health care. Through these efforts, health professionals ultimately can play a key role in eliminating health disparities within communities most in need.

The purpose of this article is to present data from a CBPR strategy initiated within a medically underserved community. In this article, we will describe the initial program components of our CBPR approach conducted at a grassroots level with community residents who were not previously organized around health promotion efforts in their economically disadvantaged community. Using a CBPR approach, we engaged a team of female community residents to work with us to understand the cultural attitudes, beliefs and behaviors underlying the problem of teen pregnancy, a community-identified priority health concern for girls. In this paper, we do not focus in detail on the specific outcomes of the CBPR research activities carried out by the community residents and the researchers. Instead, we present the methodology and process by which we engaged members of a medically underserved community that has been isolated from health care and research and how this process has resulted in action steps within their community. We conclude this article with a discussion of factors for medical students, residents, fellows and faculty to consider when adopting CBPR strategies to work more effectively in partnership with culturally diverse populations.

*Address correspondence to this author at the Harmony Garden, Inc., 1776 Mentor Avenue, P.O. Box 221, Cincinnati, Ohio 45212, USA; E-mail: kburklow@hgarden.org

METHODS

Selecting a Partner Community

Harmony Garden is an independent applied research and education organization that combines traditional research with CBPR methodology to involve community members directly in designing and carrying out initiatives to promote and support girls' health within their own communities. Particular emphasis is given to communities with girls and young women who are disadvantaged by low socioeconomic status, poor access to quality health care and education, and unsafe neighborhoods. Findings from a previous community-wide study that assessed the health status of women and girls in our region revealed unequivocally that African-American women and girls living in the urban core of our metropolitan area had poor health outcomes and were most in need of positive social change [8]. Given these data, Harmony Garden focused its efforts in an urban neighborhood that reflected the results of the health status study.

In the selected partner community 84.5% of the residents are African-American and more than 57% of families live below the United States poverty level [9]. In addition to being economically disadvantaged, the families in the neighborhood, comprised largely of subsidized and public housing, exhibit histories of limited mobility in that large networks of extended family members have lived in this same neighborhood for several generations.

Establishing Community Partnerships

The Harmony Garden established a formal partnership with the county housing authority that provides public housing to over 1,000 households in the partner community. The partnership was initiated through a program that Harmony Garden offered to mothers of girls living in housing provided by the housing authority. The program lasted 16-weeks and focused on supporting girls' health. A community liaison from the housing authority helped to recruit mothers from the community to the study group. Group meetings were held at the community recreation center located conveniently within the heart of the partner neighborhood. Conducted weekly, these evening group sessions occurred across a four-month period at no cost to participants. Attendance was voluntary. The mothers, in partnership with the group leaders, set the weekly agenda. Activities ranged from facilitated group discussions on girls' and women's health-related topics to participation in arts-and-crafts based activities. Participation rates varied weekly, with an average of six mothers in attendance each week.

Formation of Community Resident Research Team (CRRT)

At the conclusion of the mother's program, Harmony Garden and the housing authority continued its partnership by establishing a pilot program to form a Community Resident Research Team (CRRT) for the partner community. In this partnership, the housing authority agreed to provide part-time wages for up to six women for one year. In exchange for wage support from the housing authority, Harmony Garden provided office space, operational infrastructure, and research training and supervision to provide women with tools to collect information about girls' health and to

use the new knowledge to promote the health of girls living in their community.

All of the women from the mothers' group were interested in participating on the CRRT. Similar to their participation in the mother's group, joining the pilot program was voluntary. It should be noted that the housing authority had previously identified these women as a subgroup of particularly challenging and difficult-to-reach heads of households. These women were eligible for resources and opportunities provided by numerous housing authority grants to promote self-sufficiency, however they had never taken full advantage of the services offered.

CRRT Training

The women met three times weekly for 6 hours per day at Harmony Garden over a three week period. CRRT members learned about concepts underlying community-based participatory action research methodologies, including the importance of representing the voice of their community as it relates specifically to the area of girls' health and taking collective action to address community concerns. They participated in guided discussions related to oppression, prejudice, social inequality, and health disparities. Throughout the year, CRRT members continued to acquire additional research skills, including computer literacy, research ethics involving human participants, data survey and codebook development, SPSS and EXCEL database development and management, data entry, preliminary data analyses, interpretation of results, and development of methods to disseminate findings back to the community. Coinciding with this formal teaching of research methods, Harmony Garden researchers learned about the CRRT's direct experiences navigating several societal institutions, including public assistance, health care, educational, and judicial systems. Through this co-learning process, Harmony Garden researchers and the CRRT increased their understanding of the interlocking social constructs of gender, race, and class and its impact on health in the target community.

