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***Pakikisama*: lessons learned in partnership building with Filipinas with breast cancer for culturally meaningful support**

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Abstract

San Francisco Bay Area Filipinas with breast cancer underutilize support services. Our partnership engaged in community-based participatory research (CBPR) that involved formation of a community advisory board (CAB) representing low-income, low-English-proficient Filipinas with breast cancer. While CABs are a standard component of CBPR projects, the process of establishing and fostering CAB involvement has been under studied. This commentary explores the process our team used—building upon the Filipino cultural method of *pakikisama* which stresses making the other feel welcome, safe, and nurtured—to overcome barriers to active engagement. Challenges included minimizing power imbalances between the research team and CAB, and the establishment of an environment of familiarity, trust and caring among CAB members. We recorded all CAB meetings, transcribed them verbatim, and Tagalog portions were transcribed into English for analysis. Mobilizing *pakikisama* supported partnership building and allowed CAB members to engage in inclusive dialogue and formulate a culturally relevant support model.

Keywords

breast cancer; CBPR; culture; Filipinos; support

In San Francisco's Mission District in 2004, West Bay Pilipino Multi-Services Center, the University of California, San Francisco (UCSF) Comprehensive Cancer Center, and the San Francisco General Hospital Breast Care Program worked together to establish the city's first Filipina breast cancer support group. The goal of the support group program was to reach out to low-income, low-English-proficient Filipinas with breast cancer, who were either uninsured or underinsured. However, after 2 years the support group was unable to sustain a core of participants and reach a wider clientele, which prompted the collaborating institutions to ask if the support group was providing Filipinas with what they needed. To address the issue, UCSF researchers and West Bay Pilipino Multi-Services Center undertook

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Conflict of interest

None declared.

a community-based participatory research (CBPR) study, with its emphasis on power sharing and research (1), to answer the central question, ‘What support model is culturally meaningful and sustainable for Filipinas with experience of breast cancer?’ The Pilipino Senior Resource Center and its Filipina Breast Cancer Support Program replaced West Bay in the collaboration after a change in West Bay’s leadership and the disbanding of its support group in 2006.

Breast cancer among Filipina American women represents a major but largely neglected cancer disparity. Though often not as highly visible as other Asian subgroups, the US Filipino population is large, second among Asians only to the Chinese. Breast cancer is the most commonly diagnosed type of cancer among US Filipinas and the leading cause of cancer death (2). Filipinas have much higher rates of breast cancer incidence than most other Asian subgroups, and the highest rates of mortality among Asian subgroups in California (2–4). Disparities in breast cancer survival may be due to racial/ethnic differences in stage at diagnosis, tumor biology, socioeconomic characteristics, and breast cancer treatment (5–7). Annual percentage increases in breast cancer incidence between 1988 and 2004 have been reported as high as 4% per year among US-born Filipinas (2,8).

Filipinos travel to the United States from an archipelago of 7107 islands with more than 60 cultural groups and where 80 to 100 different languages are spoken. Cultural studies scholars and social scientists have argued that the emergence of ethnicity and racialized identity among US Filipinos is distinct from that of other Asian immigrants due to the colonial and neo-colonial presence of US institutions and representatives in the Philippines since at least the late 1800s, and Filipinos’ particular history of immigration to the United States (9–13). This longstanding presence confers familiarity with US lifestyles, cultural practices, and consumption patterns (11), which migration scholars argue affords smoother integration when compared with other Asian subgroups (10). Still, economic, language, and cultural barriers to health promotion programs and practices impede access to cancer treatment and support services (14), which is why partnering with community-based organizations is central to appropriate intervention.

While debates continue about what constitutes CBPR, there is basic agreement that CBPR in public health involves a systematic inquiry, with the collaboration of those affected by the health issue being studied, for the purposes of providing education or effecting change (15). Israel has defined CBPR as a partnership approach to research that recognizes community members, organizational representatives, and researchers in all aspects of the process (16,17). A primary component in our understanding of CBPR is equitable partnership and involvement of community members in all project stages (e.g. problem identification, analysis, and dissemination) (1). A common approach to ensure such inclusion is the constitution of a community advisory board, or CAB. Despite the ubiquitous use of CABs in CBPR, challenges to their constitution and active engagement have rarely been addressed in the literature (18).

This Commentary centers on the method used to form the CAB for a study of breast cancer support disparities among Filipinas with breast cancer in the San Francisco Bay Area. Called *pakikisama*, the method we utilized is rooted in Filipino cultural understandings of

relationship building. It allowed us to overcome barriers to CAB recruitment and create rapport within it, which in turn led to the emergence of a unique support model for Filipinas with breast cancer, *buong puso* (whole heart). This Commentary focuses on insights gained from our experience of using a cultural concept to establish a partnership with community members affected by the health issue under study and who became directly involved in developing the research outcome.

