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IMPROVING HAWAIIAN AND FILIPINO INVOLVEMENT IN CLINICAL RESEARCH OPPORTUNITIES: QUALITATIVE FINDINGS FROM HAWAI'I

Lisa X. Gollin, PhD, Rosanne C. Harrigan, APRN-Rx, EdD, MS, John Perez, and David Easa, MD

From the John A. Burns School of Medicine, University of Hawai'i, Honolulu, Hawai'i

José L. Calderón, MD

Drew University Center for Cross-cultural Epidemiologic Studies, Los Angeles, California.

Abstract

Objective—Investigate the barriers to participation in medical research that involves Asian and Pacific Islander (API) populations in Hawai'i.

Participants—Fifty people (27 Filipinos, 23 Hawaiian/Pacific Islanders) in five different communities on Oahu.

Design—Nine focus groups with an ethnically matched moderator were held to explore people's feelings, problems, and recommendations regarding medical research. Sessions were audiotaped, transcribed, and qualitatively analyzed with the constant comparison method.

Results—Only 12% of study participants said that they absolutely would not participate in a clinical study. Most agreed that research is vital. Filipino participants were more optimistic about the safety and value of joining in medical research. Hawaiian groups were more hesitant and fearful. Reasons for nonparticipation included negative feelings about the purpose and intent of clinical trials and language and cultural barriers. Suggestions on how to encourage API populations to participate in research investigations included improving peoples' understanding of the benefits to family and community. Hawaiian and Filipino groups differed only slightly in their assessments of the type of research needed in their communities.

Conclusions—Recruitment campaigns must improve people's awareness of the process of informed consent, research safeguards, and benefits to family and community. Attention should focus on K-12 health education to use members of the younger generations to access and educate elders, involving persons with medical research experience as a recruitment resource, returning results to study participants, and increasing the number of healthcare professionals and researchers that are culturally and linguistically matched to the community.

Keywords

Asian Pacific Islander; Hawaiian; Filipino; Clinical Trial Participation; Translational Research; Medical Research; Health Disparities

INTRODUCTION

Several decades have passed since the acknowledgement that minorities need to be included in scientific clinical research. The recruitment of diverse samples in clinical and biomedical

research is critical to ensuring that the results of such investigations are generalizable to the many different groups that make up the United States. As part of the Revitalization Act of 1993 (Public Law 103-43), the National Institutes of Health (NIH) and the National Heart, Lung, and Blood Institute (NHLBI) set out guidelines for the mandatory inclusion of women and minorities in clinical research. The NIH guidelines suggest that clinical investigators need to understand the study population by identifying potential research participants, medical settings in which they are found, and/or communities in which they reside. However, many difficulties have arisen in recruiting and retaining minorities. This issue has been identified as one of the most difficult facing clinical studies. A study of 28 past and ongoing large clinical trials indicated a severe underrepresentation of African Americans, with $\leq 8\%$ in completed trials.¹ This study also found an oversampling of African Americans for ongoing hypertension trials. The diabetes clinical trials had the most severe underrepresentation of African Americans.

Known differences in disease rates, medication compliance and response, and morbidity and mortality indicate a need for increased minority participation to elucidate specific disease processes and discover optimum treatment modalities for each group. Recent studies have shown that race and ethnicity are important predictors and factors in clinical research. For example, with regard to antihypertensive medication, blood pressure among African Americans decreases more with calcium channel blockers than with beta blockers.^{2,3} Another recent study showed that insulin sensitivity is greater in Caucasians compared to Asian Americans, African Americans and Mexican Americans, and a compensatory B-cell response to increasing insulin resistance was observed.⁴ These observations underscore the importance of including minorities in clinical research, but efforts to recruit and retain minorities face major challenges.

Only a few studies have investigated the barriers to successfully including minorities in clinical research, and most of what we know is based on studies of African Americans. These reports highlight issues related to mistrust of scientists, of Caucasian researchers, and of the medical establishment: historical events have contributed to this mistrust, particularly the Tuskegee Syphilis Study of African-American men.⁵⁻⁸ One study of African-American women revealed that although ethnic minority patients believed that participation could help them, they knew little about clinical trials, had never been asked to participate in one, and had never received any information about clinical trials.⁹ These studies also suggest that researchers are not actively informing and recruiting ethnic minorities into clinical trials, perhaps for reasons other than the concerns and fears of minority patients, and that minorities need only be asked to participate and be shown how the trial is relevant to their medical concerns.

