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Use of Community-based Participatory Research to Disseminate Baseline Results from a Cardiovascular Disease Randomized Community Trial for Mexican Americans Living in a U.S.-Mexico Border Community

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Abstract

Introduction—This article describes the development of a community-based participatory research (CBPR) process conducted in the context of a randomized community health education trial utilizing community health workers (CHWs).

Objectives—To present lessons learned from the utilization of CBPR methodology in a cardiovascular disease (CVD) prevention trial among Mexican American adults in a U.S.-Mexico border community and to disseminate the baseline results associated with risk factors for CVD and their associated demographic and psychosocial characteristics.

Methods—Participants were 328 Hispanic adults ages 30–75 with at least one risk factor for CVD (overweight, smoking, high cholesterol, diabetic or hypertensive), who were recruited through approaching households in randomly selected census tracts within a specified zip code area.

Results—CBPR methods were applied during the different stages of the research enterprise to support the development and implementation of the intervention trial aim at reducing cardiovascular risk factors for Mexican American adults. Data from baseline were used as an important component of dialogue with the community.

Discussion—CBPR proved to be a good learning process for all partners involved. The risk profile of the participants demonstrated the “epidemic” nature of CVD morbidity conditions associated with Mexican origin populations living in a U.S.-Mexico border community. The CBPR dialogue was instrumental as a process to help disseminate to the community the need for projects like the one described in this article.

Keywords

Community health workers; Hispanic; Mexican American; cardiovascular disease; randomized community trial; U.S.-Mexico border; community-based participatory research

Introduction

Many public health interventions that combine community outreach processes and participatory research utilize community health workers (CHWs) to address health disparities among minority groups (Eng et al., 1997; Minkler & Wallerstein, 2003; Brownstein et al., 2005). Building adequate models to address the full spectrum of prevention and control of chronic diseases such as cardiovascular disease (CVD) requires targeted actions from a community systems perspective (Seifer & Maurana, 2000; Brownstein et al., 2005). One way to address this perspective is through the utilization of Community-based Participatory Research (CBPR) methodologies. CBPR methods are anchored in the process of community dialogue and partnerships to better utilize research for the benefits of communities.

CBPR is very closely related to community-oriented primary care, or COPC (Rhyne et al., 1998). Both approaches are focused on the development of collaborative partnerships, facilitating equal input from the community and its stakeholders throughout the research process including planning, implementation, evaluation and dissemination. How to initiate building a community system's perspective utilizing CBPR methods is a key strategy for translating research into practice and for building some elements of sustainability (Castro & Balcazar, 2000; Luna Hollen et al., 2002). Given the burden of the disproportionate prevalence of CVD risk factors present among the Mexican American population, culturally-competent and community-based intervention approaches are needed to combat CVD and its risk factors in this minority population (Castro & Balcazar, 2000; Balcazar et al., 2005a; Balcazar et al., 2006; Allison et al., 2008; Balcazar et al., 2009). Limited empirical data currently exist on how to incorporate CBPR methodologies into the design and implementation of CVD prevention projects among Mexican American populations (Anders et al., 2006).

This article describes how CBPR methods were utilized to bring an initial dialogue to Hispanic/Mexican American families in El Paso, Texas, about their cycle of behaviors that lead to CVD. A community outreach process was guided by CBPR methodologies to disseminate baseline data as part of a four-month randomized community trial (RCT) with the purpose of changing attitudes, behaviors and clinical indicators associated with CVD risk factors. Specifically, this article summarizes the components of the CBPR process and provides baseline results associated with participants' demographic and psychosocial characteristics, as well as CVD risk factors. From a CBPR perspective, we aimed to provide feedback to study participants and the community at large (through newsletters and person-to-person contact) about their clinical results (clinical profile) generated from baseline data. It was hypothesized that given the limited access to healthcare among the anticipated participants and given the lack of collaborative ventures in the community regarding CVD prevention and control, CBPR methodologies would stimulate discussion among partners relative to the participants' clinical values and current health status in order to justify the RCT design at the community level.

