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A Community - Based Participatory Research Study of HIV and HPV Vulnerabilities and Prevention in Two Pacific Islander Communities: Ethical Challenges and Solutions

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Abstract

We describe ethical issues that emerged during a one-year CBPR study of HIV and human papillomavirus (HPV) vulnerabilities and prevention in two Pacific Islander (PI) communities, and the collaborative solutions to these challenges reached by academic and community partners. In our project case study analysis, we found that ethical tensions were linked mainly to issues of mutual trust and credibility in PI communities; cultural taboos associated with the nexus of religiosity and traditional PI culture; fears of privacy breaches in small, interconnected PI communities; and competing priorities of scientific rigor versus direct community services. Mutual capacity building and linking CBPR practice to PI social protocols are required for effective solutions and progress toward social justice outcomes.

Keywords

HIV; human papillomavirus (HPV); Pacific Islanders; Chamorro; Tongan; research ethics; community-based participatory research; social justice

Community-based participatory research (CBPR), according to its fundamental principles, has the potential to engender social justice among its institutional and community partners by promoting ethical, egalitarian collaborations through all stages of a research project. These principles maintain that CBPR involves community initiation; community relevance of the research topic; ethical review; a process-oriented approach; building on the unique strengths and resources of each partner; equitable collaboration; power sharing; varied methods; co-learning among partners; capacity building; shared ownership of data; and, when applied to health disparities, social change outcomes to improve community health (Minkler & Wallerstein, 2003; Israel et al., 1998; Wallerstein & Duran, 2006; Flicker et al., 2007).

CBPR has been associated with ethical research practice and social justice from its inception, having grown mainly out of the traditions of action research and participatory research. Historically, action research (Lewin, 1946) was used by organizational researchers in schools and industry to engage teams to solve problems, and as a means to overcome social inequalities. It rejected the positivist notion that for researchers to be “objective,” they needed to separate themselves from the communities that they studied. Action research was inherently collaborative and self-reflective inquiry (Kemmis & McTaggart, 1988), and was associated with “radical” political activism during the 1960s (Stringer, 1999).

CBPR also traces its roots to Freire’s (1970) empowerment education for critical consciousness, which stated that communities should be given the tools to critically understand the root causes of inequality, then identify their own problems and develop appropriate solutions. Building on Freire’s critical pedagogy, participatory (action) research (PAR) responded to critiques by social scientists starting in the 1970s—particularly from Asia, Africa, and Latin America—of structural underdevelopment in communities being studied and academic distance from social problems (e.g., Fals-Borda & Rahman, 1991). Participatory research encouraged the redistribution of inequitable power structures—especially from the academe to communities—and the alteration of relevant social norms and discourses on research–researcher relationships (Wallerstein, 2002; Minkler & Wallerstein, 2003).

CBPR has clear parallels with, and is linked to, other social justice-minded approaches to research and action that prioritize ethical practice. These include feminism, postcolonialism, and postmodernism in the social sciences—especially the calls for multiple voices and critical reflexivity in postmodern ethnography and social-cultural anthropology (Maguire, 2001; Linstead, 1993), and their application to research on public health, medical, and other allied health topics (e.g., Scheper-Hughes, 1995; Bourgois, 1990, 1998). In spite of an impeccable pedigree and laudable ideals, however, when CBPR actually is applied on the ground in communities, practical realities, including ethical tensions, surface. This can create barriers to reaching study objectives and being faithful to CBPR’s fundamental principles. In this article, we describe ethical issues that emerged during a one-year CBPR study of HIV and human papillomavirus (HPV) vulnerabilities and prevention in two Pacific Islander (PI) communities, and the collaborative solutions to these challenges reached by academic and community partners.

