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A Community-Based Participatory Approach to a Hepatitis B Intervention for Korean Americans

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Abstract

Background—Hepatitis B virus (HBV) infection and liver cancer are severe health problems among Korean Americans. Most Korean Americans are neither screened nor vaccinated against HBV owing to substantial access barriers.

Objectives—The primary objective of this article is to highlight how our team of academic researchers and community partners worked together to apply a community-based participatory research (CBPR) approach to developing, implementing, and evaluating a culturally appropriate, church-based HBV screening and vaccination intervention program for Korean Americans.

Methods—Guided by CBPR, multiple strategies were used to form academic–community partnerships in the development and implementation of the culturally appropriate HBV intervention program in the Korean-American community. These include the formation of a community advisory board (CAB) and adoption of CBPR principles, community needs assessment, development and evaluation of the pilot intervention program, and the full-scale community controlled trial.

Results—The pilot intervention results indicated significant increases in screening and vaccination rates in the intervention group compared with the control group. With the success of the partnership and pilot study, Korean church leaders, CAB members, and researchers are currently co-leading a full-scale intervention study to further evaluate the effectiveness of the intervention program.

Conclusion—The current study highlights the role and contributions of multiple partners through five phases and discusses the challenges and lessons learned for how to sustain intervention programs by emphasizing common vision, trust development, shared recognition, capacity building, long-term commitments to partnership building, and balance between science and community needs.

Keywords

Community-based participatory research (CBPR); hepatitis B; Korean Americans; HBV screening; HBV vaccination

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A key strategy for reducing ethnic health disparities is CBPR.[1,2] CBPR provides a collaborative approach to research that equitably involves academic and community partners in the research process.[2] Fundamental to CBPR are principles of co-learning, mutual benefit,

and long-term commitment, as well as a focus on incorporating community participation and practices into academic research efforts.[3] Despite well-documented intervention studies in mainstream and other ethnic communities, a limited number of studies have been reported using the CBPR approach to tackle health disparities among hard-to-reach Asian-American communities.[4]

Korean Americans represent a rapidly growing ethnic community, currently the fifth largest among Asian-American groups in the United States.[5] Nearly 80% of Korean Americans attend churches regularly, making churches ideal venues for promoting and implementing health programs.[6,7] For the Korean-American population, church service is an important social and educational center that provides cultural ties, identity, and acceptance as part of the community and social network.[8]

Despite the proven efficacy of HBV screening and vaccination in preventing HBV infection, most Korean Americans are neither screened nor vaccinated against HBV.[9–12] Comparative data indicate that incidence and mortality rates of liver cancer are five times higher in Korean Americans than those in non-Hispanic White Americans.[13] The substantial access barriers to health care may include limited or no health insurance, lack of regular physicians, low income, and a lack of general knowledge about liver cancer risk and the benefits of screening and vaccination, as well as a lack of familiarity with the U.S. health care system.[10,14,15]

To address these barriers, our team of academic researchers and community partners worked to apply the CBPR approach to develop, implement, and evaluate a culturally appropriate, church-based HBV screening and vaccination intervention program for Korean Americans. To the best of our knowledge, this program is the first study that has used a CBPR approach in all aspects to balance the science and community needs among Korean church-based social groups.

METHODS AND RESULTS

This CBPR Korean HBV intervention program was built on an established academic–community partnership network, part of NIH-NCI funded Special Population Networks (2000–2005), Community Networks Program (2006–2010), and Community Networks Program Centers (2010–2015), to address cancer health disparities in racial/ethnic minorities and other underserved populations by using CBPR. These academic–community partnership networks are led by the Center for Asian Health (CAH) at Temple University in collaboration with the Asian Community Health Coalition (ACHC), a community-based organization consisting of 240 partner organizations. Guided by CBPR principles, the CAH and ACHC have worked together since 2000 to ensure equal and complementary academic and community partnership in developing and implementing a series of cancer and chronic disease outreach, education, and research programs to address cancer health disparities in underserved Asian-American populations. The target populations and communities are diverse Asian-American ethnic groups, including Koreans, who reside in Pennsylvania, New Jersey, New York City, and other mid-Atlantic areas. The culturally appropriate, church-

based HBV screening and vaccination program for Korean Americans is one of these programs.