Fewer studies have reported on participation by other ethnic groups in medical research, despite the facts that Latinos are the largest minority population and that Asian and Pacific Islander (API) populations are growing at a rate that exceeds all other populations.¹⁰ Reported determinants of research participation for Hispanic men include availability of Saturday and evening hours, convenience of locations, and offering low-cost exams, Hispanic women who refused to participate in research expressed concerns about loss of health benefits, influence of family members, and recurrence of emotional stress.^{11,12} Asian and particularly Pacific Islander populations are by far the most understudied populations. Fear of deportation was reported as an important reason Asian patients in New York are reticent to participate in clinical studies, and this concern may be true for other immigrant groups as well, particularly Hispanics.¹³ Another study explored cultural, religious, and practical factors thought to contribute to delays in obtaining informed consent for treatment in oncology from Japanese-American elders in Hawai'i.¹⁴

Enhanced recruitment and retention of diverse racial/ethnic minority groups in clinical research has been reported through trust-building activities such as applying university resources during

times of critical need, participating in the political process regarding health concerns, employing researchers and staff reflective of the community, using participatory approaches to research, and communicating research outcomes to study communities.¹⁵ However, other reports cite considerable difficulty recruiting minority participants despite committing considerable time, effort, and money to meet their recruitment goals, including involvement of a community-based advisory committees, school districts, and the hiring of local staff.¹⁶

These differences emphasize that little is known about what the best recruitment practices are for different populations. Much concern exists about proper recruitment, but relatively little is known about the specific obstacles to recruitment and about attitudes of diverse racial/ethnic populations toward research.¹⁷ Furthermore, most reports are limited in scope because they are not representative of many minority communities and the institutions that serve them and because they lacked diversity in the populations studied. Even though many of these reports provide commentary on social and cultural barriers, they do not go beyond identifying the barriers and their potential mutability. Population-based studies on research participation by racial/ethnic minorities across cultures, languages and idioms and geographic locations and research strategies that would allow such studies to be implemented across diverse populations have not been reported. Given the continued suboptimal recruitment of ethnic minorities and their reticence to participate in medical research, multicultural, population-based research that gathers detailed information about the political, social, cultural and socioeconomic factors that influence research participation is needed.

This paper presents findings from the Minority Involvement in Clinical Research Opportunities (MICRO) Project in which research data were collected from Hawaiian and Filipino populations in Hawai'i. This study proposes to identify and examine the barriers to participation in clinical research and to obtain recommendations for effective recruitment of Filipino, Hawaiian, and other Pacific Islander residents of the island of O'ahu, Hawai'i.

METHODS

This study is part of qualitative phase (phase II) of the larger collaborative research initiative entitled Minority Involvement in Clinical Research Opportunities (MICRO) Project. The MICRO Project is a multi-institutional (University of Hawai'i, Drew University, Morehouse College, Meharry Medical College, University of Puerto Rico), multicultural (West Coast and Southern African American, Mexican, Puerto Rican, Filipino, Chinese, Pacific Islander, Somali, White), multilingual (English, Spanish, Chinese, Samoan, Tagalog, Ilocano, Hawaiian, Somali), and multigeographic study funded by the National Center for Research Resources, Research Centers in Minority Institutions, NIH.

The overarching objective of the MICRO Project is to identify predictors of research participation by gaining a better understanding of the factors that impede or enhance research participation among diverse racial/ethnic groups. In phase I an exploratory study used qualitative methods to successfully test the hypothesis that barriers and motivators are shared by immigrant Latinos and African Americans based on socioeconomic and environmental similarities as well as distinct barriers based on historical and sociocultural differences. In Hawai'i, phase II of this study was implemented in five different rural or periurban communities on the island of O'ahu: Waimānalo, Kahalu'u, Ko'olauloa, and Waialua on the windward (wet/rainy) coast, and Waipahu, Wai'anae on the leeward (dry) coast. These areas have high concentrations (>60%) of residents of Native Hawaiian or partial Hawaiian and other Pacific Islander ancestry.¹⁰

The study used qualitative methods, specifically focus groups, to explore peoples' feelings, perceptions, and problems related to seven standardized questions on participation in medical

research. During the interviews the following questions were presented to each group to stimulate discussion:

1. What does clinical or medical research mean to you? (Tell us what you know about medical research)
2. Has anyone you know ever participated in research?
3. What are your feelings about medical research being done on patients?
4. Would you ever participate in research?
5. What would make it more likely for you to participate in a clinical research study?
6. What would make you not participate in research?
7. What kind of research do you think is needed in our community?