There is a growing body of literature on the process of conducting CBPR among Pacific Islanders which has focused largely on Native Hawaiians in Hawaii (e.g., Nacapoy et al., 2008; Boyd, Hernandez, & Braun, 2011), but includes Chamorro, Marshallese, Native Hawaiians, Samoans, and Tongans in California (Kagawa-Singer et al., 2006; Tanjasiri et al., 2007; Tanjasiri et al., 2011). Some of the literature on CBPR in Hawaii contains references to research ethics. In describing their CBPR approach with Native Hawaiian elders, Mokuau et al. (2008) emphasized the ethical importance of community ownership of data. Fong, Brown, and Tsark (2003) described how the formation of a Native Hawaiian institutional review board (IRB) aimed to provide community and cultural perspectives during the ethical review that were lacking in other IRBs and necessary in light of Native Hawaiians' distrust of researchers and the research process. Tse and Palakiko's (2006) manual on participatory research, which has informed PI CBPR studies in Hawaii, described the need to train community researchers on the standards and rigor required for ethical research beyond IRB obligations. Other than relatively brief mentions in these works, however, research ethics is not a focus of the literature on CBPR among PIs; and to our knowledge there have been no empirical studies of ethics in PI CBPR.

HIV, HPV, and Pacific Islanders in the United States

HIV and HPV intersect biomedically and epidemiologically. Each infection is independently associated with the development of comorbid cancer (Engels et al., 2006; National Cancer Institute [NCI], 2011); and both males and females with HIV/AIDS are at increased risk of oral and anogenital HPV infection and subsequent HPV-associated cancer (National Cancer Institute [NCI], 2011; Palefsky, 2006). PIs are indigenous people from Micronesia, Melanesia, or Polynesia. Historically, they have faced numerous social and health disparities in their islands and in the continental United States (Chang Weir et al., 2009). PIs in the U.S. are economically and linguistically disadvantaged, with higher proportions of poverty and uninsured, and more limited English proficiency compared with the non-Hispanic white majority (U.S. Department of Health and Human Services [DHHS], 2011). Though research prior to our CBPR study had suggested that medically underserved and ethnic minority groups in the U.S. were at significant risk of the intersections of HIV and HPV (e.g., Palefsky et al., 1999), little was known about how these synergistic connections affected PIs. This gap in knowledge indicated a need for dedicated inquiry focusing specifically on these two health problems in PI communities.

Prior to our CBPR study, there had been sparse research assessing factors related to HIV among PIs (cf. Ellingson & Odo, 2008; Takahashi et al., 2011), no studies examining HPV risks or protections among PIs, nor any research focusing on young adults in these communities, whom the epidemiologic data indicated were at highest risk of both infections (Centers for Disease Control and Protection [CDC], 2011, 2012; Giuliano et al., 2009; Cavazos-Rehg et al., 2009; Dunne et al., 2007; Weitz, Harper, & Mohllajee, 2001). Our objective in the CBPR study was, therefore, to identify and contextualize factors that shaped HIV and HPV vulnerabilities and prevention among young adults in two Southern California PI communities: Tongans—Polynesians born in, or tracing their ancestry to, the sovereign island nation of Tonga; and Chamorros—Micronesians born in, or tracing their ancestry to, the U.S. territory of Guam and surrounding islands.

CBPR Study Design

The CBPR study design, sample, methods, and findings are described in detail elsewhere (DiStefano et al., 2012). Our partnership included two community-based organizations (CBOs) and a public university. The community partners were based in Los Angeles County: Guam Communications Network (GCN) represented the Chamorro community, and

Tongan Community Service Center (TCSC) represented the Tongan community. The academic partner, California State University, Fullerton (CSUF), was located in Orange County.

CBPR describes an orientation to research, not a prescribed set of specific methods (Wallerstein & Duran, 2006); therefore, our approach was guided by the core CBPR principles described previously (Minkler & Wallerstein, 2003; Israel et al., 1998; Flicker et al., 2007). We interviewed Chamorro and Tongan young adults and parents using focus groups; and we conducted key informant interviews with community leaders and providers of medical care, mental health, and social services who worked in the communities in Los Angeles, Orange, and San Diego Counties ($n = 95$). We convened a community advisory board (CAB) to guide us during the study, particularly on issues of cultural and community appropriateness. The CAB met bimonthly for the duration of the study and comprised eight members from the local Chamorro and Tongan communities.

