

Addressing the cancer control needs of Pacific Islanders: experience of the Pacific Islander Cancer Control Network

Abstract: **Purpose:** This paper describes the accomplishments of the Pacific Islander Cancer Control Network (PICCN). PICCN's objectives fall under two broad categories: increasing cancer awareness and enhancing cancer control research among Samoans, Tongans, and Chamorros. **Methods:** PICCN established an infrastructure for addressing the goals that include the University of California, Irvine; the UCI Chao Family Comprehensive Cancer Center; and community-based organizations (CBOs) in areas where large numbers of Pacific Islanders live. Activities that increase cancer awareness include assessing existing cancer education materials, developing new culturally-sensitive materials, and distributing the materials in a culturally-sensitive manner. Activities that enhance cancer control research include training Pacific Islander investigators and providing them with mentors to help with the development of research projects. **Results:** During the four project years, PICCN has conducted more than 180 cancer awareness activities in its six study sites: Carson, CA; San Mateo, CA; San Diego, CA; Salt Lake City, UT; American Samoa; and Guam. PICCN members have also participated in conferences and lead discussions about the importance of clinical trials for Pacific Islanders. In addition, the Network has trained nine Pacific Islander investigators (three individuals from each ethnic group) in its cancer control academy. Finally, PICCN investigators are conducting pilot research projects that will answer important questions regarding the cancer control needs of these Pacific Islanders and set the stage for interventions aimed at addressing the needs. **Conclusion:** PICCN is advancing the national goal of eliminating cancer-related health disparities through its cancer awareness and research activities for Pacific Islanders. **Key Words:** Pacific Islander, American Samoan, Chamorro, Tongan, training, cancer prevention, cancer control, research training, cultural competence

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goal of the PICCN is to provide an infrastructure to improve cancer control among Pacific Islanders by increasing cancer awareness and enhancing cancer control research. A detailed account of PICCN's organizational structure, goals, and objectives appears elsewhere¹.

The PICCN target populations make up three of the four largest groups of Pacific Islanders in the US – only Native Hawaiians are more numerous² (Table 1). The highest concentrations of these Pacific Islanders (outside of the Territories) live in California (approximately 30%). Most of the remainder live in Hawai'i, Washington, Texas, and Utah. As described below, PICCN chose community-based organizations (CBOs) with which to work based in part on the large numbers of Pacific Islanders in those regions.

American Samoans and Chamorros are indigenous to the United States (US), originating from the US Territories of American Samoa and Guam. Persons born in American Samoa are US nationals with the right of free entry into the United States; and inhabitants of Guam are US citizens. The US Department of Health and Human Services recognizes these populations within the census category *Native Hawaiian and other Pacific Islanders*². The other Pacific Islander group served by the PICCN is the Tongan-American population – a group with origins in the Kingdom of Tonga.

Cancer is the second leading cause of death among American Samoans, Chamorros and Tongans³, yet little is known about their cancer control needs. For example, reliable information about cancer incidence rates is limited. Moreover, few studies have evaluated what these Pacific Islanders believe about cancer or how often they use cancer prevention services. In addition, like most minority groups, few Pacific Islanders participate in cancer-related clinical trials so there is little information about whether the results

Introduction

In 2000, the National Cancer Institute (NCI) funded 18 Special Populations Networks (SPNs) to identify and address the cancer control needs of America's medically underserved populations. The Pacific Islander Cancer Control Network (PICCN) is one of two SPNs that focus on Pacific Islanders, in particular, American Samoans, Tongans, and Chamorros (the indigenous people of Guam). The overall

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Table 1. US Pacific Islander population according to the 2000 US Census

| | |
|------------------------------------------------------------------|---------|
| Native Hawaiian and Other Pacific Islander | 398,835 |
| Native Hawaiian | 140,652 |
| Samoan* | 91,029 |
| Guamanian (including Chamorro)** | 58,240 |
| Other Pacific Islander category*** | 99,996 |
| Two or more Native Hawaiian or Other Pacific Islander categories | 8,918 |

* An additional 57,291 Samoans resided in the US Territory of American Samoa

** An additional 154,805 Guamanians (of which 45% are Chamorro) resided in the US Territory of Guam

*** Of these, 27,713 were Tongan

are applicable. Finally, very few Pacific Islander investigators are involved in cancer control research. Each of these issues is discussed in the remainder of the introduction section.