This research program was approved by the Institutional Review Board of the lead organization and key partner organizations for the Protection of Human Subjects. It used CBPR principles to guide the process of involving partners equally across all phases of the research in developing, implementing and evaluating the protocols and pilot intervention. To date, we have undertaken five phases of the program (Table 1): (1) formation of CAB/partnership and adoption of CBPR principles, (2) a community needs assessment, (3) development of a culturally appropriate HBV intervention, (4) evaluation of the pilot HBV intervention in local communities, and (5) community voice from pilot intervention to a full-scale research intervention.

Phase 1. Formation of CAB/Partnership and Adoption of CBPR Principles

The Asian CAB was established in 2000 when the ACHC became a full partner of CAH. The CAB, composed of representatives from partner organizations (three from community-based organizations, six from Korean churches, two health care providers, and one from an academic institution), guides all aspects of the partnership and Korean HBV intervention program activities. The CAB serves as the liaison between CAH and the Asian community at large and serves as an advisory and oversight body for CAH to ensure the CBPR approach to the development of culturally appropriate cancer intervention programs. The CAB holds formal meetings and ad hoc meetings regularly. All CAB meetings are agenda driven, and members are encouraged to post agenda items for discussion. The CAB chair ensures that all members have equal and timely access to information regarding project activities.

The CAB adopted a set of CBPR principles that guided the development, implementation, and evaluation of the culturally acceptable intervention and research protocols.[2,16,17] These principles were manifested in our program planning, developing, implementing, and dissemination of the results of the community-based research protocol.

As the lead organization, the CAH formed a partnership with the ACHC and its partner organizations of 30 Korean churches in Pennsylvania and New Jersey. A critical and essential element of our successful CBPR partnership was the establishment of trust and credibility within the targeted Korean church community, which was tied together with an effective communication and equal decision-making process during the program development and implementation. To strengthen the academic–community collaboration, one of the church pastors, who was trusted and influential in the regional Korean churches and dedicated to congregational health, was intensively involved from the beginning as the community co-principal investigator (CO-PI) of the program and provided constructive inputs continually in working with the advisory board. Beyond regular group planning meetings between academic and community partners, the community CO-PI took an active role in advocating the program in Korean churches, encouraging pastors' participation and soliciting feedback from churches. Pastors of participating churches appointed a respective church liaison to interact with the research team and church members. In addition, a full-time bilingual bicultural community coordinator/educator was hired at the lead institute to closely work with the church pastors and church-designated staff in the process of project

planning, participant recruitment, and workshop administration, and provided ongoing technical assistance to participating churches. In addition, this coordinator attended regional pastor monthly meetings, church services, and other social activities to increase church partners' understanding and engagement in the program. The pastors and their congregations were engaged in all phases of the program.[2] The key collaborative partners developed memorandums of understanding to define the roles and responsibilities, implementation procedures, and timeline of the research program.

To ensure a shared understanding of both research and CBPR approach, cross-training sessions were conducted among research scientists and church leaders/community partners. Research scientists provided the training to community leaders on various aspects of research and community leaders organized training for researchers emphasizing the key elements of conducting research in the community.

Phase 2. Community Needs Assessment

To form a mutually trusted partnership and gain indepth knowledge about the Korean-American community and in particular, Korean churches, we conducted in-person interviews with Korean pastors (n = 30) in Pennsylvania and New Jersey with the aim of identifying key characteristics of church members to refine, synchronize, and ensure that intervention components were culturally relevant and that the timing of the intervention was feasible and harmonious with church activities.

Another Korean community needs assessment (n = 384) was part of the comprehensive Asian community participatory assessment (n = 2,011) to identify the needs of Asian-American subgroups (Chinese, Korean, Vietnamese, and Cambodian) in cancer screenings for breast, cervical, prostate, HBV-liver, and colorectal cancers, in addition to routine health examinations. Detailed needs assessment results have been published elsewhere.[10,18–22]

The community needs assessment results indicated HBV as one of the top priorities by Korean Americans and other Asian American groups. Of the 384 Korean Americans who participated in the study, more than 53% reported that they do not have health insurance and 52% reported that they had no regular physician. "Never screening" rates of Korean respondents were 67.8% for HBV.