Method

We engaged in a retrospective project case study analysis of our CBPR study using process data from five sources. First, we reviewed detailed notes and minutes from 38 meetings from throughout the study period. These comprised seven study coordinators meetings that brought together the lead researchers and project managers from the university and CBOs; six CAB meetings; 18 community-university coder team meetings, which were part of a shared data analysis strategy; and seven community forum organizing committee meetings, during which we planned our main study result dissemination event for our PI communities. Our analysis included only those meetings that involved representatives from all three CBPR partners; it did not account for numerous ad hoc meetings and trainings related to the project within each organization.

Second, we analyzed pre- and posttest data from two capacity-building trainings conducted by CSUF with the CBOs ($n = 17$), and notes from an additional CBO training that did not involve formal pre- and posttests. Third, we examined data from a CAB exit survey ($n = 4$) and a survey of community forum attendees ($n = 14$). We used a brief, six-item questionnaire with open-ended questions for both surveys. Our fourth data source was an audio recording (with supporting notes) of an intercommunity dialogue at the community forum. Fifth, the first author e-mailed four other lead researchers from the university and CBOs who worked on the project to elicit reflective accounts of ethical tensions and solutions during the study; we analyzed the resulting correspondence of 17 e-mails.

We used directed content analysis (Hsieh & Shannon, 2005) and a research ethics lens to selectively extract and code data relevant to ethical problems and solutions from the universe of our qualitative sources (notes, minutes, open-ended questions from surveys, audio recording, and e-mails). For the quantitative data from the two capacity-building trainings, we used a paired samples t -test to determine whether there was a significant difference between pre- and posttest mean scores on knowledge tests ($\alpha = 0.05$). Because the sample sizes for both trainings were very small ($n = 7$; $n = 10$) and our data did not necessarily meet all of the assumptions for a parametric test, we also ran a Wilcoxon matched pairs signed rank test to indicate whether there was a significant difference between pre- and posttest median scores ($\alpha = 0.05$).

Results

Four main ethical challenges arose during the CBPR study. For each challenge, the community and university partners worked together to create mutually acceptable solutions.

Mutual Trust and Credibility in Pacific Islander Communities

The first indicators of challenge in practicing ethical CBPR centered around the CAB. After having been informed that our study had been funded, the university partner submitted an application to its IRB before the CAB could be assembled and advise on Chamorro and Tongan cultural and community appropriateness of study protocols. CSUF's reasoning was that recruitment of CAB members was taking longer than anticipated, and that IRB approval was necessary to secure the release of research funds and expedite the start of participant recruitment in a study of relatively short length. Because deference to elders and respecting culturally based community hierarchies are critically important in the Chamorro and Tongan communities, this created a breach of trust. Additionally, in its efforts to recruit CAB members, GCN learned that many Chamorros did not want to serve because they had been research participants in the past with no tangible results for the community. Community trust in the project was lacking.

Part of our solution was to delay recruitment until the CAB was convened and provided feedback, after which we revised protocols and resubmitted the IRB application via an addendum. However, the CAB was initially reserved in its demeanor, which limited its critical input, and was both reflective of and antecedent to persistent mutual trust issues among the CAB, the CBOs, and the university. The CSUF team was led by the first author, a white male academic with no prior experience in the Tongan or Chamorro communities and, therefore, no pre-established rapport with CAB members. The same uninitiated status was true of the fourth author, one of the project coordinators on the university side. This lack of personal and reputational rapport presented a barrier to open participation among Tongan and Chamorro community leaders, who culturally gauge relationships based on reputation in the community more than any other measure, including professional credentials or the urgency and potential positive impact of a research project. Likewise, given some CAB members' reticence at meetings, the university team and CBOs initially speculated on collective motives and commitment.

