PACIFIC ISLANDER HEALTH II
DEPARTMENT OF FAMILY MEDICINE AND COMMUNITY HEALTH,
JOHN A. BURNS SCHOOL OF MEDICINE, UNIVERSITY OF HAWAI‘I

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Guest Editor’s Message
Neal Palafox MD, MPH

This November 2011, Volume 70 #11 issue of the Hawai‘i Medical Journal (HMJ) is the second HMJ issue focusing on the health and wellbeing of the indigenous peoples of Hawai‘i and the US Associated Pacific Island Jurisdictions (USAPIJ). Data that describes the unequal burden of illness between the dominant culture of the United States and the indigenous peoples of Hawai‘i and the USAPIJ has been shared with health care providers and health policy makers. From that data, the HMJ moves toward sharing information about what is being done and what can be done to address the unequal burden of illness. The articles of this issue underscore some of the approaches, challenges, and solutions that could/would address Pacific peoples’ health inequities in a meaningful and sustainable way.

As the data about Pacific peoples becomes more voluminous, conclusions made from the data have often been used against the Pacific peoples through deficit models of analysis. The health outcomes of the Pacific indigenous people have been couched in terms of what they lack, what their people and systems are doing wrong, and how their cultural approaches and theories do not hold muster in context of the majority systems of operation.

The Indigenous Pacific peoples are moving the discussion to discovery, resolution and sustainable approaches to their community’s health through utilization of their personal and cultural assets—an assets model of problem solving. The Pacific peoples’ assets are the means to solve and address health inequity and improve health outcomes. The articles of the current HMJ edition are written with a framework of indigenous Pacific peoples expressing their assets.

This HMJ issue speaks to the consequences of a Pacific peoples who were disempowered in their homelands. The histories of the Native Hawaiians and the specific peoples from the various USAPIJs, of course, differ because of their particular circumstances. The Native Hawaiians move toward creating equity in health workforce representation, breaking through economic ceilings, and advancing educational achievements through developing cultural assets in their ancestral homeland—Hawai‘i.

The mass movement of indigenous peoples from their USAPIJ island homes, a diaspora of Pacific islanders to Hawai‘i and the other parts of the US continent, is partly a consequence of being disempowered. As they relocate, the new cultural systems with which they interface are not ready for the necessary civic integration. The resulting economic and health system pressures on Hawai‘i, Guam, and the US continent have become flash points. The response of the dominant community to the economic and social pressure by migration has lent itself to further deficit model analysis, and exacerbates poor civic/social integration. The current response of the Pacific migrants is problem solving by utilizing models and programs that integrate their assets.

The first article in this issue, authored by a University of Hawai‘i Richardson School of Law school faculty and a member of the UH University of Hawai‘i John A. Burns School of Medicine’s faculty, cites the historical context for the Micronesian diaspora. It describes the Hawai‘i and US Federal Governments’ responses to the migrants. The authors argue that the legal and ethical response from Hawai‘i and the US Federal government is, respectively, not constitutional and inhuman. The following article, by two Native Hawaiian physicians, uses the social determinants of health to frame health care inequities found in Native Hawaiian children and adults.

Health workforce development affecting indigenous Pacific peoples is addressed in three articles by Native Hawaiian physicians. The first of the three discusses unique academic approaches to achieve cultural competency in medicine, the second speaks to indigenous Hawaiian patient/community perspectives on developing more culturally effective physicians, and the third article describes filling Hawai‘i’s primary care needs in areas of disparity with physicians who have experience and understand disadvantaged environments.

Cultural approaches to palliative care and use of indigenous foods from the Federated States of Micronesia speak to powerful health care interventions that maintain a healthy society. The power of the Samoan community in Southern California and the USAPIJ communities maintaining local cancer coalitions speaks to the effective community engagement of Pacific Islanders.