Methods

Building the CBPR organizational structure for the project

After funds were secured from the National Center on Minority Health and Health Disparities (NCMHD) of the National Institutes of Health (NIH), the organizational structure for the project was developed. The CBPR partners included: 1) three academic partners: the University of Texas at El Paso (UTEP), the UT School of Public Health, El Paso Regional Campus (UT-SPH), and the El Paso Community College (EPCC); 2) the Centro San Vicente (CSV) clinic that provides services to families and individuals in El

Paso, Texas who do not have access to adequate healthcare; 3) existing CHW network organizations in El Paso (e.g. organizations employing CHWs in a variety of health education and disease prevention settings); and 4) a Community Health Advisory Council (CHAC) developed specifically for this project. This organizational structure was chosen to represent a variety of partner organizations that have great interest in cardiovascular risk factor reductions among Mexican Americans living in the target community. In the context of the CBPR structure, three academic institutions joined forces with the community clinic (CSV) that employs CHWs to support educational health promotion and disease prevention activities. The project also utilized existing CHWs' networks that supported the project in terms of providing feedback to the partners at different stages of the project (including a community forum). The CBPR approach was enhanced by the development of a CHAC to keep the different community stakeholders involved as the project developed.

A project coordinator and student research assistants from UTEP and UT-SPH provided support for the project. As Spanish was the primary language of many people involved in the project, all materials and presentations were available in both English and Spanish.

Implementation of a CHW community forum, focus groups and development of the CHAC

An initial CBPR methodology included inviting CHWs to a forum where different agencies presented their best practices with the delivery of services CHWs performed in the El Paso area. Ten community agencies utilizing CHW services were invited and accepted to participate in a community forum. These community agencies represented a variety of health service organizations with CHW programs associated with chronic diseases including CVD, cancer and diabetes. Each of the community agencies sent two CHWs and an agency representative. Each agency received a small stipend and support from a research assistant to prepare a poster. The forum was attended by 75 people including CHWs representing the ten community programs, the research team and community-based organizations working on CVD prevention and control. Each of the CHW programs' representatives presented their work using a poster display. The forum was held in Spanish with simultaneous English translation available. The CHWs participated in a dialogue with the CBPR partners (academic institutions, the CSV clinic, EPCC) about ideas on outreach and education methods used by CHWs. After an orientation on what constituted an RCT, CHWs provided feedback on the proposed RCT design. The CBPR research partners presented the initial ideas (through simple figures and graphs) of what an RCT that addressed risk reduction in El Paso would look like.

Another strategy to stimulate community involvement included conducting three focus groups consisting of 8–10 participants per group (following recommendations from CHWs of CSV and EPCC). One included women, one included men, and one included community stakeholders (community-based organization personnel, priest, school representatives, police, etc). The focus groups included Mexican Americans living close to the CSV clinic and other areas located near CSV in the lower valley of El Paso. Similar to the participants living in the zip code selected for the study, the focus group participants lived in neighborhoods characterized by a high percentage of Hispanic residents, low educational attainment and low median household income. The focus groups were conducted in Spanish by members of the research team in a community-based organization located in the “Colonias” surrounding El Paso. Colonias are unincorporated settlements that lack the minimum basic services provided by the city/county like water, sewage, garbage collection, electricity, etc. Colonia residents living in the zip code for this project were very low in socioeconomic status and less than 5% of residents have attained a post-high school education (Balcazar et al., in press).

We probed participants' knowledge of CVD and associated risk factors. The topic of CBPR was introduced and their impressions were sought. Finally, we inquired about participants' knowledge and opinions regarding CHWs and their role in the community. The results of these focus groups were used to begin the development of the CHAC and identify potential members. Through the focus groups, community members were nominated who were considered influential and involved in the health and well-being of the community. Potential members were then approached to assess their willingness to serve on the CHAC and invited to one of the monthly meetings. The CHAC consisted of about 15 members and included the head physician of the partner clinic, the local districts' police chief, influential business people, a priest, a parent liaison of an elementary school, CHWs, and the principal investigators of the project. The first function this group performed was to name the community project and approve a logo. The group decided on the acronym H.E.A.R.T.: Health Education Awareness Research Team.

At this point in the project, CBPR methods (focus groups, conducting a community forum, development of the CHAC) focused on engaging all project partners and community members and soliciting input to enhance the development of a health intervention. These activities are very similar to Community-oriented Primary Care (COPC), where community involvement is emphasized in every step of the process of defining the community of interest and their health problems, leading to the development of interventions that have gained input from all parties involved.