Our solution evolved to engage the CBO partners in bridging the cultural gaps between the CAB and CSUF. To this end, both the academic and CBO partners augmented efforts to nurture their relationship with the CAB and with each other. We achieved this mainly by conducting PI-style CAB meetings, attendant to Tongan and Chamorro cultural traditions. Central components of our approach included sharing Chamorro and Tongan food before initiating research business; a religious blessing before eating; overt deference to community elders and use of PI honorific forms of address (e.g., "Auntie" for female elders); humor; and "talk story" (i.e., informal chats with a high degree of communal participation). Acknowledging these social protocols, and the attendant process of relationship building, nurturing, and constant communication, helped us to leverage the core value of community interdependence—*inafa' maolek* (Chamorro) or *fonua* (Tongan)—which depends on a spirit of cooperation. We were successful in raising the level of mutual trust and, therefore, also the degree of open and frank communication during CAB meetings and other meetings involving the academic and community partners.

Nevertheless, we had an additional challenge of inconsistent attendance by CAB members, in spite of efforts to remind them of meeting times and providing evening meals and monetary incentives (\$20 gift cards) for each meeting. This appeared to be exacerbated by a PI cultural practice of maintaining face by making commitments when directly confronted, irrespective of the person's confidence in being able to meet the commitment. If a CAB member had a conflicting obligation or reservations about the subject matter, according to PI cultural values, it would be more respectful to confirm attendance at a meeting and simply not show up. We addressed this issue by giving some CAB members rides from their homes

or places of work to and from CAB meetings; but we were unable to resolve this challenge completely. At our final meeting, only four members—half the CAB—were in attendance.

Pacific Islander Religio-cultural Taboos

Both communities highly valued their unique PI cultures, and Christianity was closely tied to those cultures. For Chamorros, this was Catholicism; and for Tongans, it was mainly Methodism, the Church of Jesus Christ of Latter-day Saints, and the Seventh-Day Adventist Church. The intersection of reverence for PI traditions, a high degree of community religiosity, and Christian mores created strictly guarded religio-cultural taboos in both communities against discussing sex and sexual health in the presence of the opposite gender or across generations. Linked to this taboo (a term that entered into English from the Tongan word *tapu*), the cultural value of shame (*mamahlaho* in Chamorro; *ma* in Tongan) was maintained not only by elders in both communities but also by the younger generation.

This was problematic, and we carefully deliberated on the most ethical course. Our solution was a compromise approach, enacted in two ways: the first deferred to the taboos, whereas the second challenged them. First, in our data collection, we stratified focus groups by gender and generation consistent with community norms. Accordingly, we conducted separate focus groups for young adults and parents; and for each of these, we conducted separate focus groups for men and women. Second, in planning our community forum, we considered whether we should again conduct separate events by gender and generation. After giving a mock community forum presentation to the CAB and receiving their counsel, however, we decided that holding separate events would preclude an opportunity to challenge the religio-cultural taboos that contributed to community HIV and HPV risk. We concluded that a mixed event would allow the genders and generations to intermingle while sexual health was being discussed—not by the attendees themselves at first, but by our research team and volunteers from the CBOs.

University and CBO researchers presented study results together with basic health education on HIV and HPV. We supplemented this by tailoring prevention messages based on our findings and embedding these in cultural skits designed to communicate results in a different way and stimulate dialogue. We combined the formal program with performances of traditional Chamorro and Tongan music and dance; prayer; and food—an approach that benefited by our choice of venue: the Pacific Island Ethnic Art Museum in Long Beach, California. The forum was thus an intentional mini-community intervention. The challenge of any such strategy was, as one forum survey respondent stated, “trying to change generations of ‘tradition’ and taboo without changing the culture that we hold so dear to us.”

