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CBPR-Informed Recruitment and Retention Adaptations in a Randomized Study of Pap Testing Among Pacific Islanders in Southern California

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Abstract

Background—Pacific Islanders (PIs) experience high cervical cancer rates in the United States. Stage of diagnosis is also later for PIs than non-Hispanic Whites. The Pap test is severely underutilized among PIs: only 71% of Asian American and Pacific Islander women age 25 years or older received a Pap test within the last 3 years (U.S. average, 82%). Community-based participatory research (CBPR) is increasingly seen as an essential approach in designing and conducting culturally relevant and appropriate studies that reduce cancer incidence and other health disparities among minority and other medically underserved populations.

Purpose—The purpose of this article is to describe the lessons learned thus far regarding the identification, recruitment, and retention of PI community organizations and members into a CBPR-informed, randomized, community trial promoting Pap testing.

Methods—This 5-year study used CBPR to develop and test the efficacy of a social support intervention for Chamorro, Samoan, and Tongan women to increase Pap testing in southern California. Eligible women were between the ages of 21 and 65, and married or in a long-term relationship with a man for at least 5 years. Women and their husbands or significant others received a 2-hour, culturally tailored workshop that include a group activity, information on Pap testing, a video, and corresponding materials. Comparison participants received a brochure about Pap testing. Three waves of data are collected from all participants: pretest (before workshop or brochure), posttest 1 (immediately after workshop or brochure), and posttest 2 (6 months follow-up).

Results—Of the 76 organizations approached to participate in the study, 67 (88.2%) eventually agreed to participate. Thus far, 473 women and 419 men completed the study pretest, post-test, education, and 6-month follow-up. Only 242 women and 204 men of the eligible participants have completed the follow-up survey (63.5% of women and 60.5% of men retained after 6 months).

Lessons Learned—The main strategy to overcome initial recruitment challenges was study staff persistence, because they averaged five contacts with each church or clan leader before receiving confirmation that an educational session can be scheduled. Personal connections provided an introduction to the most appropriate church or clan leader. Other efforts for retention include creation of an online version of the survey, re-attending church services, and creating special events organized around clan activities.

Conclusions—Although CBPR improves the cultural competence and relevance of study activities for ethnically diverse populations, selected past research shows that it does not ensure that such designs overcome all of the unique challenges in ethnically diverse communities. PI-specific organizational recruitment and individual retention is influenced by study issues and cultural factors in each community.

Keywords

Community health research; health promotion; process issues; health promotion; vulnerable populations

PIs are one of the fastest growing populations in the United States, numbering more than 1.2 million in 2010.¹ Outside of Hawaii, California is the state with the largest PI population, with nearly 40% of California PIs living in the Los Angeles area.² PIs experience high cervical cancer rates in the United States. Stage of diagnosis is also later for PIs than non-Hispanic Whites: only about 40% of cervical cancers in non-Hispanic Whites are found at the regional or distant stage, compared with nearly 60% of Native Hawaiian and Samoan women.³ Pap tests remain an important cervical cancer prevention and detection method for U.S. women.⁴ The American Cancer Society recommends that women begin Pap testing no later than 21 years of age, and get them on a regular basis. The American Cancer Society defines regular Pap tests as annually for women from ages 20 to 30, and every 2 to 3 years after age 30 after at least three consecutive past normal tests.⁵ Unfortunately, the Pap test is severely underutilized among PIs: a large national study found only 71% of Asian American and Pacific Islander women age 25 years or older received a Pap test within the last 3 years compared with the U.S. average of 82%.⁶

CBPR is increasingly seen as an essential approach in designing and conducting culturally relevant and appropriate studies that reduce cancer incidence and other health disparities in minority and other medically underserved populations.⁷ Unfortunately, relatively few CBPR health disparity efforts have included PIs despite their disproportionately high rates of cervical and other cancers.^{3,5,8,9} CBPR promotes the active collaboration of community members and university researchers in all aspects of a research endeavor, leading to improvements in intervention design, participant recruitment, data analyses, and interpretation.^{7,10} Although there are an increasing number of studies documenting successes in these processes and outcomes,^{11–13} relatively few discuss how CBPR collaboratives identify and adapt to the many challenges that arise from empirically rigorous research aims and designs.¹⁴ For instance, one purported benefit of CBPR is the increased ability to enroll and maintain significantly underserved and unengaged community members in research through community-informed recruitment and retention strategies,¹² yet past studies with impressive recruitment and retention rates lack descriptions of how the

collaborative successfully addressed challenges and adapted strategies.¹⁵ As new researchers enter the CBPR field, such lessons learned are increasingly important to inform future studies. Therefore, the purpose of this article is to describe the lessons learned thus far regarding the identification, recruitment, and retention of PI community members into a CBPR-informed randomized community trial promoting Pap testing among PI women in the United States.

