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Permalink

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Journal

Journal of Cancer Education, 34(4)

ISSN

0885-8195

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Publication Date

2019-08-01

DOI

10.1007/s13187-018-1352-6

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Biospecimen Education Among Pacific Islanders in Southern California

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Abstract

Despite increasing rates of cancer, biospecimen donations for cancer research remains low among Pacific Islanders (PIs). To address this disparity, researchers partnered with PI community organizations to develop and test a theory-based culturally tailored educational intervention designed to raise awareness about the issues surrounding biospecimen research. A total of 219 self-identified PI adults in Southern California were recruited to participate in a one-group pre-post design study. Participants completed questionnaires that assessed their knowledge and attitude regarding biospecimen research before and after viewing an educational video and receiving print materials. Results showed that participants' overall knowledge and attitude increased significantly from pre-test to post-test ($p < .0001$). Over 98% of participants also reported that they would be willing to donate at least one type of biospecimen sample. Efforts such as these that utilize culturally tailored education interventions may be instrumental in improving biospecimen donation rates in the PI community as well as other minority populations.

Introduction

In the United States, Pacific Islanders (PIs) make up a small but rapidly growing segment of the population. From 2000 to 2010, the number of PIs increased from approximately 875,000 to 1.2

million, a rate of 37.1%, as compared to the national average of 9.7% [19]. During the same timeframe, cancer incidence rates among PIs escalated. Samoan women experienced steadily rising rates of breast, uterine, and colorectal cancer. From 1996 to 2008, incidence rates per 100,000 for uterine and colorectal cancer in Samoan women nearly doubled from 47.3 to 85.0 and 20.8 to 40.7, respectively. Over two decades, Guamanian and Chamorro men also experienced increasing incidence rates of prostate cancer (65.1 to 87.1) and colorectal cancer (17.4 to 28.7) [8]. Despite these trends, PIs remain one of the most underserved and understudied populations [15]. Genetic research in particular may be vital to future efforts designed to address these growing cancer health disparities [1].

Clinical research of genetic materials has become an increasingly important factor in effective cancer research and treatment. Unfortunately, the proportion of biospecimen samples collected from ethnic minority populations, including PIs, is very low [2, 9]. Critical research is being done using biospecimen samples to draw links between genetics, disease, and cancer disparities, but due to the lack of appropriate representation of minorities in clinical trials, conclusions from this research may not adequately serve all populations [6]. Various reasons have been established as to why minorities have not participated in genetic research, including lack of

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culturally relevant materials, unwillingness to undergo donation procedures, and concerns around confidentiality, privacy, ownership, and discrimination [3, 7, 13].

PIs in Southern California report similar reservations about participating in biospecimen research. The most common concerns include fear of pain or discomfort and not wanting to uncover potential health problems [7]. These concerns are counterbalanced by a belief that biospecimen research would benefit the PI community as a whole [7]. Native Hawaiians (NHs) share these views, embracing research as a way to improve health among the NH population yet still voicing concerns about participating in biobanking due to the lack of transparency in current practices and the lack of NH representation in the governance of biobanks with NH specimens [18].

To address these concerns, the Weaving an Islander Network for Cancer, Awareness, Research, and Training (WINCART) Center developed the Pacific Islander Biospecimen Education and Collection (PIBEC) project. WINCART is a community-based participatory research (CBPR) center comprised of two universities and six community-based organizations (CBOs) with the overarching goal to reduce chronic disease mortality and morbidity among PIs in Southern California [16, 17]. PIBEC was created as a demonstration study to test whether an education program could improve knowledge and awareness of biospecimen research among PI communities in Southern California, providing potential participants with information needed to make an informed decision about biospecimen donations. The study utilized CBPR methodology and involved leaders from multiple PI communities (Chamorro, Marshallese, Native Hawaiian, Samoan, and Tongan). Together, academic researchers and community leaders conceptualized the study and co-created the educational program. To our knowledge, this is the first study to develop a theory-based, culturally tailored educational program aiming to improve knowledge and awareness regarding biospecimen research and donation among PIs. This article reports on the development of the intervention and its effectiveness among PIs in Southern California.