We could not predict the outcome of this community forum strategy with confidence. The result could have been decidedly unfavorable. Fortunately, according to our community forum survey, young men and women, and older mothers, fathers, grandmothers, and grandfathers enjoyed the scientific content and culturally tailored skits. Our recording of the intercommunity dialogue also documented how attendees were able to discuss ideas for how to move past taboos and move forward as a united community to solve problems. They agreed that the community forum format was a significant first step. As a young adult attendee stated, “Opening up the door for us to speak up ... is going to lead to positive change ... It just takes the first step ... But then talking about it [i.e., HIV, HPV] is going to become the norm.” Similarly, a parent attendee commented on the open dialogue at the community forum: “This study is very exciting ... I questioned myself: ‘Am I open to talk ... to go beyond the *tapu*?’ ... It’s challenging, but I think just openness and communication will be better.”

The community forum served two additional purposes: (1) it ensured that the dissemination of study results was not exclusively academic, but rather accessible and useful to the community; and (2) it assured community approval of study findings. Regarding the second purpose, our mock community forum presentation to the CAB sought its approval of the results, especially regarding potentially unflattering findings (Flicker et al., 2007). The CAB recommended minor edits to language, but requested no major changes.

Fears of Community Gossip

Concerns among participants regarding gossip in their small Chamorro and Tongan communities created fear that even discussing HIV/AIDS openly in the focus groups would label a person as HIV-positive, leading to stigma and ostracism. The CBO researchers, who facilitated the focus groups, dealt with this issue by intensive advisement of participants and research staff before, during, and after the focus groups to dispel these fears and emphasize the sacredness of confidentiality. The fact that the CBO focus group moderators had known community reputations, and were matched with the focus group participants on gender and generation, helped to allay concerns regarding confidentiality. The cultural appropriateness of such matching stemmed from an implicit understanding that a young woman facilitator, for example, would respect and be beholden to the same concerns around taboo as the young women whom she interviewed.

We additionally required all persons who worked on the study to acquire IRB certification through CSUF's online training program, which included modules on privacy protection. These efforts were successful. Participants were supportive of each other during the focus groups, which yielded rich qualitative data; and there were no reports of negative consequences of personal disclosures.

Balancing Scientific Quality and CBO Capacity

The demands of the rigorous qualitative and quantitative methods required by our design, and the high degree of community involvement in data collection and analysis, were unprecedented in the CBOs' experience; thus, developing skills and exercising them had to occur simultaneously. Ethical tension was created by the university partner pushing the scientific agenda on the CBOs while being tempted to recommend and accept less rigorous procedures, particularly in recruitment and analysis, in the interest of not jeopardizing its relationship with the community. Concurrently, the CBOs were faced with competing priorities of direct services to their communities, which were often unpredictable and urgent, and the increasing proportion of their time spent to conduct high-quality research. Consequently, they had valid concerns that appropriating the communities' priorities by leading this study, combined with the taboo subject matter, would negatively affect community participation in the CBOs' other critical programs.

We resolved this dilemma using two strategies. First, CSUF led three capacity-building trainings to enhance the CBOs' substantive knowledge and research skills relevant to the study. Training 1, which covered participant recruitment and data collection, was instrumental in preparing the CBOs to lead those efforts. However, we did not plan for pre- and posttests for Training 1, so we could not show any change in knowledge. Realizing our error, we included pre- and posttests in subsequent trainings. Training 2 comprised basic biomedical and epidemiologic education on HIV and HPV. There was a significant increase in participants' scores from pre- to posttest on a 15-item evaluation instrument that assessed knowledge covered in the training ($t = -10.954$, $p < 0.001$; $z = -2.388$, $p = 0.017$). Similarly, participants in Training 3, which addressed data analysis and dissemination, demonstrated a significant increase in knowledge on a 12-item instrument ($t = -7.236$, $p < 0.001$; $z = -2.820$, $p = 0.005$).

Second, we initiated frequent meetings of the lead university researchers and the community-university coding teams to provide additional analysis training. We also trained translators (Tongan ↔ English) and transcribers, who included university students, and CBO staff and volunteers. For this effort, we produced written guidelines to standardize translation and transcription methods and formatting, and we engaged in one-on-one transcription training sessions. Process data acquired from CBO staff suggested that this capacity building created new interest in research and science that could be leveraged for long-term community sustainability.