Focus groups consisted of 3–10 individuals and an ethnically matched moderator and recorder. In total nine focus groups were held: four groups of Filipinos, four groups of Hawaiians, and one group of Hawaiian and other Pacific Islanders (Samoans, Tahitians). Fifty people, 23 Hawaiian and other Pacific Islanders (including 3 Samoans and 1 Tahitian) and 27 Filipinos participated in the study. By sex, 35 were women and 15 were men. Group participants were recruited by the focus group facilitators via church groups, health centers (eg, Waimānalo Health Center), and other community organizations located in the five aforementioned communities on O'ahu. Informed consent was obtained from study participants before each focus group interview. Each participant was given a \$30 gift certificate in recognition of their time and travel, and food and beverages were served following cultural protocol for gatherings in Hawai'i. Interviews generally lasted approximately one hour, though a few went beyond the suggested hour limit as participants were eager to continue the discussion. All sessions were recorded for data analysis. Audiotapes were transcribed and analyzed with the constant comparison method. In addition to preparing these preliminary results for publication, the researchers are in the process of compiling a short (1–3 pages), reader friendly (jargon-free) summary of responses for distribution to study participants and community organizations. This “following up and feeding back” step is especially important if investigators are committed to working in an area for a sustained time and building trust with local communities.¹⁸

Analysis

The research data gathered from the focus groups were organized and analyzed with the constant comparison method.¹⁹ The authors conducted a cross-case analysis of the nine interviews, using the constant comparison method “to group answers ... to common questions [and] analyze different perspectives on central issues.”²⁰ We began by dividing responses to the interview questions into two separate groups: answers to the seven questions provided by Filipino focus groups participants, and answers provided by Hawaiian and other Pacific Islander participants. Comments were then coded according to the question asked with particular attention to barriers and motivators and further classified by category and subcategory. A barrier was defined as any factor that negatively affects possible participation in clinical research. A motivator was defined as any factor that positively influences possible participation in clinical research. For instance, responses from Hawaiian study participants to the first question, “What does clinical or medical research mean to you?” yielded a number of categories (topics, barriers, values, venues, feelings) and subcategories. Topics included indigenous medicine, herbal medicine, genetics, stem cells, health issues (eg, smoking, drug abuse, etc), diseases (eg, kidney, heart, cancer, etc), and more. Researcher bias was managed by the first and second authors of this paper, who independently identified, cross-checked, and consentaneously agreed on the categories and subcategories gleaned from the interviews.

Concomitant with identifying barrier and motivator categories and subcategories, the number of times a word or phrase (eg, guinea pig, lab rat, trust, improve health, hope) appeared in an interview was noted as a measure of salience to facilitate qualitative and incipient quantitative analysis.

RESULTS

Experience, Knowledge, and Perceptions of Medical Research

Eighteen percent of our study participants had personal experience participating in a medical study. Four (14%) participants in the Filipino groups ($N=27$) had participated in a clinical investigation, all of them involving birth control, and 5 (21%) participants in the Hawaiian/Pacific Islander groups ($N=23$) had been part of clinical research including experimental cancer chemotherapy, non-Hodgkin lymphoma stem-cell transplant, diabetes and hypertension in Hawaiian women, rubella, and in vitro fertilization. A few participants had family members involved in medical research, eg, Kawasaki disease, asthma medication, and sleep apnea. All participants with current or prior experience in medical research reported being satisfied with how they were treated in the course of experimental therapy even if the outcome was ineffectual, as in the case of the participant in the in vitro fertilization study:

I'm pro for this research. In vitro fertilization could have got me pregnant. But if they had done more research on the Delton shield, which is an IUD, the very first IUD that came out, the one that they inserted into me, that caused all the problems that made me sterile. So, you can really go either way. But I think you weigh it out and the best things that they could do for the people is more research.