METHODS

Study Population

In California there are more than 280,000 PIs, including more than 60,000 Samoans, nearly 23,000 Tongans, and more than 44,000 Chamorros, who are indigenous people from Guam and the Northern Mariana Islands.¹⁶ The counties of Los Angeles, Orange, Riverside, and San Bernardino comprised the study's geographical area, and has more than 105,000 PIs, including nearly 30,000 Samoans, more than 14,000 Chamorros, and more than 6,600 Tongans.² PIs in this area face significant barriers to regular health care: average per capita income is only \$21,887 compared with \$27,724 for Californians overall, and only 20% hold bachelor's degrees compared with 28% for Californians overall. More than one third (37%) of PIs in this area speak a language other than English at home, and 17% lack health insurance.¹⁷

Study Overview and CBPR Collaborative

This 5-year randomized study used CBPR to develop and test the efficacy of a social support intervention for PI women to increase Pap testing in southern California. Eligible women were Chamorro, Samoan, or Tongan between the ages of 21 and 65, and married or in a long-term relationship with a man for at least 5 years, and willing to participate in an educational session and three waves of data collection, which include a pretest, immediate post-test, and 6 month follow-up. Eligible men were married or in a long-term relationship with an eligible PI women, and willing to participate themselves. Although this study was designed for heterosexual couples, same-sex female couples were not excluded from participating if interested, although to date none have participated. Both women and men were recruited and invited to bring their partner to participate, after which they were assigned to one of two educational options: a gender-specific social support-informed intervention session, or gender-specific "usual care" control session. An immediate post-test assessed changes in intentions for women's Pap testing and men's support of Pap testing, and the 6-month follow-up assessed changes in women's and men's behaviors.

The study partnership involved one university and three PI-serving community-based organizations in Southern California. All partners have had long-standing research relationships with one another,^{18–20} and the partnership is led by two principal investigators, one community and one university, who successfully spearheaded two past studies on women's breast cancer screening. Co-investigators include two theoretical and statistical experts from the university partner to participate along with the directors of the Chamorro, Samoan, and Tongan community-based organizations, all of whom have worked in their ethnic-specific communities for many years. Study staff includes two program managers,

one university and one community, who coordinated all study planning and implementation activities. Two health educators from each of the three populations conducted all organizational and individual recruitment, intervention and control sessions, and data collection. Monthly all-staff study meetings, monthly health educator meetings, and more frequent phone and email interactions occurred throughout the study period. Last, the community advisory board (CAB) met twice a year and was composed of three leaders from each community, such as pastors, clan leaders, and cancer survivors. The CAB advised the study team on specific aspects of the study design and implementation, including strategies for recruitment in the church and clan setting, appropriate wording for surveys, and feedback on the overall study from the point of view of well-connected members of their respective communities.

Educational Sessions and Instrument Design

Development of separate women's and men's education sessions was guided by social support theory, which posits that emotional and instrumental support from close others improves health behaviors, health status, and well-being.^{21,22} Through a 1-year process of monthly meetings with all staff, a 2-hour group-based educational session was designed that encouraged women's Pap testing for the health of the woman, her relationship with her significant other, and her entire family. After presentation of basic cervical cancer and Pap testing information, in-depth discussions were facilitated by the PI staff. A video was designed that reinforced these messages from the point of view of Chamorro, Samoan, and Tongan couples, and ends with men urging their wives or significant others to be screened. The session ended with verbal commitments by women to get screened, and with handwritten notecards promoting screening by men to be shared with their wives or significant others. In the gender-specific control sessions, existing Chamorro, Samoan, and Tongan materials on Pap testing for women and general men's health information for men were distributed and discussed by the health educators.²³

After the development of the educational sessions, three instruments (pretest, posttest, and 6-month follow-up) were designed for women and for men to assess the following: demographics, acculturation,²⁴ social desirability,²⁵ Pap testing knowledge,^{26–28} cervical cancer knowledge,^{29–31} attitudes and beliefs,^{29,31} social support,^{32,33} and family function.^{34,35} The women's pretest survey also included questions about past Pap testing and decision making, and the posttest survey asked about future Pap testing intention.³⁶ Questions concerning Pap tests included the following: when was their last Pap test, who may have recommended that they receive the test, and the main reason why they had the test. The women's and men's follow-up surveys also included questions on Pap testing for women, provision of social support for men, and exposure to the intervention or control information for both women and men. All survey translation from English into the Samoan and Tongan languages was completed by bilingual and bicultural translators, and then independently reviewed by another translator for clarity, simplicity, minimal use of jargon, and use of words with equivalent conceptual and cultural meaning to PI adults. Discrepancies between translators were discussed, with resolutions shared with the CAB for final approval. Most Chamorros age 21 to 65 speak and read in English; therefore, survey translation was deemed unnecessary by the Chamorro health educators and CAB members.