Discussion

Our experience with ethical challenges resonates with previous CBPR conducted in PI communities and with HIV CBPR in other populations. For example, a recent CBPR study of factors associated with obesity among Tongan, Samoan, and Marshallese youth in Southern California reported significant time pressures related to participant recruitment and data analysis (Tanasiri et al., 2011). Additionally, though the researchers endorsed CBPR in PI communities overall, they found it challenging to balance PI cultural practices with research protocols and raised caution regarding the limits of CBPR approaches in such contexts. Similarly, a growing body of literature on HIV CBPR across several populations has documented the ethical challenge of sustaining scientific rigor while accommodating other community priorities, particularly as this has manifested in the time dedicated to partnership development rather than to the research study itself (Rhodes, Malow, & Jolly, 2010).

Though the ethical challenges that we faced had the potential to obstruct our progress, our findings suggest that such issues are not intractable. The collaborative solutions that we reached resulted in enhancements not only to trust among CBPR partners, but also to scientific rigor, the mere maintenance of which had been a significant ethical challenge. We surmise this was largely due to adherence to the CBPR principle of equitable collaboration (Israel et al., 2001). Because all three partners were involved in each stage of our project, we were able to integrate scientific rigor with what has been called community wisdom. The importance of leveraging community wisdom in research has been emphasized in reference to CBPR among PIs in Hawaii (Nacapoy et al., 2008), CBPR on HIV and other sexually transmitted infections (STIs) among Aboriginal and Torres Strait Islander people in Australia, and HIV/STI CBPR among indigenous peoples of Canada and New Zealand (Mooney-Somers & Maher, 2009). This is consistent with the CBPR principles of building on the unique strengths and resources of each partner, and mutual co-learning (Minkler & Wallerstein, 2003; Israel et al., 1998).

There is also a growing body of evidence in support of involving the community in all phases of CBPR, rather than relegating their contributions to participant recruitment and advising on cultural appropriateness of protocols and instruments (Israel et al., 2001; Silka et al., 2008). This research has shown that community involvement in all CBPR stages helps to augment the quality of empirical inquiry and increase the perceived relevance and acceptance of results (Newell & South, 2009). This paralleled our experience. The benefit of dual community-university perspectives on the data and the attendant boost to the validity of our findings outweighed concerns about time. Specifically, this approach amplified our results' cross-cultural validity (Kleinman, 1987; Eyton & Neuwirth, 1984) and qualitative validity (Creswell & Miller, 2000; Morse et al., 2002). Thus, prioritizing ethical considerations and conducting scientifically rigorous HIV CBPR in PI communities need not be mutually exclusive endeavors.

The importance of mutual trust to ethically sound and effective HIV CBPR among Chamorros and Tongans was also evident in our findings. Rhodes, Malow, and Jolly (2010) have indicated that trust (more often distrust) by the community has been examined amply in the literature (e.g., Becker, Israel, & Allen, 2005; Corbie-Smith et al., 2003), but trust by researchers in the CBPR process has been less well explored. Our study provides evidence that mutual trust is indeed a multilateral phenomenon, and that it must be earned not only by the academic partner, but also by the community partners. To conclude otherwise would be to engage in cultural essentialism, reifying stale tropes of the community representing an idealized “other.”

Deference by the academic partner to the PI communities in our CBPR study was certainly appropriate in many instances to build trust and access the community wisdom described previously. Our findings additionally suggest that this should be balanced by reciprocity by community partners in welcoming the academic researchers and openly acknowledging the value of their contributions to the CBPR effort. This could help to mitigate academics’ potential marginalization from the communities with which they engage in CBPR (Minkler, 2004). In short, application of the CBPR principle of power sharing (Wallerstein & Duran, 2006) should start with neither a deficit model for PI communities nor a presumption that all the power lies with the academic partner.