A testimonial from another participant:

I was a part of a non-Hodgkin's Lymphoma medical research... I was stage-four... a candidate for medical research [given] a fifty-fifty chance...this was...for a stem-cell transplant program...I had to wait a long time to find out if they were even going to pay for it or not...I honestly don't think I would still be here [if not for this research]. They don't promise that it's never going to come back but, you know, six years now and I haven't gotten it... There was one social worker, my transplant doctor, and a transplant coordinator that just kind of guided me. I didn't even realize I was in research until I knew I was...I thought it would be like you'd be a science project. But the coordinator was excellent. She made everything so easy for me and they scheduled everything for me...If I couldn't come, they would reschedule and change it. She was the one who actually went down the line with me, holding my hand every step.

And a report from someone whose son had participated in a study:

I know one that impacted my family, research on Kawasaki's disease. Because of the research, they were able to come up with treatment for it. Not necessarily the cure or even the cause but they know the treatment. In the case of my son, because of the Kawasaki disease and the number of times that he had to undergo treatment, by default he actually became one of their participants. He was not an "experiment." ... they had all these students coming in to survey us and assess and find out about his condition or what condition he was in, he had to undergo so many treatments. To undergo three treatments for Kawasaki was very rare. But it wasn't like we signed him up for it. He was in the research just because of the circumstances. He became a subject in their studies.

Statements from these participants also encouraged other focus group participants to consider involvement in clinical trials.

When I hear 'medical research,' I kind of think it gives me hope that there could be a cure for something, a certain disease. And I guess before doing this survey, I really thought I would never be a part of medical research because when I think of medical research, I think of a clinic on the mainland that tested people. But as far as information sharing, now I have a different understanding of it.

Filipino and Native Hawaiian/Pacific Islander study participants perceive medical research as primarily geared toward "studying disease" and "finding cures" to specific diseases such as diabetes, cardiovascular disease, heart defects, lupus, muscular dystrophy and cancer, to name a few. "Advancing" or "improving" medications and studying the side effects of new drugs were also mentioned in many interviews. While Filipino focus group participants viewed clinical research as being centered on curing specific diseases or drug development, Hawaiian participants discussed more categories of research such as exploration of herbal or indigenous medicines, preventive medicine or programs (diet/weight loss, smoking cessation), drug abuse, as well as research on genetics, stem cells, and the role of the environment or ethnicity in determining peoples' health.

The first question generated mostly positive feelings and values from Filipino participants. Medical research is vital, beneficial, "reduces the need to cut people up," "improves health," "helps MDs do a better job," "helps the next generation," "makes a difference in other peoples lives," and "provides answers." Many of the Hawaiian group respondents also see medical research as positive, particularly for "improving health for future generations," "helping family and community," "paying your medical bills/insurance," "providing something to try when nothing else is working," and for helping you "live longer."

Only Hawaiian focus group participants responded to the initial question with negative associations, and a sense of uncertainty. The descriptors "fear," "afraid," "scary," and "secretive" as well as "lab rat" and "guinea pig" were used by several interview participants. However, participants in all Filipino and Hawaiian groups used these terms when discussing subsequent questions (2–7). In fact, "guinea pig" and "lab rat" were of high salience, ie, mentioned first and frequently throughout the interviews. To paraphrase a discussion between two of the participants:

I feel like a lab rat. I guess that comes from testing products. You're going to be a part of a group to see if it works or not, I don't want to be tested on.

[Yeah] *That's the first thing I think of when I hear medical research, "guinea pig."*

TV shows and commercials for prescription medicines play an influential role in how people regard medical research and may be the source of peoples' fears:

I think they're afraid because... you hear it on TV or ads because they test out drugs and research on field mice or some type of animal. And so... some of us [are] thinking [they're] reducing us [to] guinea pigs, experimenting on human beings [using] any type of medical research.

For a few participants, the mystery surrounding medical unknowns undermines their confidence in medical investigators and investigations. The purpose of research is "to find out about something that's baffling." For some participants, this uncertainty leads to a general mistrust in the whole process of research. According to two participants:

Medical research can be scary... without knowing everything and when the doctors don't know everything, it's scary to commit to being a part of it or encourage somebody to, you know.