RESULTS

CRRT Demographics

The six African-American women on the CRRT reflected the demographic characteristics of women living in the target urban community. All CRRT members received public assistance and lived in subsidized and public housing. At the time the team was established, most had been consistently absent from the work force for several years. Two of the six women had high school diplomas, with the remaining four intermittently attending GED classes over the past 9 years. All CRRT members were teen mothers and single heads of household with three to five children ranging in age from newborn to 16 years. The average age for the women at the launch of the CRRT was 27.8 years. Only one woman dropped out of the program after two weeks of participation because she reported no perceived personal benefit to continuing in the program.

CRRT Research Activities

Over the one-year period of the study, the CRRT engaged in the following research-related activities within their community:

Development of Community-Friendly Surveys and Focus Group Facilitation Guides

CRRT members provided significant input with regard to the best way to pose survey questions to lay community members that ensured gathering quality research data as intended. Similarly, the CRRT provided critical input during the development of focus group moderator guides for use with the target community that reflected the language and cultural perspective of its residents.

Administration of a Community Health Needs Assessment

To identify residents' top three health concerns for the girls in their community, the CRRT designed a purpose-built Health Assessment Survey (HAS) and recruited community residents to complete the survey voluntarily during two community events, an annual neighborhood reunion and the monthly resident council meeting. *All* residents approached by CRRT members agreed to complete the survey (CRRT members had received extensive training to ensure that eligible participants were not coerced in any way to complete the surveys). Participant recruitment exceeded expectations in that the CRRT administered all surveys to community residents within a brief two-hour time period. The CRRT maintained data security during the collection process and transferred all data to Harmony Garden offices and helped analyze the results. From a list of 11 possible health concern topics provided, residents endorsed three primary health concerns for girls in their community: teen pregnancy/STDs (83%), drugs (60%), and safety (45%).

Recruitment for and Joint Facilitation of Community-Level Focus Groups

In response to the findings of the health needs assessment, the CRRT followed up with the results by bringing the priority concern of teen pregnancy back to the community for several facilitated focus group discussions. The CRRT helped to target the focus group composition in terms of gender and age and successfully recruited 10 to 12 residents to comprise five separate focus groups (i.e., teen girls with children, teen girls without children, teen boys, men and women.) Even though focus group participation was meant to be by CRRT 'invitation only', community participation exceeded target goals for recruitment since additional community members meeting eligibility requirements arrived on-site hoping to participate in the focus groups. Given the 100% show rate of the participants who had been recruited, these new arrivals could not be accommodated, but they were given the opportunity to be added to a contact list for participation in future research activities.

In addition to recruitment activities, several CRRT members helped to facilitate focus group discussions, often reframing questions for and clarifying responses from focus group participants. CRRT facilitation enhanced group discussions by asking candid questions in terminology familiar to the residents. This CRRT facilitation deepened the level of discussion within the focus group since CRRT members were able to bring their familiarity of their community to the focus group by posing thought-provoking questions to the participants. In turn, participants entered into lively discussions revealing important themes that likely would have never emerged without the CRRT involvement.

Dissemination of Research Findings Back to the Community

CRRT members are currently preparing to share the results of the focus group discussions with the broader community in a community-friendly manner. The intent of disseminating the findings is to provide a summary of the CRRT work to the community and to obtain feedback from community residents with regard to the next action steps. The newly discovered knowledge from the surveys and interviews should help them further address their identified concerns.

DISCUSSION

Although presented from a community research agenda perspective, the CBPR process described above has implications for medical education and training. CBPR strategies are particularly useful to include in medical education efforts, especially within the context of teaching and training of medical professionals who will be, or are, working within economically disadvantaged and medically underserved communities.

Given the growing recognition of the need for future health professionals to be able to communicate with and understand the unique issues of patients coming from diverse backgrounds, the Institute of Medicine has called for health professional programs to include CBPR as a core competency to ensure that students are well-prepared to address health problems and challenges they may face in their work [10].

Most successful academic-community partnerships in the medical education literature reflect service learning models in which physicians in training are provided with opportunities to interact with community members and patients within community-based settings [11, 12]. Although service learning models promote volunteerism and advocacy among medical residents as well as benefits the community by reinforcing their understanding about their own health [13, 14], service learning primarily addresses professional development and clinical care training issues within medical education rather than training in alternative methods for conducting medical research. Thus, service learning, albeit reflective of successful community engagement, should not be confused with CBPR. CBPR involves academic and community partners engaging in mutual *research* efforts. Many examples of effective CBPR studies exist addressing a variety of health issues (e.g., asthma and diabetes care [15, 16], but integration of CBPR opportunities into medical education is much less common. One excellent example, however, in which a successful community-academic partnership model has offered public health and medical student training and experiences in CBPR is the Harlem Community and Academic Partnership (HCAP) [17]. The HCAP has resulted several medical education, research and clinical care initiatives that work to improve the health of residents of East and Central Harlem.