Reliable estimates of cancer incidence rates among Pacific Islanders are limited by the relatively small number of cancer cases per year (due to the small population sizes) and the lack of systematic data collection on cancer incidence and mortality. Therefore, only proportional incidence rates are available for these groups. Data from the Los Angeles County/University of Southern California Cancer Surveillance program⁴ indicate that the most common cancer sites among American Samoan women in California are breast, lung, cervix uteri, and corpus uteri. For men, the sites are lung, prostate, colon/rectum, and stomach. According to the Guam Cancer Registry, the most common cancers for Chamorro women are breast, colon/rectum, uterus and blood. For men, they are lung, prostate, colon/rectum, and liver. Cancer statistics for Tongans are very limited. However, the California Cancer Registry indicates that the most common cancers among Tongan women in California are breast, cervix, lung, and colon/rectum. For men, they are lung, prostate, colon/rectum, and stomach.

The limited research that exists regarding cancer-related knowledge, attitudes and preventive practices among these Pacific Islanders suggests that knowledge about cancer is incomplete and use of cancer prevention services is low. The best studied group to date is American Samoans. A population based survey of American Samoans in Los Angeles, Hawai'i, and American Samoa found that over one third of respondents believed that there was little they could do to prevent cancer^{5,6}. Moreover, only 33% of women of appropriate ages had ever received a mammogram⁷ and only 64% had ever received a Pap smear⁸. Likewise, a study of Chamorros in southern California found that they had a limited understanding about the risk factors for breast cancer and only 25% received yearly mammograms⁹. Finally, in the only published study on cancer screening in Tongans, the investigators found that only 26% of Tongan women in

southern California had ever received a mammogram¹⁰. These findings point out the need for cancer education programs for Pacific Islanders regarding cancer as well as the necessity for additional studies on the cancer control needs of these populations.

Participation rates in cancer prevention and treatment trials are low for ethnic minority groups in general¹¹. In the case of Pacific Islanders, the rates are difficult to obtain; however, they are also likely to be quite low. For example, there were only two Samoans and one Tongan among the thousands of patients entered into cancer prevention and treatment trials by the Southwest Oncology Group from 1995-2000 (personal communication). The reasons for low participation rates are thought to be due, in part, to a lack of knowledge. However, in the case of Samoans, Tongans, and Chamorros living in American Samoa, Tonga, and Guam, respectively, clinical trials are not available to them unless they travel to the continental US, Hawai'i or another country.

Finally, relatively few American Samoans, Tongans, and Chamorros have advanced degrees and, it is believed, only a handful participate in cancer control research. The success of research designed to reduce cancer-related health disparities in Pacific Islanders will depend substantially on the presence of a cadre of culturally sensitive, well-trained competitive Pacific Islander researchers. Therefore, programs are needed to begin the development of potential cancer control researchers in these populations.

The purpose of this paper is to describe the methods by which PICCN is addressing the issues described above and the results of those efforts to date.

Methods

Infrastructure development

During the first year of the grant, the investigators developed the PICCN organizational structure. PICCN provides an infrastructure for collaboration between the University of California, Irvine (UCI); the UCI Chao Family Comprehensive Cancer Center; and community-based organizations (CBOs) in areas where large numbers of Pacific Islanders live. UCI, in conjunction with the National Office of Samoan Affairs, is responsible for the administrative oversight of PICCN. The Network is coordinated by a Steering Committee, a Pacific Islander Community Committee, and six advisory boards located in areas with large concentrations of the Pacific Islanders of concern to this project. Directors of Pacific Islander community-based organizations or State agencies in these sites serve as chairs of the PICCN advisory boards. These organizations include the Office of Samoan Affairs in Carson, CA; Taulama (Advice) for Tongans in San Mateo, CA; Sons and Daughters of Guam Club in San Diego, CA; Office of Pacific Islander Affairs in Salt

Lake City, UT; Native Samoan Advisory Council in American Samoa; and the Department of Public Health and Social Services in Guam. In addition to the chair, board membership includes other Pacific Islander community members and individuals from academic medical centers, NCI, NCI-designated Cancer Centers, the Cancer Information Service, and other organizations that focus on cancer research and education. It is through this infrastructure that PICCN achieves its objectives.

Cancer awareness activities

The Pacific Islander Cancer Control Network enhances cancer awareness by evaluating existing cancer educational materials, developing new culturally sensitive pamphlets and brochures when necessary, and conducting cancer education events in each of the six geographical areas. The advisory boards are responsible for reviewing educational materials from the NCI, the American Cancer Society and other cancer-related organizations and making recommendations about the appropriateness of them for their populations. The advisory boards also identify the specific cancers of most concern for their communities and the best approaches for increasing awareness about them. They work closely with other organizations such as the Cancer Information Service, American Cancer Society, Tell-a-Friend, and State/Territory Breast and Cervical Cancer Control Programs to coordinate activities.