I have doubts because all the things of that haven't been solved with all the years and the money that's gone into it. Exactly what are you guys doing?! If it's been this long and it's taken so many people and so much money and we still haven't found solutions to certain things then that raises an eyebrow.

Across focus groups there was little awareness of research protocols or safeguards to protect the patient or reduce risks. Many respondents, especially in the Hawaiian group discussions, did not know, or expressed concern, about the process of informed consent. The most critical recurrent negative theme to emerge from this study was the perception that research is "secretive," and that research participants are not provided with enough information to make an informed decision.

In three of the Filipino groups, participants discussed the belief that routine visits to the doctor or a clinic is a form of clinical research and/or experimentation, as described by two of the participants:

The one thing I noticed, every time when you do go to the doctors, you are partly already in research. Because they give you this certain pill... It was so funny because one day he gave me this eye-drop, for my ear. I had an earache but he gave me the eye-drop. I said, "Oh, that's for eye-drops."...It kind of helped. I was kind of puzzled...Are we guinea pigs? But the thing is, with the medical industry, what they do is they go step by step by step. Because if they give us one pill, the strong one one-time, and it's not able to fight the disease or anything, we got nowhere else to go. So they try to see which one can help before they go to the next.

When you go for a small check-up, it is research. Because not everybody is the same. Body systems are not same. Some people can take certain things, some people can not. And then the first thing they ask us is, "Are you allergic to this? Are you allergic to that?" One of my co-workers has a baby, she's allergic to latex. She just brushed up against her skin and the kid had to go emergency. In a way it's like weeds. We keep thinking weeds, and digging them out.

Willingness to Participate in Medical Research

Although most focus group respondents had certain reservations about participation in medical research, only 12% of our study participants said that they absolutely would not participate in a clinical study. Most agreed that medical research is vital. Filipino participants were more optimistic about the safety and value of joining in medical research. However, four Filipino participants stated emphatically that they would not become involved in a clinical study. By contrast, only two Hawaiian focus group members made a definitive statement about nonparticipation. Nevertheless, Hawaiian groups were more hesitant and fearful, and their involvement with medical investigations was far more situational (associated with a specific illness needing treatment). Beyond these definitive responses, the balance of study participants said they didn't know if they would participate or that participation would be determined by a variety of factors.

For Filipino interviewees, research participation was dependent on the type of research, whether drugs would be administered ("if the research is external that is OK"), whether the purpose was to test new medicines ("[If] I feel like a lab rat... that comes from testing products. You're going to be a part of a group to see if it works or not, I don't want to be tested on"), workload and/or family responsibilities (time availability), and whether risk of harm existed ("It depends. I would if they wouldn't do anything that would harm my body"). One participant based his decision of nonparticipation on observing a family member's experience with the medical establishment:

You know for myself I wouldn't. Take for instance, cancer, they've done so much research in cancer and we still haven't found a cure. And it's an on-going thing and it affected me because of my brother-in-law. I would have thought after all these years they would have some kind solution, some kind of cure for things like that. They're still doing research. And I just gave up hope.

Hawaiian groups named many of the same factors in addition to the following conditions: only if I was really old (“When I'm 98 years old, then I would do whatever because hopefully I should be almost *pau* [finished]”), if it would make a family member's life better, if it would save another person's life, and if I had a personal need (eg, “If it has to do with weight loss, I'm there!”). Although Hawaiian focus group participants discussed many more conditions under which they would be willing to join a clinical study, they also made a few strong statements about the potential of research and confidence in researchers. For instance:

I'd probably do it even if it was harmful. The people who are conducting the research are going to try, as much as possible, to be as safe and secure as possible. I accept the fact that anything can go wrong. But then again, there's always that hope that something might come from it.

Another condition of research participation is ensuring that the community has control over what and how findings are reported and that findings are returned to those involved in an investigation and the larger community (as discussed in two of the Hawaiian group interviews).

A repeated theme of both Filipino and Hawaiian groups was that participation is contingent on complete disclosure of risks and an explanation of benefits and generally, on the potential benefits to family and/or the larger community. For example:

It would all depend on if my father had something or my mother had something, and they wanted to figure out what was wrong, then I would. If I could help them, I would do it. But for every one else, no, I wouldn't do it. If it's internal, and you have to take a medicine, I probably would not do it. It depends on what the risks are. For family I probably would. You have to take risks sometimes.