The experiences described in our example above highlight several salient components consistent with CBPR principles that contribute to the success of this effort. First, CBPR principles assume the formation of a genuine partnership between the academic and community partner in which

co-learning occurs [18]. Supporting grassroots involvement in intervention research from start to finish requires patience, respect for diverse opinions, and a significant amount of time [7]. Indeed, partnership formation between our research organization and community residents was an essential first step to forming the CRRT. Our initial efforts to join with community residents benefited because they occurred within an existing relationship, (e.g., weekly programming) offered at a familiar location (e.g., the neighborhood recreation center) and in partnership with an already trusted local organization in the community (e.g., housing authority). Most important, we dedicated ample *time* (i.e., 6 months to one year) to forming our relationship with the members of the CRRT. In fact, we largely attribute our success with involving these previously disengaged women in this collective effort to the time we dedicated to relationship development. Medical educators must underscore for students the importance to dedicating sufficient time to develop trusting, working relationships with members of community groups or neighborhoods. Such time dedication to building academic-community partnerships may feel very difficult due to the need to meet academic or clinical demands and achieve accreditation standards. However, this time spent in relationship building must be regarded as a necessary part of the work, rather than a step that needs to be completed prior to getting to the intended “real work”, be it research, education, or clinical activities. This time frame allows repeated, consistent contact providing academic partners opportunities to learn from community partners about culturally-related beliefs, attitudes and behaviors underlying health in select communities. Similarly, community partners have opportunities to learn from academic partners about the benefits of engaging in healthy behaviors as well as the importance of being involved in health-related research. Through this shared partnership and co-learning, both academic and community partners reach deeper levels of mutual understanding and discover new knowledge that will lead to better health for the community and improve clinical practice and research for the academics.

In addition to formation of genuine partnerships, CBPR principles assume that there is a commitment to training community members in research [18]. CBPR acknowledges that communities already have local knowledge that is crucial to understanding and addressing their own social problems [3]. By training community members in research, we have helped to build the capacity of residents to take successful concrete actions to improving girls’ health in their communities through relevant research initiatives. In this manner, the CRRT has not only identified and answered specific needs of their community, but they have become better connected with and have provided a “voice” for an otherwise marginalized population. The CRRT’s ability to meet and exceed recruitment goals for their research initiatives demonstrates, perhaps, the greatest reflection of their significant connection with community residents. Whereas prior participation rates in health-related research in their community was limited at best, community interest in research participation following interactions with trained CRRT members has increased substantially. As a result of this expanded community interest in research, we, as researchers, have been able to uncover many commonly held beliefs and attitudes in the community, especially the

perceptions that pose potential barriers to health. This information will be critical to developing culturally-sensitive, community-relevant health interventions, research initiatives, and programming in the future. Thus, this approach has produced findings and knowledge that has benefitted both the research/academic and community partner, a principle consistent with CBPR [18].

When educating students, trainees, and faculty on CBPR approaches, medical educators cannot ignore the issues of power and privilege and how these issues intertwine with gender, class and racial/ethnic discrimination. Researchers from academic centers must be aware of how they often hold (and the community gives them) power in research projects due to factors related to a long history of institutional, interpersonal, or internalized oppression [19]. For example, not only do researchers come representing an institution of higher education in the community, they also bring scientific expertise and technical knowledge to a project. Similarly, community members bring unique knowledge of community attitudes, beliefs and norms, but may be hesitant to share, or may even be unaware of the importance of communicating, this knowledge with the academic partner. As such, students, fellows and faculty must recognize the need to engage constantly in self-reflection about power and privilege issues and to share these reflections with community partners so that the voices and perspectives of all partners can be heard and valued. Through this open dialogue, academic and community partners deepen their trust and collaboration which further promotes mutual understanding.

This article provides one snapshot of a broader process of a CBPR project initiated to join academic researchers with community residents to address health disparities in their economically disadvantaged, medically underserved neighborhood. Although this example highlights the process and benefits of using CBPR strategies as a means by which to give a voice to underserved and culturally diverse groups, it is important to recognize that this example is, nonetheless, written from an academic/research perspective. Absent from this article is the individual perspective of the CRRT members who have participated in this research process. Faculty and students interested in engaging in CBPR, therefore, need to remember that the primary aim for community partners is not to disseminate information *via* a peer-reviewed publication. Instead, the primary aim of community partners is to engage with researchers in a participatory research process to improve conditions in their community and eliminate health inequities. This is a worthwhile goal in which everyone should engage and all will ultimately benefit.

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