In most cases, educational materials have not been available in the Samoan, Tongan, or Chamorro languages nor have they been sensitive to the culture of the groups. Therefore, it has been necessary for PICCN to develop new educational materials. The process begins with a review of materials in English that have been developed by the National Cancer Institute or the American Cancer Society. Certified translators from the communities then translate the materials after which they are presented to focus groups for evaluation of cultural sensitivity and readability.

In addition to educating Pacific Islanders about cancer, PICCN has begun to educate its target populations about clinical trials. The general cancer awareness activities demystify cancer and stress the importance of early detection and treatment. From this baseline, the benefits of clinical trials can then be discussed.

Research activities

To address the need for more Pacific Islanders with expertise in cancer control research, PICCN developed a program to begin training potential cancer control re-

searchers in these populations. At the core of the program is an educational training course called the UC Irvine Cancer Control Academy. The course is based loosely on the successful model designed by Dr. Thomas Becker at Oregon Health Sciences University¹² and our program is conducted over a three-week period each summer. There is a core curriculum that remains constant but other parts of the curriculum are updated each year according to needs assessment of the trainees.

The coursework is geared toward the development of a pilot research project to be submitted to NCI for funding consideration. The curriculum has evolved over the past several years so that it now follows the outline of an NCI research proposal. For example, coursework during the first week focuses on information necessary for the background and significance section, including discussions about cancer among Pacific Islanders and literature searches. The second week focuses on methodology, and the third week focuses on grant writing skills. Using this curriculum, the students gain insight into the field of cancer control research and how such research can benefit their communities.

The program trains three students each year, one from each of the Pacific Islander groups. The advisory boards at each of the study sites selects the candidates for participation in the academy using specific criteria including having at least a bachelors degree, having a background in the sciences, being committed to work in the field of cancer control research in one's community, and being committed to work with the advisory boards to identify the unique needs of the community that deserves further study.

The students, in consultation with their advisory boards, chose the topics for the pilot project proposals. As described below, the research topics have varied and are based to some extent on the stage of research development in the respective Pacific Islander group. By the end of the course, the students have prepared a draft of a pilot project proposal. They work with faculty members during the next three months to finalize the projects for submission to NCI by the proposal submission deadline.

Results

Cancer awareness activities

During the last four years, PICCN has conducted more than 180 cancer educational programs in the three Pacific Islander groups. The types of activities include media campaigns using radio, television, and newspapers; health

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Table 2. Educational activities by ethnic group

| Cancer related topic | No. of times presented to | | |
|-----------------------------|---------------------------|-----------|-----------|
| | American Samoans | Tongans | Chamorros |
| Breast & Cervical Cancer | 15 | 20 | 33 |
| Cancer Statistics/Awareness | 6 | 25 | 11 |
| Cancer Prevention | 3 | 2 | 11 |
| Tobacco Education | 36 | 0 | 4 |
| Cancer Survivorship | 0 | 1 | 3 |
| Nutrition Education | 0 | 0 | 3 |
| Prostate Cancer | 5 | 12 | 1 |
| Total | 60 | 60 | 66 |

fair booths and presentations; and didactic presentations. The educational programs reached groups as small as 10 individuals for interactive discussions to over 40,000 individuals through media campaigns in American Samoa where virtually all residents have access to the local television and radio stations. The educational activities were most often presented both in English and in the native language of the participants (Samoan, Tongan, or Chamorro) by individuals from these ethnic groups in the communities.

As shown in Table 2, featured educational topics varied with each group of Pacific Islanders. For example, the American Samoans stressed tobacco control, particularly in the Territory, and collaborated with the government in educational programs aimed at children. The Tongans stressed general cancer awareness in collaboration with the “Tell-a-Friend” program. The Chamorros focused particularly on breast and cervical cancers and worked closely with the Breast and Cervical Cancer Control Program in Guam.

To improve education about clinical trials, PICCN members have participated in regional conferences attended by Pacific Islanders that address clinical trials. The conferences reviewed what clinical trials are, their purposes and importance, barriers to participation and suggestions for overcoming the barriers. PICCN staff has also made presentations about clinical trials to the PICCN advisory boards and measured knowledge change before and after the presentations. Knowledge significantly increased. Finally, staff worked with cancer centers in the geographical regions to make available to the Pacific Islander communities information about clinical trials that are being conducted and about how to enroll in them.

The Pacific Islander Cancer Control Network has developed cancer awareness brochures in the Samoan and Tongan languages and is in the process of developing similar materials in Chamorro. To date, cancer education brochures have been developed in the Samoan language for prostate, colorectal, lung (including a separate brochure on tobacco), breast and cervical cancer, and in the Tongan language for prostate, breast, and cervical cancers. As part of a pilot research project, investigators are also evaluating

the appropriateness of NCI clinical trials educational brochures for Pacific Islanders.