Phase 3. Development of Culturally Appropriate HBV Intervention

Based on the in-depth interviews with Korean church leaders and community needs assessment results, we identified the needs and received strong support from the Korean community to develop a culturally and linguistically appropriate HBV intervention program to increase awareness of HBV and liver cancer and participation in HBV screening and vaccination. A series of intervention planning meetings were held with CAB members and Korean church leaders to further develop the intervention by discussion, providing input, and making recommendations to ensure that the program was culturally appropriate, responded to community needs, and was feasible, acceptable, and accessible to the Korean-American community members. For example, to respond to the high proportion of community members who are underinsured or uninsured, do not have a regular physician, or have limited English ability, we negotiated with health providers to lower the cost of HBV test,

vaccination, and clinical consultations, as well as providing patient navigation and assistance.

Goals for this HBV intervention were to increase knowledge and awareness about HBV, to increase HBV screening and vaccination rates, and the utilization of health care for chronic HBV carriers. Church leaders and CAB members were actively involved in the intervention planning and development; their views on cultural issues as well as the program settings were well received and incorporated into the program curriculum. For example, through our communication with the Korean-American community, we found that the reason some Korean Americans have for not testing their HBV infection status is that they feel embarrassed or ashamed of being diagnosed with HBV infection and fear that their relatives and friends might find out their status and become distant from them. In response to this issue in the cultural context, the program educated the community about HBV transmission channels, including vertical transmission, to eliminate misperceptions, as well as to emphasize the benefits of HBV testing and vaccination to reinforce the community's perceived responsibilities and value to protect their family members.

Phase 4. Evaluation of the Pilot HBV Intervention in Local Communities

Design and Implementation—The pilot study used a quasi-experimental design with intervention and control groups. The purpose of the pilot intervention was to assess the intervention program's feasibility, study design, evaluation methods, and challenges encountered by implementing the program at churches. Representatives from four Korean church sites, who are CAB members, volunteered to be part of this HBV intervention pilot study. Two sites were assigned as the intervention group and two sites as the control group. Pastors and community health workers announced the study to church members and invited them to participate. Participants (n = 330), aged 21 and over, were recruited. Workshops were conducted after church services on weekends. Assessment time intervals were at baseline, postintervention, and 6-month follow-up for HBV screening and 12-month follow-up for HBV vaccination. Baseline and postintervention assessments were conducted in person; the 6- and 12-month follow-ups were conducted by phone. We were able to verify self-reported screening and vaccination for 95% of participants who provided consent.

Design elements that facilitated the intervention include direct engagement of church leadership, church health workers, bilingual physicians, and experienced multicultural field research staff. Participant recruitment strategies and tools were co-developed by the community CO-PI, church coordinator, CAB, and the project PI. These included church pastors' announcements after mass services, community coordinators' project assignments, trained church health workers' program flyer distribution to church members, and assistance with registration. Church leaders and staff used an HBV fact sheet, program recruitment flyer, and registration sheet to facilitate participants' recruitment, and trained church health workers worked with research team staff to co-deliver the educational sessions. Most of the sessions were conducted after church services. The involvement of bilingual physicians, provided with clinical support, ensured successful vaccination follow-ups. For example, physicians provided more flexible open hours of clinic operation with bilingual medical staff on site.

It is noteworthy that, in the pilot study planning phase, academic researchers and church partners discussed the strategy for a control group. The discussion resulted in a joint decision of a delayed HBV intervention for the control group to balance research and ethical consideration for community benefits.

Results of the Pilot Intervention—The pilot study results indicated a significant increase in HBV screening in the intervention group from baseline to the 6-month follow-up, but not in the control group (intervention, 58.5% to 95.8% [$p < .001$]; control, 38% to 39.8%; group difference, 37.8% vs. 1.8% [$p < .001$], respectively). The conversion screening rate of baseline noncompliant (those who never had HBV test) to 6-month follow-up compliant was 93.1% for the intervention (82 screened/88 never screened) and 2.9% for the control (2 screened/70 never screened) groups. The demonstrated significant short-term intervention effects of primary outcomes are 90.2% (93.1% vs. 2.9%) for screening conversion rate and 33.0% (33.0% vs. 0%) for vaccination prevalence rate.