Methods

Participants

Participant recruitment was performed by advocates from PI organizations who had established relationships in their communities. Partner PI organizations included Empowering Pacific Islander Communities, Guam Communications Network, Pacific Islander Health Partnership, Samoan National Nurses Association, Tongan Community Service Center/Special Services for Groups, and Union of Pan Asian Communities. These

organizations conducted participant outreach between May 2015 and October 2015 in the counties of Los Angeles, Orange, and San Diego. The majority of the participants (86.3%) were recruited through face-to-face contact at local PI-led CBOs, churches, social clubs, and events. The remaining participants (13.7%) were recruited through phone calls, text messages, and emails. Collectively, advocates enrolled 219 participants ages 18 and older who were able to read and understand English and self-identified as Native Hawaiian, Marshallese, Samoan, Chamorro, Tongan, or another PI sub-group [24]. Eligible individuals were invited to view an educational campaign focused on improving awareness of biospecimen donations and emphasizing the importance of biospecimen research to the PI community.

Study Design and Procedures

The study utilized a one-group pre-post design to evaluate the culturally tailored educational intervention. The pre-test assessment was completed prior to the delivery of the intervention and the post-test was completed immediately after. The study was reviewed and approved as exempt by the Institutional Review Boards from the two participating universities. Informed consent was obtained from all individual participants included in the study.

Recruited participants were invited to take part in an educational session held at various sites in the community, such as churches, universities, and community centers. Sessions occurred in small groups of individuals with an average of five participants per group. At each session, trained staff provided a scripted overview of the study and answered questions from participants. Individuals who agreed to participate were then directed to an online consent form and pre-test questionnaire programmed in Qualtrics and administered using a smartphone, tablet, or laptop. Once participants viewed and electronically signed the online consent form, they were asked to complete a 10-min online pre-test. Following the pre-test survey, participants were shown an 8-min educational video on biospecimens and biospecimen research that was culturally tailored for the PI community. After viewing the video, participants were given additional materials to review including a brochure that contained a concise summary of the information in the video and a Frequently Asked Questions (FAQ) sheet that provided responses to common questions about donating biospecimen samples. Participants then completed a 15-min online post-test during which they were allowed to view the printed materials, though they did not receive any instructions to utilize them for the post-test. From beginning to end, sessions lasted

about 30 to 45 min and participants received \$20 as compensation for the time.

Intervention Development

A scientific advisory committee, comprised of researchers who had prior experience conducting community-based biospecimen research, was created to aid in the study development process. Through a series of conference calls held throughout the 6-month planning process, the committee identified existing forms and protocols that could be utilized for PIBEC and reviewed adapted forms, protocols, educational materials, and questionnaires. WINCART community partners from multiple PI CBOs also met regularly to provide feedback on the form, content, and design of the educational materials along with the cultural appropriateness, potential impact, and general appeal of the project. Frequent meetings between academic researchers and community partners resulted in community input on all aspects of the study. Discussions ranged from the reasons why biospecimen donation would be important to PIs to the best method of delivering information. One discussion focused on the amount and form of compensation suitable for this study. Community partners conveyed that PI community members preferred cash to gift cards and that too high of an amount could discourage community members from joining future studies. As a result, \$20 cash compensation for participation was determined to be an appropriate amount for this study.

Information in the educational program was guided by the Health Belief Model (HBM), which is widely used in health research to explain and predict behaviors. It was originally developed to understand why people refused to get tuberculosis screenings and is therefore useful as a guiding framework when creating educational interventions intended to encourage a one-time event, such as biospecimen donation [14]. The HBM consists of several constructs to explain why people will engage in certain health behaviors to prevent, screen for, or control illnesses, diseases, or health conditions. These constructs are outlined as perceived threat (perceived susceptibility and perceived severity), perceived benefit, perceived barriers, cues to action, and self-efficacy [12].

The PI-narrated educational video addressed each of the key constructs from the HBM. The video begins by addressing the perceived threat construct explaining the disproportionate susceptibility of PIs to certain diseases. Statistical figures are displayed in the video as the narrator states:

Here are some statistics that might surprise you. Did you know that Pacific Islanders are at greater risk of getting heart disease, cancer, and diabetes compared to other groups in California? For Native Hawaiians and Pacific Islanders, heart disease is the leading cause of death, and cancer is the fastest growing cause of death.