Barriers to Participation in Medical Research

Common barriers to participation that emerged across focus groups included: “cutting me up,” “If I couldn't ask a lot of questions about the research,” “If it was secretive and kept from the public,” “If my heart had to be stopped,” and “If I was one of the first in the study,” and “If there was no sense of purpose.” Many group participants stressed the language barrier between hospital staff, researchers, and patients.

Among Hawaiian/Pacific Islander participants the most frequently mentioned barriers were lack of trust or confidence in the investigator (seven participants), that research is a secretive process (four participants), that participants are not provided with enough information (three participants) (“You have to keep the subjects informed”), and that the agenda of the researcher may not serve the community (“Is it for the researchers, or is it for us?”).

Cultural barriers between researchers and potential participants, misinterpretation of data (intentional or nonintentional), and misrepresentation of a community are viewed as problems by some of the Hawaiian study participants, as suggested by the following discussion:

I guess we were saying that we wouldn't want a strange group of researchers to come into our community and just use us as tests or to get data.

And then go back and misuse it, like using it to benefit them and not helping the community. It's happened here before. Not with medical research, but when it happens to deal with culture. There are always assumptions. Because people come over here and they say "Oh, Hawaiian culture is this and that," then they go back, it's all about hula. But it's not all about hula. They say, "Oh, go get a grass skirt," or "cellophane skirt and let's be Hawaiians," that's what happens.

It is misinterpretation of the information that they collect. They come out here, they take a few tests, they say, "Okay, this is 100 people. We tested them. Fifty of them have diabetes. So, you know, we just assume it's because they're Hawaiian" Maybe that is [true]. But I don't think that it's all Hawaiians [who get diabetes].

There's no substantial connection.

I think it's just our way of life. Just like a lot of African Americans and Native Americans and all of these other indigenous cultures. There is misinterpretation of information. They assume that taking 100 people's information is the same for all...48 to 50 thousand [live on our coast]. How can you assume that 100 people's information is the same thing for 48,000–50,000 different people?

Researchers are likely to encounter closed-mindedness on the part of potential participants for a number of reasons:

Also it is not only Hawaiians that live on the Wai'anae Coast. The community is a mixture of ethnicities.

And the host culture is already a minority. And they come over here and say, "Okay, this is Hawai'i."

I think that's the hard thing is that a lot of people close their doors so quickly that they don't try to hear anything. They don't try to hear what the point is. So maybe that's a big reason. I don't know how much research is done out on this side [of Oahu] and I don't know how much it helps our coast but I would think that [people not wanting to hear about the research] would be a problem.

[People may not be receptive to researchers] *depending on what happened to you that day and what you went through. You just don't like people to be niele [nosey], like they might think they know you. They ask too many questions so they maha'oi [intrusive]... I mean [outsiders] come to the house and don't even find out what [we're] about...we just say, "Oh, not interested Thankyou."*

Finally, a barrier that emerged in a focus group with younger members was the issue of age as a determining factor not only in pursuing health care, but participation in medical research. Young people play a key role in helping elders access and understand health care, both as translators of technology and language:

The younger generations are more open and aware of technology and the way they use it, when compared to our grandparent's generation when they only knew certain things...They don't know how they incorporate all of the new technology and new types of medicines that they use nowadays. So it'll be us translating that information to them so that they can have a better understanding and a better grasp of the whole situation themselves...that generation kind of shies away from doctors and medical.

By contrast, one of the youth group participants is disillusioned by Western biomedicine:

I have an uncle and he had a stroke about four years ago... he's been taking every single medicine that the doctors have given him. . He's always popping pills. And he just gets sicker and sicker. And I sit and I look at him and I'm looking at the doctors and telling them, "He's doing it. We're doing what you're telling us to do. Why isn't he getting better? He's only getting worse." So when I see stuff like that happen I lose faith in Western medicine. I have faith in Hawaiian la'au lapa'au [plant medicines]. But it's a lifestyle. Maybe it's just I don't like going to doctors. The doctor comes in for five minutes and says, "Okay, breath, breath, heartbeat, heartbeat, pau".