In terms of the program evaluation, more than 95% of participants in the intervention group reported that the program taught them how to obtain HBV screening and vaccination and they learned new skills through participation in the intervention. The results of the pilot intervention, presented to community partners, demonstrated its feasibility and promising effect.

Phase 5. Community Voice from Pilot Intervention to a Full-Scale Intervention Research

The pilot study indicated that CBPR and a culturally appropriate HBV intervention can increase Korean Americans' awareness and participation in HBV screening and vaccination. After the completion of the pilot study, the academic–community research team discussed the preliminary results with participating church leaders and clinical partners to inquire about challenges and facilitating factors associated with the pilot study implementation and how the intervention could be improved to more effectively address participants' needs and better fit the organizational structure of Korean churches.

Feedback was helpful in fine tuning the content of education, survey questions, and language expressions, as well as the education delivery format. The data collected from the interviews with church leaders and the group discussion after the pilot study clearly demonstrated the desire and need from the Korean church community to expand the program into the larger Korean community. Thus, a large, community-based, controlled trial of HBV intervention was officially recommended by CAB members.

With the success of the pilot study, fine tuning of the intervention program as well as the CAB recommendations, the research team submitted a grant proposal and was awarded by NIH-NCMHD to implement a full-scale, 5-year intervention research protocol (R24MD002756). The program is co-directed by academic researchers and church leaders who share equal decision making powers. Currently, 30 Korean churches have participated in this large-scale community intervention trial in Pennsylvania and New Jersey.

In addition to efficacy evaluation, process evaluation is used in this full, large-scale project to monitor the impact of CBPR process on HBV intervention in Korean churches. Data from

both evaluations will be reported separately later. This is an ongoing effort that focuses on compliance of study protocols, attrition, intervention satisfaction, and cost tracking. For example, participants are asked to evaluate their satisfaction of the education intervention. Furthermore, the research team adapted Bell-Elkins questionnaire[23] to assess the level of adherence to each CBPR principle in various stages of the research project, organizational partnerships, and resources.

We anticipate that the results of this large CBPR intervention will further demonstrate the effectiveness of a culturally appropriate HBV intervention for the Korean community. In addition, this academic–community partnership guided by CBPR principles will be strengthened and expanded to potentially make sustainable contributions to reducing cancer health disparities.

CHALLENGES AND LESSONS LEARNED

Our study demonstrated that using a CBPR approach to guide the research process will be more likely to increase the success and sustainability of a research program. It is imperative that community partners participate in all phases of a research project so that the academic–community research team can work together to better respond to the needs of targeted communities and adopt community inputs into the program. Although our program was successful overall, we did encounter a number of expected and unexpected challenges and learned some critical lessons during the process; some of these might be unique to this community. For example, some of the important challenges we faced during the implementation of this CBPR program include financial constraints, access barriers encountered by underinsured and uninsured program participants, participants with limited English proficiency, and pastors with limited time. In the following section, we will how we established a CBPR research model in the Korean-American community to overcome these challenges through our collective efforts and innovative strategies.

Common vision and shared responsibilities to improve the health and quality of life of Asian Americans including Korean Americans has drawn all partners together to tackle HBV infection, one of the most prevalent but preventable diseases among Asian populations. With a common interest, researchers, church leaders, community health educators, and community health workers, and health care providers have volunteered their time to participate in the delivery of the intervention. Through the comprehensive intervention of HBV education, patient navigation for screening and vaccination, community partners witnessed the benefits that the community received, and thus were motivated to continue their long-term efforts and commitment to the program. For example, to overcome financial constraints, we made efforts to leverage resources from private sectors to provide low-cost treatments for uninsured individuals with HBV infection. In addition, we were able to negotiate a lower cost for HBV screening, diagnostic tests, vaccination, and clinical consultation. Our goal is to use a CBPR approach to work with all partners to make HBV early detection, vaccination, diagnostic testing, and treatment affordable and sustainable in daily clinical practices.

Another constraint that our participants faced was clinic hours, which conflicted with their long work hours. To resolve this issue, the clinics offered extended and more flexible hours, including evenings and weekends. For those clients with limited English proficiency, we provided bilingual clinical support and patient navigation.