We wish we knew why Pacific Islanders suffer more from heart disease, cancer, and diabetes compared to other groups.

The video narrator then defines biospecimens and explains how genetic research may help scientists to understand why PIs suffer disproportionately from these diseases and how biospecimens are used in different types of research:

Biospecimen samples can be used to develop new tests, drugs, and treatments for different kinds of diseases like cancer. They can be used to find the causes of diseases or to better understand how those diseases are passed down in families. By studying biospecimen samples, we can get a better idea of why some groups of people have a greater risk of developing a certain disease than other groups. All biospecimen research helps scientists understand how genes affect health and illness.

The video further addresses perceived barriers, such as matters of confidentiality and the right of donors to withdraw their sample at any time. It explains why biospecimen research is important to PIs in particular, addressing present and future perceived benefits to their community, such as its potential impact to improve the health of future generations. Self-efficacy was addressed when participants were later asked how willing they were to donate samples and what type of samples they were willing to provide.

Study materials were developed over a period of 6 months with significant input from the PI community. Findings from a previous WINCART project that assessed knowledge, attitudes, and beliefs on biospecimen research among PIs informed the creation of the culturally tailored education materials [6]. Once an initial draft of the video and the brochure was prepared, discussions were held with two groups of community members ages 18 and over to provide further direction on the content and overall esthetics. Examples of feedback included having more PI representation in the visuals used in the brochure and having the video voiceover performed by a PI. Community members were also asked if they would be willing to donate a biospecimen sample after viewing the materials. One participant who answered yes stated, “Because not a lot of us have reported statistics for our communities and just the fact that [the video] pointed out that we have a high rate of cancer and diabetes, that stood out to me why it’s very important for our community to participate in this.” Another participant, who answered no, said there wasn’t enough information that they could personally relate to. Overall, the feedback from community members and community partners led to several revisions of the materials resulting in an 8-min educational video, an informational brochure, and a FAQ sheet. These materials were pilot-tested with a subset of 15 adult PIs before being finalized and disseminated.

Measures

Demographic survey items included gender, age, ethnicity, primary language, highest level of education, personal health history, and family health history of chronic diseases, such as cancer, diabetes, and heart disease [22]. Biospecimen knowledge and attitudes were measured via a 5-item scale that assessed the understanding of what a biospecimen sample was, the use of biospecimen samples in research, and its relevance to the PI community. These items were adapted from materials provided from the scientific advisory committee [20, 23]. Four questions evaluated biospecimen knowledge and one question focused on biospecimen attitudes. Participants were asked, “What is considered a biospecimen or biospecimen sample?” with a multiple choice list of response options: (a) Blood, (b) Hair, (c) Nail, (d) Urine, (e) Skin, (f) All of the above, (g) None of the above, and (h) I don’t know the answer. The following items were “True or False? Biospecimen samples contain information that can help scientists learn more about diseases such as cancer.” and “True or False? If a person donates their tissue or blood sample for research or other purposes and changes their mind later, they can always ask the research team to remove or discard their sample.” with the following response choices: (a) True, (b) False, and (c) I don’t know the answer. Participants were then asked, “Why are biospecimens from Pacific Islanders important to researchers?” Answer options were (a) Researchers just want biospecimens from Pacific Islanders. There are no particular reasons, (b) Pacific Islanders may have specific information in their biospecimens that make them more at risk for certain diseases, (c) Biospecimens from Pacific Islanders are better than biospecimens from other ethnicities, and (d) I don’t know the answer. Correct individual knowledge items were scored with a value of one and summed to create a total score, ranging from zero (for no correct responses) to four (for all correct responses). Attitude regarding biospecimens was assessed by asking participants to rate how strongly they agreed or disagreed with the following statement using a 5-point Likert scale: “Donating my biospecimen sample is important because it helps scientists learn more about diseases that can affect me and my community.”