Facilitators/Motivators to Participation in Medical Research

The main conditions under which people would participate in a study were if:

- The doctor explained all aspects of the research, the purpose, and possible side effects: *"If you can ask a lot of questions, and fully understand the research process."*
- Patients had more confidence in research personnel, hospital staff, and medical facilities (confidence was particularly low in Hawaiian communities).
- Language and cultural barriers were addressed by providing more interpreters, translated material, and culturally matched research personnel.
- Research makes a clear contribution to future generations. Interest was strong in research that addresses health conditions that run in families: *"If I knew that it was a family inheritance thing. Something that could be detected early if my kids were going to have it down the line...I would want to do it."*
- Research makes a clear contribution to community: *"I got involved in a study of Hawaiian women. I did it because there were such a high percentage of Hawaiian women that had high blood pressure and diabetes. It isn't as rare as Kawasaki disease, but... I thought that was quite interesting."*
- Study findings are reported back to the community, and community members have some measure of control over research investigations (Hawaiian groups).
- Better medical facilities were provided to communities in which research is conducted.
- Money is provided as an incentive, and all medical bills are paid.

The last in the list, although a theme common to all groups, came with a caveat in some of the discussions. Again, suspicion toward researchers' motives was particularly high in the Hawaiian groups. Four of the study participants stated that researchers "take advantage" of lower income people by offering money as an incentive for participation in clinical trials. A discussion between Hawaiian participants:

Well, [medical research] doesn't seem to be working. A lot of commercials I hear, they're trying to pay people to volunteer... they're not getting the word out there so they have to put some bait out there so they can get some people to help with the research.

But I don't know if the word should be "bait" because bait is out there. They have the money, yeah.

Well, a lot of people are not making money. They're paying people... They need money to buy food and stuff so they're going to [participate in the research].

That's for the wrong reason though... You sell yourself to medical research for the money.

... *That's the wrong approach. . You're simply using people.*

Maybe they think, "Well, I paid them. So I can do whatever I want with this research and with them." They shouldn't have that kind of an attitude.

If they come in with a feeling that they really want to help the community, they really want to help Native Hawaiians, then they have to be sincere and have some degree of integrity when they come in and treat us as human beings.

The payment is no sort of ownership.

And one person believed that investigators themselves receive monetary advantages by enlisting people in research:

Whoever is having it done is out just to get money because they get a bonus. To me it's like they are just egging on people to do it because maybe they need the money.

Perceived Needs for Medical Research in Local Communities

Participants were especially eager to discuss clinical trials that investigate illnesses prevalent in their community. The question that stimulated the most responses was "What kind of research do you think is needed in our community?" Filipino and Hawaiian/Pacific Islander groups mentioned many of the same health concerns (in approximate order of most to least salient): gout, diabetes, obesity, high blood pressure, heart disease, sleep apnea, and asthma. Filipinos also emphasized cancer (colon, skin, thyroid), and other thyroid conditions. Skin cancer is a problem because of broader environmental health questions:

...a lot of [Filipinos] are farmers. And they have to practice good hygiene, you know, because nowadays you don't know what the hell is going on in the dirt. There's so much pollution and fumigation ...[and]... cesspools going. They don't realize that.

Several participants also expressed interest in development of research and education programs on drug and alcohol abuse, nutritional (the effect on health of processed foods and loss of traditional ways of eating) and environmental (eg, polluted water) aspects of disease, and efficacy of traditional herbal remedies (eg, noni, *Morinda citrifolia*, and 'awa, *Piper methysticum*). Food and diet was a common theme in many Filipino and Hawaiian group discussions. As one of the Filipino participants said, "Most health problems are cultural... eating habits are horrible." One of the Polynesian focus group participants commented:

What comes to my mind is how processed foods have affected us. So many people are either allergic or it reacts with our body chemistry differently, in Polynesians and Pacific Islanders. I would like to know how those foods, what kinds of qualifications they have to pass in order to be able to be processed and put in the stores so we can all buy them. I want research on these foods foreign to our islands.

Hawaiian participants were especially concerned with psychosocial and behavioral aspects health:

Mental, psychological, research, getting to the source of what causes decisions to be made on what you eat, how you treat yourself. And what is the problem? What is the source? Is it home life, financial the feeling of a community or not, being looked down upon... The attitudes of people, getting to the source.