Trust, mutual respect, and commitments are foundational elements for engaging communities in research. CAH and ACHC have a longstanding history of a cordial and professional working relationship with Korean communities, and many Korean Americans have participated in the community assessment and intervention planning process that led to the development of the pilot intervention and full-scale program. Trust was built on mutual respect and benefits; it cannot be taken for granted, and research partnerships and community and faith-based organizations must continually foster and nurture trust over time.[24–27] In addition to the planned meetings and discussions for the intervention program, CAH, the Asian CAB including Korean community leaders, and the ACHC meet frequently to provide opportunities for all partners to express their opinions, exchange ideas, and share resources to increase trust and garner a commitment from one another. Cultural beliefs and customs are taken into careful consideration in the communication and interaction among all partners. For example, attending community gatherings and cultural festival events are always carried out in a culturally sensitive and appropriate manner. Similarly, to overcome the challenge of pastors with limited time for this program, we worked closely with the pastors to make social and health concerns part of their mission. They then “bought in” to the program as part of their overall pastoral goals.

In contrast with a one-way relationship in which only researchers benefit, facilitating a sense of partnership through co-learning and an empowering process undoubtedly increase the capacity building among all partners. In this program, community partners received not only direct services, but also training about research design and implementation procedures; the academic team members have gained firsthand experiences in applying CBPR principles and methods, obtained opportunities for community-based training, and, most important, this process established platforms and built foundation for implementing other intervention programs such as Korean cervical and colorectal cancer prevention programs. Clinical partners have gained knowledge of research and expanded their service zone, which in turn, may lead to long-term practice enhancement. For example, we navigated those HBV nonimmune and carriers identified through our HBV intervention program to see our clinical partners for immunization or clinical evaluation and treatment. These participants became regular patients to these clinical partners and some of them participated in clinical trials through these doctors’ recruitment. This process enabled us to make more efficient use of community resources, which have greatly contributed to the accomplishments of our HBV intervention among Korean communities. One of the lessons that we learned from this project is that it is essential to work with long-term committed and passionate community/church health workers to maintain sustainability. We built on the strengths and resources within the church, including volunteer church members, nurses, and physicians as part of our co-sharing model. It is also important to avoid overburdening community leaders in the recruitment and retention process. Through these strategies in working with Korean churches, which arguably are the pillars of the Korean immigrant communities, we were able to draw on key community assets to fully engage the community in the program.

As important as sharing responsibilities, sharing credit and recognition among partners is another central principle in CBPR. We ensured that church leaders and CAB members involved in the project are co-partners in program dissemination. The entire research team, consisting of academic investigators, church, leaders and members of the CAB, co-authored and co-presented the study results at national scientific conferences and community meetings. We believe that shared recognitions will facilitate sustainable partnerships for future collaboration.

Corroborating with the findings from other ethnic groups,[28] we recognized the importance of establishing rapport among partners. To strengthen the collaboration among pastors, church coordinators, and health educators, it is essential for health educators to attend services at participating church sites. This participation not only indicates the appreciation for community services, but also provides valuable opportunities for health educators to mingle with church members and become familiar with the operation and facilities of each church, which enhances the quality of implementing intervention sessions and maximizing community resources that are available for program participants.

Balancing research goals while meeting community needs can be challenging.[29] In contrast with traditional research design, much of CBPR to date has been focused on process.[30] It may be unacceptable to community partners that only some sites will receive the intervention program by using a traditional research design. However, the effectiveness of interventions often requires a rigorous scientific design and concrete data collection. For example, our academic–community partners co-designed the HBV intervention program and found ways to both adhere to evidence-based research principles and to incorporate community needs. An agreement was reached that the delayed intervention was provided to the control group. Our program demonstrated that it is possible to achieve the balance between scientific design and community acceptability by using a CBPR approach.

CONCLUSION

Guided by CBPR principles, the multicomponent HBV intervention program was developed and implemented by a collaborative team of academic–community–clinical partners to address the unmet needs of the Korean-American community. We highlighted the role and contributions of multiple partners through various phases and discussed the challenges and lessons learned for how to sustain intervention programs by emphasizing common vision and shared responsibilities for sustainability, trust and shared recognition, capacity building, long-term commitments to partnership building, and balance between science and community needs. These strategies enabled us to draw on key Korean community assets by fully engaging Korean churches in the program.