Educational materials were evaluated with six survey items. Three items asked participants to rate each biospecimen educational material (video, brochure, FAQ sheet) on a 4-point Likert scale ranging from “Very Informative” to “Not Informative.” Three items asked participants to rate how strongly they agreed or disagreed with statements about the design and value of the materials such as, “The Pacific Islander theme of the materials helped me to stay interested” and “The questions raised in the video and brochure were the same questions I had.” Participants were also asked, “Compared with what you know about

biospecimens and biospecimen donation before you saw the educational materials today, how would you rate your knowledge now?” with answers on a 5-point Likert scale ranging from “I know a lot more” to “I know less.”

Statistical Analyses

Paired *t* tests were conducted to assess the significance of differences between pre-test and post-test scores of overall biospecimen knowledge and attitude with $\alpha = .05$ and 95% confidence intervals. McNemar’s tests with $\alpha = .05$ were performed to analyze the significance of differences between pre-test and post-test scores for individual biospecimen knowledge and attitude items. All analyses were performed using SAS version 9.3.

Results

A total of 219 self-identified PIs participated in the study (Table 1). Of those participants, 63.9% were female and over half of all participants (53.9%) were in the 18–35-year-old age group. Those who identified as Samoan made up the largest ethnic group (56.6%), followed by Tongan (22.4%), and Native Hawaiian (10.1%). English was reported as the primary language for 70.3% of participants. Nearly a third of participants (31.9%) reported some college or trade school as their highest level of education. The top three reported personal health conditions included obesity (27.9%), hypertension (18.6%), and diabetes (17.7%). Family health history had higher reported rates of diabetes (70.4%), heart disease (49.5%), and cancer (47.2%). Prior to this study, 57 (26%) participants reported having previously donated their saliva, blood, tissue, or other biospecimen samples for research purposes. Of these participants, 31 (56.4%) reported having a family history of cancer.

Table 2 shows the evaluation of educational materials at post-test. All three educational pieces (e.g., video, brochure, FAQ sheet) were evaluated as either informative or very informative by over 95% of the participants (96.8, 96.7, and 97.5%, respectively). When asked if the Pacific Islander theme of the materials helped to keep the participant interested, 213 (98.6%) participants either agreed or strongly agreed. The majority (95.4%) of participants either agreed or strongly agreed that the questions raised in the video and brochure were the same questions that they had regarding biospecimens. Nearly all (99.1%) participants agreed or strongly agreed that the educational materials were easy to follow and understand, and 88.9% also reported knowing a little to a lot more about biospecimens and biospecimen donations compared to their knowledge before seeing the educational materials.

Table 1 Demographic characteristics

	Number	Percent
Gender		
Female	140	63.9
Male	79	36.1
Age		
18–35	117	53.9
36–55	62	28.6
> 55	38	17.5
Ethnicity		
Samoan	124	56.6
Tongan	49	22.4
Native Hawaiian	22	10.1
Chamorro	10	4.6
More than one	12	5.5
Primary language		
English	154	70.3
Samoan	36	16.4
Tongan	23	10.5
Chamorro	3	1.4
Hawaiian/Native Hawaiian	1	0.5
Other	2	0.9
Highest level of education		
Less than high school	8	3.7
High school or GED	58	26.9
Some college or trade school	69	31.9
Trade school or 2-year college	37	17.1
4-year college	30	13.9
Graduate degree	14	6.5
Personal health history		
Arthritis	21	9.8
Asthma	22	10.2
Cancer	11	5.1
Diabetes	38	17.7
Heart disease	13	6.1
Hypertension	40	18.6
Obesity	60	27.9
Family Health History		
Arthritis	66	30.6
Asthma	79	36.6
Cancer	102	47.2
Diabetes	152	70.4
Heart disease	107	49.5
Hypertension	79	36.6
Obesity	99	45.8

Individually, knowledge significantly increased for each item from pre-test to post-test, as presented in Table 3. Overall biospecimen knowledge scores from pre-test to post-test also significantly increased, with the overall mean score increasing from 3.15 (SD ± 1.1) at pre-test to 3.77 (SD ± 0.7) at post-test ($p < .0001$). There were also significant differences found in attitude regarding biospecimen donation from pre-test to post-test. At post-test, 196 (90.7%) participants either agreed or strongly agreed with the statement, “Donating my biospecimen sample is important because it helps scientists to learn more about diseases that can affect me and my community” compared to 171 (78.1%) at pre-test ($p = .0001$). At post-test, 98.6% of participants also reported