Surveys were pilot tested with three women and three men from the Samoan, Chamorro, and Tongan communities.

Organizational Recruitment

PI communities are highly collective, and churches and clans are important avenues for reaching PIs in the United States.^{37,38} For this study, lists of the Chamorro, Samoan, and Tongan organizations in Southern California were developed by staff from the three community organizations based on their deep knowledge of and experiences with their own communities. Each organization was either a Chamorro clan, or Samoan or Tongan church, and was characterized based on ethnic affiliation and the estimated number of women who would be eligible for the study. Each organization was then randomly assigned by the study statistician to either the intervention or control arm of the study so that organizations were evenly distributed in each arm with respect to estimated numbers of eligible women. In addition, organizations with preexisting relationships to other organizations, such as through joint youth choirs or women's social groups, were assigned to the same arm to prevent potential information sharing between intervention and control group participants.

Each organization was contacted by study staff and asked for a meeting to introduce the study aims and procedures. During individual meetings, study staff provided interested organizations with an introductory letter signed by the study principal investigators and an overview of the study needs. Each organization was to recruit a minimum of six women and six men per site, and to host a 2-hour educational session regarding Pap testing. Study staff provided information on available incentives for the individual participants, which include a \$10 gift card for participating in the session, pretest, and post-test, and a \$15 gift card for participating in a 6-month follow-up survey. Organizations that agreed to host an education session were given \$200 in cash or the equivalent in food as a thank you for hosting the study activities.

Participant Recruitment

Once invitations were sent out and organizational participation was obtained, individual recruitment of women and men varied. In the Samoan and Tongan communities, individual recruitment of women and men usually began by study staff attending the church service and making an announcement to the congregation about the study. Interested women and men were asked to meet at a designated place and time, such as a church meeting room, after the church service. At that time, eligibility was established and gender-specific educational sessions were conducted. In the Chamorro community, the study staff usually worked with a clan leader to schedule a date for education. Study staff prescreened clan members before the education sessions to identify women and men who fit the eligibility criteria. Education sessions were held at a convenient meeting place and time, such as individual homes in the evening or on weekends, to maximize attendance of clan members. All study procedures were approved by the university institutional review board, including organizational and individual recruitment protocols and individual signed consent forms.

Data Management and Power Calculations

Completed surveys were collected and entered into SPSS by university staff, with regular updates on organizational and individual recruitment and retention numbers shared with all staff during monthly team meetings. These updates included the total numbers of PI women and men who successfully completed a pretest survey, educational session, post-test survey, and follow-up survey. According to the original study design, at power equal to 0.80 we estimated needing a minimum of 52 organizations for a total of 416 women and 416 men to detect a small to medium effect size of approximately 0.36 or larger, or about a 14% Pap testing difference between intervention and control groups at follow-up.³⁹ At this point, we have achieved nearly all recruitment goals, but the team has experienced a number of challenges and adaptations in organizational recruitment and individual participant retention. The remainder of this article is devoted to the lessons learned thus far, with plans shared for how we hope to overcome remaining obstacles toward the successful completion of the study by year 5.

LESSONS LEARNED

Organizational Recruitment Challenges and Solutions

Despite the intensely community-informed CBPR processes that guided the development of all organizational recruitment procedures, we have mixed results. Of the 76 organizations approached to participate in the study, 67 (88.2%) eventually agreed to participate. Although the final number exceeded our goals, recruitment was slow and initial reasons for organizational nonparticipation varied widely, including changes in church leadership requiring the reestablishment of relationships by study staff, and changes in study staff personnel who brought with them different ties to clan leaders, thus necessitating a change in the original universe of organizations to be approached. Other difficulties included navigating different church leadership structures, and competing organizational priorities that often displaced planned study activities, such as unanticipated deaths that mobilized church and clan leaders for funeral planning. Furthermore, among Chamorro clans we found participation interest varied by how many generations they have lived in the United States; more recently arrived Chamorros with stronger cultural ties to their island heritage expressed greater interest in participating in the clan-based study activities.