We believe the publication of this study is a unique contribution to the body of literature in the CBPR research field. In illustrating how we used a CBPR approach in our HBV intervention program, we hope the methods for intervention development and implementation can be adapted to develop education interventions to address other health issues (e.g., cancer screening and chronic disease screening) among Korean Americans. We anticipate that the systematic and comprehensive evaluation of CBPR in our full-scale

intervention research will shed more light on future CBPR research. Moreover, we call for further research to replicate our program and examine the degree to which our findings are unique to Korean churches or whether they are applicable to other ethnic faith-based communities.

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Table 1

Phases of CBPR Activities and Role of Partners

CBPR Principles	Role of Academic Researchers	Role of Community Partners	Joint Decisions
Phase 1: Formation of CAB/partnership and adoption of CBPR principles			
Recognizing the community as a unit of identity. Building on strengths and resources within the community. Facilitating collaborative partnerships in all phases of the research. Integrate knowledge and action for mutual benefit of all partners. Promote a co-learning and empowering process that attends to social inequalities.	Provide research expertise.	Serve as the liaison between research team and the Asian community at large.	Develop memorandum of understanding (MOUs). Decide orientation session on CBPR and research methods. Provide cross-training. Meet regularly.
Phase 2: Community Needs Assessment			
Build on strengths and resources within the community. Facilitate collaborative partnerships in all phases of the research. Involve a cyclical and iterative process; address health from both positive and ecological perspectives. Disseminate findings and knowledge gained to all partners including community members in ways that are understandable and useful.	Work with the church leaders to collect information in a comfortable and respectful way. Determine what information is relevant. Provide examples of best practice for in-depth interview, survey data collection, and analyses. Discuss common challenges in conducting in-depth interview and survey, Conduct in-depth interview and survey.	Reflect the community's perspective on in-depth interview Provide suggestions on questions to ask and wording Provide suggestions for recruitment methods and for selection of church leaders and community health workers. Share information to help better understand strengths and challenges within the community. Recruit survey participants.	Decide on questions, wording, and format of questions. Select locations in which to conduct in-depth interview and survey. Code and analyze data, discuss and interpret the results. Convene community forums.
Phase 3: Development of a culturally appropriate intervention			
Facilitate collaborative partnerships in all phases of the research. Integrate knowledge and action for mutual benefit of all partners. Involve a cyclical and iterative process; address health from both positive and ecological perspectives.	Conduct a systematic literature review. Summarize primary findings from best practice program, identify specific needs from Korean Americans. Design core elements of the intervention program.	Help to format key findings from literature to enhance the program development. Provide feedback on what is appropriate and what is missing from the program.	Intervention planning meetings. Develop education curriculum.

CBPR Principles	Role of Academic Researchers	Role of Community Partners	Joint Decisions
		Provide views on cultural issues and program settings.	
Phase 4: Evaluation of the pilot hepatitis B intervention in local communities			
Facilitating collaborative partnerships in all phases of the research. Integrating knowledge and action for mutual benefit of all partners Involve a cyclical and iterative process; address health from both positive and ecological perspectives. Disseminating findings and knowledge gained to all partners including community members in ways that are understandable and useful.	Develop easy to understand questions to help participants express their knowledge, behavior, and health beliefs Conduct the pilot intervention Assist patient navigation	Recruit participants Church health workers support professional staff with administration Bilingual physicians provided with clinical support Discuss the strategy for the control group Provide honest feedback about strengths, challenges, and recommended changes to the program	Delayed hepatitis B intervention for the control group Discuss feedback and how best to modify and expand current programming Recommend a full-scale intervention
Phase 5: Community voice from pilot intervention to a full-scale intervention research			
Build on strengths and resources within the community. Facilitate collaborative partnerships in all phases of the research. Integrate knowledge and action for mutual benefit of all partners. Promote a co-learning and empowering process that attends to social inequalities. Involve a cyclical and iterative process; address health from both positive and ecological perspectives. Disseminate findings and knowledge gained to all partners including community members in ways that are understandable and useful.	Write the full-scale research proposal and seek for funding. Oversight the full-scale intervention. Assist patient navigation.	Assist publicizing the program. Recruit participants. Church health workers support professional staff with administration. Bilingual physicians provided with clinical support.	Fine tuning the content of education, survey questions, and language expressions, as well as education delivery format. Assess the level of adherence to each CBPR principle.