The need for better community medical facilities was mentioned in a few groups:

Our community is one of the... poorest communities in Hawai'i, and I think we need a facility with doctors that have knowledge of things that can help out Polynesian people. We have doctors that are friendly, but we still can't pay. But if we have some doctors that have knowledge or keep research on a lot of sicknesses. For instance, a lot of the community hurts from gout. There's a lot of the sleep apnea... All they do is they give medications and they make the pain even worse. So if there's research out there, we need doctors' research that can say "Hey, we have a drug that can help with gout right away." "Hey, you know, this is a good community project."

Related suggestions were:

People are not being educated enough...It would be good to just let the community be more aware of whatever they're researching and what's out there. ...There could be more learning clinics where you can make the public aware of research... having clinical research at the school level. If the parents are not going to come, maybe the kids will listen and come educate their parents.

Finally, building trust is critical to improving research opportunities as stated by one of the Hawaiian participants:

Trust. So if they want to do research, they have to get into the community and be part of it. And not just, sitting up in their office somewhere. They have to go where people are relaxed and calm. Like I said, at functions happening in the community. The first start is introducing themselves and letting people know who they are and then opening up, then it'll be safer. Then, I think, they're better able to get more participants in filling out research forms.

And,

If they want people to participate, then they have to come to the community and meet the people in the community and get to know the people the community. They cannot just send a piece of paper in the mail and expect people to fill it out and think, "Okay, they're gonna do it." You build a trust.

Trust can be built and maintained by full disclosure of what clinical trials entail and by returning research findings to the community:

So the next person is going to come and do research again because "Oh, we did research two years ago", but nobody told us what happened...If they establish trust and keep everybody informed everybody's going to talk about it. And of course they'll get more participants. But once it's bad, that's it. You may as well close shop, lock up, and leave the community because you won't get anything.

Finally, a question posed in one of the Hawaiian focus groups:

Are we going to get a followup on this talking about research? Are we going to get feedback from what happened tonight, information, the outcome of it? We want to know the outcome.

DISCUSSION

Participants in the MICRO Project focus groups conducted in Hawai'i had more interest and prior (personal or family) experience in medical research than the authors expected. People with former or ongoing experience in medical investigations were quite positive and served as boosters for encouraging other focus group participants to consider being part of a clinical trial. Focus group discussions can serve as a catalyst for expanding peoples' knowledge of research

and research opportunities. For the 82% of focus group respondents with no personal medical research experience, the greatest misconceptions about research (particularly for Hawaiian participants) were the lack of awareness an informed of consent protocol and a general belief that medical investigations are conducted in a clandestine way. Monetary incentives, although mentioned by several respondents, are not always the best motivator, particularly in an environment of suspicion. Participatory research approaches may also boost involvement as suggested in Hawaiian focus groups. A few members of the Filipino and Hawaiian/Pacific Islander focus groups expressed interest in research on broader, “big picture” questions of health and the environment, in preventive programs related to diet and drug/alcohol abuse, and in exploring the psychosocial aspects of health. Sleep apnea was of relatively high salience as a health problem. Like diabetes and cardiovascular disease in Pacific Islander populations, sleep apnea is tied to biocultural factors such as poor eating habits and obesity and is worthy of greater attention by researchers and health promotion programs. The authors also note that far more women than men were part of the MICRO Project focus groups in Hawai'i. Future phases this project will of seek to obtain a better understanding of the barriers and motivators to clinical trial participation from men.

Recommendations for Improving Participation in Medical Research

Based on these MICRO Project findings, we recommend that campaigns to improve recruitment and retention of Asian/Pacific Islander populations in Hawai'i address fear and mistrust of medical research and researchers by: 1) increasing awareness of the purpose and intent of clinical studies (especially the process of informed consent and patient safeguard measures) and the potential benefits to family and community; 2) providing information about the value of clinical research to younger children through health education classes to aid in the education of their parents and elders; 3) employing participants in previous research projects as a recruitment resource and; 4) employing participatory techniques similar to those presented by Moreno-John et al, namely: a) contributing to the political process to better the medical facilities/infrastructure in API communities; b) responding to the expressed health needs of local communities to generate new investigations; c) increasing the number of culturally and linguistically matched healthcare professionals and researchers to these communities; and d) returning the findings from projects to patients and communities in a user-friendly way.

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