The main strategy to overcome initial recruitment challenges was study staff persistence, and they averaged five contacts with each church or clan leader before receiving confirmation that an educational session could be scheduled. For instance, in the Samoan and Tongan communities, study staff found a personal connection that provided an introduction to the church pastor, pastor's wife, and/or other representative of the church, such as the ladies auxiliary president from Latter Day Saints churches. Once an introduction was made, the study staff met in person to describe the study and benefits to the church and members. If the leader agreed, the study staff then scheduled another time to visit the church after service or during a women's or men's group meeting to recruit individual women and men who met the study criteria. If a meeting was set for after service, the study staff attended the service as well to show respect to the church leaders and members. Although approximately one

half of the scheduled sessions occurred as originally planned, the other one half experienced at least one postponement owing to competing priorities in each organization.

Individual Retention Challenges and Solutions

Once collaboration with an organization was established, recruitment of PI women and men into the study was relatively smooth: so far, 473 women and 419 men have successfully completed the study pretest, intervention or control education session, and post-test. PI women who met the eligibility requirements were allowed to participate in the study, even if their male partner was unwilling or unable to participate. Unfortunately, we have had less success in retaining participants at 6-month follow-up. Only 242 women and 204 men of the eligible participants who completed the original educational session six months prior have completed a follow-up survey, representing only 63.5% of women and 60.5% of men retained after 6 months. This is significantly lower than the originally estimated 80% based on past research experiences of the principal investigators.⁴⁰ Unique follow-up challenges to retaining individual participants have included disbelief that the survey was actually brief, feedback that the incentive item was not large enough to motivate individuals to return in-person for survey completion, and the inconvenience of completing the survey in the absence of a gathering. In the Tongan community, a unique challenge has been the necessity of re-obtaining church leader approval for the survey. Research studies are guided by the principle of participant autonomy and agency, defined as the individual's ability to act intentionally, as evidenced by signed consent forms.⁴¹ Despite this fact, we have found that it is culturally less respectful to Tongan pastors for follow-up surveys to be conducted with Tongan participants from that church without also re-obtaining the formal approval of the pastor. Such approvals were discussed in the Samoan community,³⁷ and were difficult to obtain for the reasons described in the previous section.

Given these ongoing individual retention challenges, study staff devoted much discussion on ways to overcome barriers to 6-month follow-up. For instance, we attempted a minimum of five follow-up contacts that included face-to-face, phone, mail, and Facebook contact with participants to remind and request survey completion. We also developed an online version of the survey that is emailed to participants; once successfully completed, health educators arrange to meet and drop off the \$15 incentive gift card. Thus far, approximately 26% of all follow-up surveys have been completed in this manner. Last, strategies have also varied by community, and reflect the deeply cultural ways in which engagement in research must occur for each population. The Samoan and Tongan staff often re-attended a church's entire service and/or social event, such as a bingo night, rather than just arriving afterward to reach out to individual participants; this attendance was often at the expense of missing their personal Sunday church worship services. In the Chamorro community, follow-up survey "events" have been organized around clan activities to increase the ease of participation. We are hopeful that these many strategies ultimately increase our participant retention rate to 80%, which has been achieved or exceeded by past cancer screening intervention studies.^{42,43}

CONCLUSIONS

Although CBPR improves the cultural competence and relevance of study activities for ethnically diverse populations, past research describes how it does not ensure that such designs overcome all of the unique challenges in ethnically diverse communities.^{44,45} In our experience, PI-specific organizational recruitment and individual retention has been challenging, and influenced by study issues and cultural factors in each community. Our church- and clan-based recruitment has relied on intense interpersonal interactions with pastors and leaders, similar to approaches described by other PI community leaders and researchers.^{46,47} Currently, our retention rate (63.5%) is lower than that achieved by Blumenthal et al. (2010) in their colorectal cancer screening intervention among church- and community-recruited African Americans (70%).⁴⁸ With the additions of an online survey option and intensive church and clan re-contact, we hope to obtain a retention rate that is similar to the 6-month follow-up rate (78%) achieved by Maxwell et al. in their colorectal cancer screening intervention among church and community-recruited Filipino adults.⁴⁹

Through CBPR, we have documented and discussed these challenges, and developed strategies that will hopefully allow us to meet the long-term aims of the study. We understand our experiences might not be generalizable to other non-PI populations, although previously described work with African Americans and Filipinos suggest that organizational recruitment and retention issues might be similar. Also, it is too soon to understand to what extent potential nonresponse biases may impact our longer term study findings. Although we remain committed to the belief that CBPR will ultimately enhance the recruitment and retention of underserved PI women and their husbands/significant others, we also understand the need to remain flexible in the field to adapt to ongoing organizational and community priorities.

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