Establishing the RCT for the project

The CHAC identified the region outlined by a zip code "X" as the target area, in part because it represented the primary clientele of our partner clinic, the Centro San Vicente (CSV). A windshield survey of the living conditions of the study area was conducted. This was a neighborhood characterized by houses, apartments and small businesses. While most of the buildings were old, they were kept in fairly good condition. Most windows had steel bars on them, but few were broken. Residents' yards were fenced off and some had broken down cars. Streets were kept clean and were mostly in good repair.

The decision of the selection of the target zip code "X" took place in one of the partners' meetings which were held on a regular basis. The selection of the area received full consensus from the CHAC members and the partner organizations. CSV provided further support for the decision given that the educational sessions could be held at CSV. There were no additional suggestions provided by the CHAC relative to whether other areas needed to be considered for the implementation of the RCT intervention.

The Salud Para Su Corazón (SPSC) program from National Heart Lung and Blood Institute (NHLBI) of NIH served as a catalyst for discussion with the CHAC to develop the action plan for the community intervention. Information about prior experiences regarding the implementation of SPSC utilizing CHWs has been published elsewhere (Luna Hollen et al., 2002; Balcazar et al., 2005a; Balcazar et al., 2006; Anders et al., 2006; Medina et al., 2007; Balcazar et al., in press).

After development of the action plan, the research team (staff from the CSV clinic, academic partners, the project coordinator and research assistants) initiated recruitment for the RCT. The target was to recruit 330 Hispanic adults ages 30–75, with at least one risk factor for CVD (defined as having either hypertension, high cholesterol, diabetes, being overweight or being a smoker). Exclusion criteria included having a history of heart disease, non-Hispanic descent, current pregnancy or if the person was likely to move during the intervention. The desired number of participants was based on a priori power analyses

revealing this sample size would be sufficient to detect effect sizes found in prior research (for more details, see Balcazar et al., in press).

The intervention study used an RCT design where participants' selection to the intervention or control groups was based on the census tract they resided in. To account for anticipated higher attrition rates in the experimental group, stratified random sampling was employed, so that a larger number of census tracts would be assigned to the experimental condition. Larger attrition was expected for the experimental group based on the higher intensity of participation with a larger amount of required contacts (Medina et al., 2007).

The intervention group was offered a series of eight health education classes based on the “*Su Corazón, Su Vida*” (*Your Heart Your Life*) curriculum of NHLBI and taught by CHWs (including topics such as ‘*Diabetes*’, ‘*Healthy Nutrition*’ etc.). Each class (2 hours) was delivered weekly for two months. In addition, two months of continued contact with the CHW encouraged participants to make changes as suggested by the educational modules. Control subjects were given the basic educational materials from the curriculum at the baseline assessment. No CHW involvement was provided to the control group. All participants were measured at baseline and at four month post-test for clinical measures and a questionnaire. The clinical research question for the intervention as a whole was: “*Can Promotores de Salud positively change clinical (and behavioral) outcomes in a population of at-risk Hispanic adults?*”

Building the baseline assessment

All measurements were conducted in a portable facility at an elementary school, located in the residential area where most of the participants lived. Informed consent was completed, followed by clinical measures and a questionnaire. Clinical measurements included height, weight, BMI, waist circumference, blood pressure, blood glucose, HbA1c and a lipid profile. With these measurements, risk factors for Metabolic Syndrome and Framingham 10-year CVD were calculated using standard protocols (Wilson et al., 1998; American Heart Association, 2008).

After completion of the clinical measurements, a trained member of the research team administered the questionnaire (approximately 30 minutes) by interviewing the participants in their preferred language. The 82-item questionnaire included questions regarding demographic characteristics, psychosocial measures, behavioral constructs and nutrition indicators.

The behavioral measures were adapted from the SPSC promotora interventions (Moayad et al., 2006) and included perceived susceptibility (feeling that a series of CVD risk factors puts them at risk); perceived severity (feeling that CVD is a serious condition); perceived benefits (benefits of behaviors that will help them control CVD risk factors); perceived barriers (feeling that it is difficult to control their CVD risk factors) and self-efficacy (confidence in the ability to perform behaviors to control CVD risk factors). Finally, the ‘My Habits Scale’ previously tested in several SPSC promotora models (Balcazar et al., 2005b; Balcazar et al., 2006; Anders et al., 2006; Medina et al., 2007) assessed participants’ heart-healthy nutrition behaviors associated with sodium consumption, cholesterol and fat intake and weight-related nutrition intake.