Pakikisama

Barriers to forming the CAB for this study included membership recruitment and partnership building, particularly challenging due to Filipino cultural attitudes toward outsiders (19), which can manifest in superficial, vague, and indirect ways of communicating (20). Turning to *pakikisama* (21,22) as a method meant we focused on creating a welcoming, safe, and nurturing environment for relationship building. *Pakikisama* stresses empathy, seeing the self in the other (23) and facilitates feelings of harmony among strangers of different backgrounds and between entities with a power imbalance by acting as an equalizer. For partnership building with the CAB, *pakikisama* allowed members inhibited by cultural constraints and fear of being silenced, laughed at, or gossiped about to open up and engage in inclusive dialogue (13).

Potential CAB members were mostly immigrants with breast cancer who worked two jobs or more as domestic servants, caregivers, and hotel housekeepers. In consideration of their overtaxed schedules and feelings of obligation, we invited potential members indirectly by informing them of the CAB but waiting for *them* to express interest. Asking them to become CAB members without regard for their life situation would have put them on the spot. It would have signaled that we were considering our own goals above their situation and interests, which would have been inconsistent with *pakikisama* and not a good basis for a partnership.

In keeping with the concept of *pakikisama*, recruiting participants from the study's first, ethnographic, phase facilitated partnership building. Participants had become familiar and comfortable with us as they shared experiences in one to two hour-long face-to-face interviews, and spent time with us in support group meetings and community and church events. After we identified 11 potential participants and successfully recruited six who expressed interest, our next goal was for these new members to become comfortable with each other and cohere as a group.

To accomplish this goal, we devoted the first meeting to socializing. Over food, we introduced individual members to each other, and highlighted informal, personal connections from our own knowledge of each of them. For instance, we knew that one of the single mothers in the group had a daughter who had just won a children's prize in poetry at school. The mother was looking for someone to publish her daughter's winning poem as well as the other poems that she had written. We made sure that the mother talked with a group member whose relative was a publisher of children's books.

The next meeting heightened their comfort level as they openly discussed reactions to our presentation of ethnographic findings, which included statements from interviewees about

the meaning and impact of breast cancer on their lives (24). After the presentation, members shared their own struggles with breast cancer, forging a deeper and caring relationship with each other. By the third meeting, members started to grapple with thinking through a support model; specifically, identifying what elements were really needed in their community. The comfort level participants had reached with each other was evidenced by good-natured disagreements, joking, and diplomatically framed critiques of possibilities presented. At the last session, after intense yet amiable discussions, they came up with a culturally meaningful concept of support, *buong puso*, as a basis for a sustainable support model.

Buong puso

Through the deliberate use of the *pakikisama* cultural norm, we were able to build a partnership with CAB members that allowed them to articulate their needs and formulate their own response to those needs. To them, a *buong puso* model meant a comprehensive and holistic approach: provision of support services not only for them but for family members, particularly their children. A CAB member explained, ‘I was thinking about something that can help the woman as a whole—the woman as mother, as sister, as daughter, in dealing with the illness.’ *Buong puso* also meant the location of interconnected health services in one place (25), which they described as similar to ‘one-stop shopping.’ They described their experience of being sent from one facility to another, from one social service agency to the next as fragmentary, a discontinuity that left them confused and vulnerable. A member related: ‘A navigator or case manager tells me to go here, to go there, do this, do that. But what I really need and want at the moment is one person or one place I can go to [for my needs].... I don’t have to go to [another place] and talk to someone else and start all over again.’ Lastly, they defined support as ‘walking side by side’ with someone like them as they went through their breast cancer experience, rather than being ‘helped’. One member distinguished ‘help’ from ‘support’ with the statement: ‘To me, “help” means “doing something for someone” but “support” means “walking side by side” with that person.’ Another member pointed out: ‘*Buong puso* already includes assistance, but it means more than that. It includes the idea of mentoring someone who is just beginning. Also, bonding....It’s all support coming from your whole heart.’

Conclusion

By emphasizing relationship building, we were able to establish credibility and communication that assured and motivated CAB and research team members. The successful outcome of our CBPR approach indicates that properly understood and mobilized, a cultural norm like *pakikisama* can be a powerful asset in studies that call for community input in the design of culturally relevant health care models. The approach creates a balance of power that enables dialogue between partners, and facilitates an empowering experience, as illustrated by the CAB members’ engagement in the formulation of a support model based on their own needs and experiences with the health care system. Input from those directly affected by a disease could go a long way in decreasing health disparities in underserved communities. As noted by James and colleagues in their report on the ECHHO Community Action Board in Central Harlem, CABs become more effective when they prioritize action and relationship building between academics and community

members (18). In global health, attention to appropriate forms of relationship and trust building can help address challenges posed by North–South partnerships where imbalance in resources is a common hurdle to productive collaboration (26,27). As our experience illustrates, cultivating smooth and comfortable communication within CABs requires thoughtful attention and care.

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