Table 2 Evaluation of educational materials at post-test

	Number	Percent
1. How would you rate the biospecimen education materials that you just saw?		
Video		
Very Informative	142	66.4
Informative	65	30.4
Somewhat Informative	5	2.3
Not Informative	2	0.9
Brochure		
Very Informative	127	61.7
Informative	72	35.0
Somewhat Informative	6	2.9
Not Informative	1	0.5
FAQ Sheet		
Very Informative	130	64.0
Informative	68	33.5
Somewhat Informative	5	2.5
Not Informative	–	–
2. The Pacific Islander theme of the materials helped me to stay interested.		
Strongly Agree	141	65.3
Agree	72	33.3
Disagree	3	1.4
Strongly Disagree	–	–
3. The questions raised in the video and brochure were the same questions I had.		
Strongly Agree	113	52.3
Agree	93	43.1
Disagree	10	4.6
Strongly Disagree	–	–
4. The materials were easy to follow and understand.		
Strongly Agree	158	72.8
Agree	57	26.3
Disagree	2	0.9
Strongly Disagree	–	–

that they would be willing to donate at least one type of biospecimen sample (saliva, urine, blood, toenail, or hair).

Discussion

This demonstration study tested a theory-based culturally tailored education program designed to increase knowledge and awareness about the use of biospecimens for health-related research among PIs. Although literature regarding PI participation in genetic research and clinical trials is severely limited and similar biospecimen studies involving mainland PIs are scarce, the current study shows that a directed health education effort has the potential to improve PI representation in genetic

Table 3 Biospecimen knowledge at pre-test and post-test

Individual knowledge items	Pre-test <i>n</i> (%) ^a	Post-test <i>n</i> (%) ^a	<i>p</i> value
1. What is considered a biospecimen or biospecimen sample?	167 (76.3)	205 (93.6)	< .0001
2. True or False? Biospecimen samples contain information that can help scientists learn more about diseases such as cancer.	199 (90.9)	215 (98.2)	.0006
3. True or False? If people donate their tissue or blood sample for research or other purposes and change their mind later, they can always ask the research team to remove or discard their sample.	143 (65.3)	203 (92.7)	< .0001
4. Why are biospecimens from Pacific Islanders important to researchers?	180 (82.2)	202 (92.2)	.0005
Overall knowledge index score	N 219	Difference in mean score 0.621	<i>p</i> value < .0001
Overall mean knowledge scores	Mean ± SD (range) 3.15 ± 1.07 (0–4)	Mean ± SD (range) 3.77 ± 0.71 (0–4)	

^aNumber and percentage of correct responses

research. Results showed that PI participants had significantly improved knowledge and attitude after viewing the educational intervention about biospecimens and biospecimen donation. Most participants were also willing to donate at least one biospecimen sample, suggesting positive behavioral intentions. These results support the growing body of literature showing that minorities are open to education programs on biospecimens and are willing to donate biospecimen samples, given the appropriate circumstances and education, so they can make informed decisions [10]. The success of PIBEC's educational program signals how culturally relevant materials can effectively reach minority populations to increase awareness and improve health and scientific literacy. Culturally tailored education on biospecimens and biospecimen research may also increase the likelihood that minority populations will donate biospecimen samples to cancer research in the future. This is particularly important for PIs, who are 46% more likely than average to be diagnosed with cancer, a rate higher than any other racial group [8, 11, 21].

Efforts to utilize culturally tailored education to improve health knowledge and literacy can be instrumental in reducing cancer health disparities. A recent meta-analysis suggests that culturally tailored cancer messages have a significant influence on attitudes, intentions, and behaviors [5]. Moreover, the effect can be intensified through deep tailoring that addresses the values, norms, and religious beliefs of the target population. The current study provides further evidence for these findings since over 98% of participants agreed or strongly agreed that the Pacific Islander theme of the educational materials helped them stay engaged with the program. This suggests that PI adults may be more

receptive to biospecimen education and donation when outreach and education efforts are culturally appropriate.