Results

CBPR and the Community Health Advisory Council (CHAC)

All CHAC members received a handbook developed for the project containing a manual of procedures. This manual included: information about the proposal; the purpose of the

project; CBPR principles; the organizational structure with project partners and their roles; and a roster with contact information of the CHAC members. Two bilingual newsletters were produced explaining the activities of the project to the community (available upon request). All partners helped produce these newsletters. The purpose of the newsletters was to inform the community of the project and create awareness, and indicate the recruitment strategies including visiting the neighborhoods to recruit participants for the study. The CHAC had a chairperson and a vice-chairperson, elected through voting by all members at the first CHAC meeting. The CHAC members volunteered their time and met monthly for about 90 minutes. Their participation at the meetings was encouraged but not enforced. CSV staff was in charge of conducting the meetings with support from the academic partners. Input from the CHAC was sought at the meetings regarding the overall project and the progress with collecting the baseline assessment. The CHAC was also instructed to the nature of the RCT that was implemented with community input.

CBPR, research design and implementation of baseline data collection

Integrating CBPR methods with the development and implementation of a robust research design was challenging. Several steps were implemented in the project to assure community participation. First, the CHW-intervention was established by a very demanding recruitment effort. Recruiters visited a total of 3,959 households to recruit 328 participants who completed baseline measurements (192 in the experimental group and 136 in the control group) (Balcazar et al., in press). A total of 286 participants completed the post measures indicating a retention rate of 87% (Balcazar et al., in press).

The recruitment team consisted of graduate research assistants from the academic institutions (UTEP and UT-SPH), CSV personnel, a phlebotomist and CHWs from CSV who provided advice to the team for approaching households. The recruiters approached the households in pairs including at least one bilingual recruiter at all times. When necessary, the CHAC was approached to obtain feedback for the adequate implementation of the recruitment process and to keep them informed about progress.

To maintain enthusiasm from both the experimental and control groups, results of their blood profile at baseline (i.e. lipid profile, fasting glucose, HbA1c) were given to them by the PI and Co-PI of the project. CHWs made appointments with participants in support of this effort. Baseline demographic data were used to provide feedback to the CHAC regarding the implementation of the project and are described elsewhere (Balcazar et al., in press). Of great interest for the CHAC were the results of the lack of health insurance and the percentage of participants in both groups having a family history of CVD and diabetes. The newsletters describing these results were disseminated in the community.

Data from psychosocial information obtained at baseline were also used to provide feedback to the CHAC and the community partners regarding the need to integrate these factors as control variables in the research design. Factors discussed included, for example, the bicultural-bilingual nature of participants and their high family cohesiveness. A conceptual framework was produced to illustrate how social and psychosocial factors are integrated into a research design (Anders et al., 2006). The concept of behavioral theory was also introduced by collecting data from Health Belief Model constructs.

Participants generally scored high on perceived disease severity, susceptibility, benefits, and self-efficacy, but had poor self-reported heart-healthy behaviors. Participants had a low level of acculturation, but stressors of migration mobility and acculturative stress were low among participants (Balcazar et al., in press).

Nearly half of participants had more than three risk factors for metabolic syndrome. Medication use was common: over 40% of the participants used blood pressure medication, nearly 30% used medication to reduce blood cholesterol, and 27.5% used medication to control diabetes. More than one-half of the participants were considered obese (BMI > 30 kg/m²) and none were of healthy weight (BMI ≤ 25 kg/m²). A total of 40% of participants had high systolic blood pressure (≥ 140 mmHg), 44.1% of participants had high total cholesterol (> 200 mg/dL) and 42.1% of participants had high LDL cholesterol (> 130 mg/dL). This CVD risk information was shared with the CHAC members and disseminated via a HEART newsletter.

Discussion

Capturing baseline data: The research interface with CBPR

Linking community action and research can be challenging when community-based interventions require the implementation of experimental designs such as an RCT for disease prevention. For the research team, for example, the recruitment effort was demanding in visiting almost 4,000 households. For participants, understanding of research protocols such as randomization was challenging at times. From a CBPR perspective, baseline data were used to provide feedback to community participants (through newsletters and person-to-person contacts) and to illustrate the importance of data to tell “an initial story” to the community. Also, data were used to stimulate discussion from partners, CHWs and the CHAC regarding the rationale for the RCT and its methods. Unfortunately, specific data to measure success of this interaction were not collected.