To address the challenge of competing priorities of scientific rigor versus service to communities, one of our main strategies was capacity building. The pre- and posttest results from our trainings alone did not capture the broader capacity building that occurred on both the community and university sides. PI CBO researchers were trained to conduct a scientific study that responded to the health priorities set by their communities; and key members of the university research team, with no prior background in Chamorro and Tongan communities, gained invaluable experience. However, we heed Mooney-Somers and Maher’s (2009) admonishments and acknowledge that it is too early to evaluate the long-term sustainability or success of our capacity building, which might include seeking additional research funding, creating research jobs, and expanding our CBPR partnership to include other PI communities.

By comparing the results of our case study analysis against CBPR’s fundamental principles (Minkler & Wallerstein, 2003; Israel et al., 1998; Wallerstein & Duran, 2006), and with recommendations for ethical review of CBPR by Flicker et al. (2007), we conclude that in spite of ethical challenges, we conducted our CBPR study ethically. In assessing CBPR ethics, Flicker et al. (2007) espouse a community ethical framework, part of a new paradigm that attends to potential community risks in CBPR, rather than the exclusive focus on individual risk typically associated with the more pervasive biomedical framework of current IRBs. Through implementing the solutions to our ethical challenges, we protected our PI communities against several of these risks, including risk to community privacy, and the risk that communities would feel over-researched, coerced, or misled.

Because ethical issues are a common theme in guidelines proposed for *successful* HIV CBPR (Rhodes, Malow, & Jolly, 2010), we believe our project also met this threshold. In their conceptual logic model of CBPR, Wallerstein and Duran (2010) list increased social justice as a long-term outcome. Social justice will only be achievable via the ethical practice of CBPR. Through our collaboration, we have ensured the production of a shared discourse on HIV and HPV vulnerabilities and prevention in PI communities, not a discourse dominated by either the academic or CBO side, and we have solidified a trusting and respectful relationship for future projects. This is critical, as social justice in the wider community can begin in the microcosm of such equal partnerships.

Finally, beyond the ethical issues that were linked to unique PI cultural factors, we conclude that the overall CBPR experience with PIs in Southern California was not so different from CBPR as documented in other ethnic minority populations in the U.S. and elsewhere (e.g., Griffith et al., 2010; Mooney-Somers & Maher, 2009). That our PI results are thus somewhat confirmatory of CBPR with several other communities is itself novel, as such a finding has not been previously reported.

Best Practices

When conducting CBPR in PI communities, researchers should use strategies familiar to community members to provide a bridge for communication, such as talk story; deferring to elders and using honorific address; and other Island-style, communal meeting practices. Additionally, as Flicker et al. (2007) suggest, though it is often challenging to find appropriate community representatives for a CAB, it is sometimes important to obtain community-level consent from respected community leaders. This was particularly important in our PI communities, where the approval of elders is paramount. This underscores the risk taken by the academic partner in acquiring IRB approval before the CAB could provide feedback. When placed in similar time-sensitive positions, we recommend that the academic partner explain to community partners their plan to submit an addendum to the IRB application early and explicitly. This might help to prevent community feelings of distrust toward the academic partner early in the project that could color the CBPR experience from that point forward.

Research Agenda

When conducting analyses of CBPR ethics in PI communities, researchers should be cautious not to create ethical problems that do not exist, with the misguided intention of uncovering something “uniquely Pacific Islander.” Such an approach could comprise a slippery slope leading to cultural essentialism and exoticization of PIs living in the U.S. and in other countries. Such a result would be clearly anathema to the principles of ethical CBPR.

Educational Implications

Considering the strong PI cultural taboos surrounding HIV and other sexual health topics, all persons who work on HIV CBPR projects in PI communities, from note-takers and transcribers to interviewers, focus group moderators, data analysts, and senior researchers, should be trained and certified in research ethics/human subjects protections with a special emphasis on confidentiality issues. Senior researchers should additionally receive at least a rudimentary training on the history and culture of each PI community with which they will work, and on the theoretical underpinnings of CBPR that link ethical practice to the development of social justice.

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