Previous studies have also shown that minority populations are open to biospecimen education efforts and are, in fact, willing to donate biospecimens once they learn more about it [10]. Tong et al. [20] found that Cantonese-speaking Chinese Americans were highly receptive to a culturally relevant theory-based education program and many were willing to participate in biospecimen collection. In another community-based study, Gao et al. [4] developed a culturally tailored education program for Chinese Americans while also integrating key constructs from the HBM. Results showed significantly improved knowledge, as well as higher donation rates of blood samples among the intervention group compared to the control group. The results of the PIBEC study corroborate these results. Overall, current research signals that theory-based education programs may be able to reach minority populations more effectively when utilizing cultural tailoring.

Limitations

Despite the positive findings, several limitations may impact generalizability. First, we recruited a non-probability sample of Pacific Islander adults that may have been more comfortable with research participation due to prior WINCART studies conducted within this community [6, 7]. Thus, it is difficult to know how representative our sample was to the larger population in Southern California. Another important feature of the sample is the unexpectedly high baseline knowledge and positive attitudes regarding biospecimen research. It is conceivable that the effect of the educational materials will be even greater among less-informed individuals.

It is also noteworthy that while community advocates aimed to recruit equal numbers of men and women, the final sample had about twice as many female participants as male participants and over 50% of the participants were between the ages of 18 and 35. Though no significant differences were found between genders or age groups, this could have still affected results. Eligibility criteria for the study included the ability to read and understand English as a requirement since the educational intervention and survey items were developed in English. However, nearly 30% of our sample reported that English was not their primary language. This may have affected survey responses and future projects should consider translations in other PI languages.

Another key limitation is that since the one-group evaluation design lacked a control group, it is not possible to determine the extent to which knowledge and attitudes increases might be due to influences beyond the educational intervention. Future studies should consider incorporating both an experimental and control group to better understand the effects of culturally tailored interventions. Without longitudinal data, it is also difficult to know how long the effects of the intervention will be sustained. However, we believe we achieved the aim of this demonstration study to develop and evaluate an education program designed to increase support for biospecimen donations among PIs.

Implications

The current study contributes to the growing body of literature showing that biospecimen research efforts can be successful in minority populations when conducted in a culturally sensitive manner. The use of cultural tailoring to address many of the barriers that challenge PI participation rates showed positive results, as has been reported in similar CBPR efforts performed with other minority communities. By working in equal partnership with community members, our study saw successes in the development of culturally tailored materials, participation in the educational intervention, and changes in knowledge and attitudes toward biospecimen research. The study also showed that, through the use of CBPR methodology, cultural tailoring can extend past intervention development to the entire research process, including key decisions in the study design, recruitment strategy, and data collection procedures. In addition, this study demonstrated that continued engagement within PI communities could improve the odds that PIs will join future studies regarding biospecimen research. Maintaining relationships with the community in regard to research would further improve researchers' understanding in how to engage in a culturally competent manner. Based on these findings, researchers should consider conducting large-scale CBPR projects that aim to improve knowledge of biospecimen research within the broader PI population and cultivate a database of PIs willing to participate in genetic

research that has the potential reverse current trends in cancer health disparities.

Acknowledgements The authors would like to thank Empowering Pacific Islander Communities, Guam Communications Network, Pacific Islander Health Partnership, Samoan National Nurses Association, Tongan Community Service Center/Special Services for Groups, and Union of Pan Asian Communities for their support and contributions. In addition, we also show our gratitude to the members of our advisory committee at University of Hawai'i, 'Imi Hale, Asian American Network for Cancer Awareness and Training, and Fred Hutchinson Cancer Research Center. The contents are solely the responsibility of the authors and do not necessarily represent the official views of the National Cancer Institute (NCI) Center to Reduce Cancer Health Disparities (CRCHD).

Funding Information

This project was supported by the Weaving an Islander Network for Cancer Awareness, Research, and Training (WINCART) Center Parent Grant No. U54CA153458 and CHE Supplement No. U54CA153458-S2.

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