A snapshot picture of CVD risk factors in the projects' zip code

Results of the clinical measures provided a strong justification for the need to develop and implement health promotion and disease prevention CBPR programs in the Hispanic (Mexican American) community in El Paso, Texas. Results showed that this community suffers from socioeconomic limitations including low educational attainment and no health insurance for over 40% of participants. The social profile associated with family structure and family support is similar to reported census data and empirical public health studies – high family support, high percentage being married and high family cohesion (Moayad et al., 2006). Further, in the bicultural environment in the border community, residents have kept many cultural traits from Mexican culture, a reflection of their low acculturation status. Thus, the effects of concepts of acculturation, acculturation stress and migration mobility may be different (Byrd et al., 2001).

The cardiovascular risk profile of study participants is of great concern to public health (Hertz et al., 2006). The high family history of CVD and diabetes, poor dietary habits and high prevalence of CVD risk factors (see Balcazar et al., in press) demonstrates the “epidemic” nature of CVD morbidity conditions associated with Mexican origin populations living in El Paso. These statistics are similar to those shown in many other epidemiologic studies and reports conducted in Hispanic/Mexican origin populations (Center for Border Health Research, 2005; American Heart Association, 2007). Baseline data from this RCT set the stage for the CBPR dialogue in the community. We are currently using the baseline-post intervention RCT results to move forward with the second five-year phase of this project (Balcazar et al., in press).

Lessons learned from CBPR at baseline prior to the intervention

Several lessons were learned at the early stages of the CBPR approach prior to the implementation of the community intervention. These included: 1) data from the initial baseline phase of RCTs can be used to provide feedback to the community and its

stakeholders; 2) RCT data from baseline can be presented using simple formats (i.e. charts, pies, graphs) that the community can understand and use to engage in a dialogue with the CBPR team; and 3) both groups (intervention and control) received benefits at the onset of the project regarding their risk profile for CVD.

Lessons learned from the CBPR regarding the planning of the RCT included that the RCT is a method that requires highly-intensive planning from the research team. At times, establishing a rich dialogue with the CHAC was challenging, given the constraints of implementing the RCT design and the need to follow a somewhat “rigid” protocol. Satisfaction data from partners and the CHAC were not collected on a regular basis, which limited the possibility to learn from CHAC feedback and the extent to which CHAC members felt empowered by the CBPR methods used in the project. However, the concept of “ownership” of the project was embraced by the partners, by the CHWs and to a lesser extent by the CHAC given the RCT requirements for maintaining project fidelity associated with the intervention. Finally, CHWs were able to engage very effectively with project participants (both intervention and control groups) given the CBPR action of providing clinical data results at baseline and involvement throughout the project.

The process of empowerment could further be realized through the development of a back-and-forth dialogue between the research team and community partners (i.e. CSV, EPCC) including the CHAC. This dialogue should be maintained throughout the project with a sustainability goal in mind. This goal of sustaining the CBPR efforts should be part of a community discourse that sets goals for building an infrastructure that can operate to empower the process of communication among partners. This effort of empowerment and engagement of CHAC members and partners, including the research team, should be carried on as an important step in the CBPR agenda for the HEART Phase 2 project.

Finally, this project could apply to other countries and cultures in the sense that CBPR methods are not exclusive to any community and these methods need to be part of an important agenda for the elimination of health disparities and for building health equity (Balcazar et al., manuscript submitted for publication).

Conclusions

Working with communities to deliver culturally-competent and evidence-based health promotion and CVD prevention is an art and requires a complex process of research and action (Balcazar et al., 2005b). Engaging in CBPR strategies and activities when delivering RCT designs is challenging, but also provides opportunities for community participation. Given the complexity of RCT methods, engaging the community in CBPR activities at the planning stages of the project before intervention requires a strong method of community engagement with a limited window of opportunity, in terms of time and place requirements, and possibly limited flexibility of action for changing RCT design elements. However, CBPR provides an opportunity for building an initial buy-in with the community if a strong collaborative process is developed at the forefront of the research-community engagement enterprise. Educating all partners about “health concerns” with the CBPR process within an RCT methodology can be done, but the “right” investment has to be made in communities when integrating culturally-competent elements with evidence-based health promotion programs for Hispanic communities, like the one presented in this project in El Paso, Texas.

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