Research activities

To date, faculty members have trained nine students in cancer control research: three American Samoans, three Tongans, and three Chamorros. Of these students, five were women and four were men. All of the graduates returned to their communities and most planned to

pursue careers related to cancer control. Four of the students planned to apply to graduate or medical school. Two others were already in positions to carry out cancer education activities and research. Each of them developed a pilot research project that served as an entry into the field of cancer control research. A senior faculty member provides mentorship for the student during the conduct of each pilot project. The mentor is responsible for review of study progress, steering students towards submission of a larger research project, encouraging the submission of abstracts to scientific meetings, and preparing manuscripts for publication.

Table 3 lists the pilot research projects and provides a brief description of them. The studies of Tongans and Chamorros focus primarily on knowledge, attitudes and use of cancer prevention services because there is little published information about these topics and this basic information is necessary to plan cancer control intervention studies. Because the state of cancer control research is somewhat more advanced among American Samoans, the studies regarding this group are more targeted. For example, one project is evaluating the impact of *fa’aSamoa*, the traditional Samoan way of life, on the use of cancer prevention services. Results from this project will help us to determine whether an emphasis on *fa’aSamoa* should serve as the basis for a future intervention study.

The projects are in various stages of completion from hiring of personnel to completion of data collection. Results of the studies, which will be available during the next several years, will make important contributions to knowledge about the cancer control needs of Pacific Islanders and set the stage for intervention projects to address those needs.

Discussion

The Pacific Islander Cancer Control Network has accomplished much in its first four years. The Network developed some of the first culturally sensitive cancer awareness activities and materials, including education about clinical trials for American Samoans, Tongans, and Chamorros. As documented by process evaluation, thousands of Pacific

| Table 3. Pilot research projects | |
|-----------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Family History and Cancer Beliefs among American Samoans | This study is using ethnographic interviews to evaluate what family history means to American Samoans in terms of its role as a risk factor for certain cancers. |
| <i>Fa'aSamoa</i> and Cancer Screening | This study is using focus groups to evaluate the influence of fa'a Samoa (traditional Samoan way of life) on beliefs about and use of prostate and colorectal cancer screening among Samoan chiefs, pastors, and male community members in Los Angeles. |
| Cultural Meaning and Cancer among Tongans | This study is using ethnographic interviews to evaluate cancer related knowledge, attitudes and preventive practices among Tongans in San Mateo, CA and Salt Lake City, UT |
| Predictors of Cancer Screening Exam Use among Chamorros in Guam | This study is using survey methodology to evaluate cancer-related knowledge, attitudes and preventive practices among Chamorros in Guam. |
| Breast Cancer among Chamorro Women in San Diego | This study is using focus groups and survey methodology to evaluate breast cancer-related knowledge, attitudes, and preventive practices among Chamorro women in San Diego. |
| Social Support Use among Chamorros with Breast Cancer | This study is using survey methodology to evaluate the quantity and quality of social support use and quality of life among breast cancer survivors in Guam. |
| Evaluation of Clinical Trials Education Materials | This study is using focus groups to evaluate NCI pamphlets and brochures regarding clinical trials and will make recommendations to make the materials more culturally sensitive for Samoans, Tongans, and Chamorros. |

Islanders have been exposed to information about cancer because of PICCN. However, it is not yet known if this exposure has led to increased screening for preventable cancers or even if it has led to improved knowledge about the disease. Population-based outcomes studies are needed to answer these questions.

PICCN has also developed and conducted the first cancer control research training program specifically designed for these Pacific Islanders. As the result of the training program, seven pilot projects are being conducted that will determine knowledge and attitudes about cancer, explore other cancer control needs of the populations and set the stage for larger projects that will address the identified needs.

Despite these accomplishments, much more needs to be done to improve cancer control among Pacific Islanders. PICCN plans to play an important role in the efforts. For example, there are plans to make the cancer awareness activities and materials available to a wider audience of Pacific Islanders by interacting with a larger number of community-based organizations. In addition, PICCN is working with the NCI and the ACS to have the education materials approved so that these organizations can distribute them to a larger audience.

It is also important to increase cancer control research among Pacific Islanders. PICCN will continue to conduct its training program with the expectation that some of the students will pursue careers as cancer control investigators. The program will also encourage researchers who are not of Pacific Islander heritage to become involved with research

in this population. Along these lines, PICCN will work more closely with the cancer centers in regions where the community-based organizations are located to enhance the cancer control research efforts. Through these means, PICCN will advance the goal of improving cancer control among Pacific Islanders and will help to eliminate cancer-related health disparities in the U.S.

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Small bait, small fish.
Big bait, big fish.
Mokilese proverb