This HMJ issue celebrates Pacific Islanders assets, their cultural approaches, and the effectiveness of their communities and peoples to address their health problems. HMJ looks to critical examination of the socioeconomic dimensions of disparities. The articles here are about health care solutions and about addressing the social determinants of inequity.
Health Care for Micronesians and Constitutional Rights

Dina Shek JD, MA and Seiji Yamada MD, MPH

Abstract

Under the Compacts of Free Association (COFA), people from the Freely Associated States — the Republic of Palau (ROP), the Republic of the Marshall Islands (RMI), and the Federated States of Micronesia (FSM) — have been migrating to the United States in increasing numbers. In 1996, Congress passed broad welfare reform (Personal Responsibility and Work Opportunity Reconciliation Act) which limited certain federal benefits previously available to COFA migrants, including Medicaid benefits. Prior to July 2010, the State of Hawai‘i had continued to include COFA migrants under its state-funded Medicaid program. In the face of budget constraints, the State removed these people from its Medicaid rolls. A challenge on the legal basis of the denial of equal protection of the laws, ie, the Fourteenth Amendment to the US Constitution, was successful in reinstating health care to the COFA migrants in December 2010. From the health worker’s perspective, regardless of various social justice arguments that may have been marshaled in favor of delivering health care to the people, it was an appeal to the judicial system that succeeded. From the attorney’s perspective, the legal victories are potentially limited to the four walls of the courtroom without community involvement and related social justice movements. Together, the authors propose that in order to better address the issue of health care access for Micronesian peoples, we must work together, as health and legal advocates, to define a more robust vision of both systems that includes reconciliation and community engagement.

Background

In the aftermath of World War II, most of the small islands of Micronesia — the Northern Marianas, Palau, Yap, Chuuk, Pohnpei, Kosrae, and the Marshall Islands — were held in trust by the United States through a 1947 United Nations Mandate as the “Trust Territory of the Pacific Islands” (TTPI). From 1946 to 1957, the United States tested the vast majority of its megatonnage of its nuclear weapons in the Marshall Islands. Subsequently the Marshall Islands have been used to test ballistic missiles and ballistic missile defense. In the early post-war period, the rest of the islands received little attention, as the United States failed to fulfill its mandate to develop their health and educational infrastructure. Beginning in the 1960s, US aid for the Trust Territory increased: many islanders were employed by the government, and the cash economy expanded. In the late 1980s, the former Trust Territory split into the Commonwealth of the Northern Marianas Islands (CNMI) and the three Freely Associated States (FAS) through separate Compacts of Free Association (COFA): (1) the Republic of Palau (ROP), (2) the Republic of the Marshall Islands (RMI), and (3) the Federated States of Micronesia (FSM). The FSM consists of four states: Yap, Chuuk, Pohnpei, and Kosrae.

In the last decade, migration from the FSM and the RMI to the United States has burgeoned, with many migrants having first relocated to the more economically developed jurisdictions of the CNMI and Guam. The Compacts of Free Association allow citizens of the ROP, the FSM, and the RMI free entry into the United States and the right to employment, without a visa and without requirements for health screening. In return for these travel and employment rights, the United States maintains exclusive military control over the entire region, as exemplified in its development of the Ronald Reagan Ballistic Missile Defense Test Site on Kwajalein Atoll in the RMI. The US military also recruits heavily among COFA residents, who have the highest per capita Army recruitment as compared to all US states.

Episodic disasters and gradual ecological change, making human habitation unsustainable will likely lead to increasing numbers of people migrating from the low-lying atolls of Micronesia — which are particularly vulnerable to sea level rise and severe weather. In December 2008, swells washed over Majuro, the capital of the Marshall Islands, damaging homes and forcing people into shelters. From 2007 through 2008, high tides and wave surges led to salt water damage of up to 90% of the taro crops in the outer islands of the FSM. Since it takes five years of better water conditions (no saltwater intrusion and normal rainfall) for taro to recover, Father Francis Hezel, authority on Micronesian history and culture, states, “Perhaps the larger issue is whether life in the remote atolls remains viable in today’s world.”

As shrinking government budgets lead to fewer jobs and under-funded education and health care, as global climate change leads to inundation of low-lying atolls, as ballistic missile defense testing winds down on Kwajalein it is little wonder that Micronesians are choosing to relocate to the United States. The movement of people from the former colonies from the periphery toward the center is a time-honored historical phenomenon.

Many COFA migrants travel back and forth between the islands and the United States. Migrants report a number of motives for moving: employment, as dependents of job-seekers, education, and for medical reasons. The US Census Bureau estimates that 12,215 people from the FAS resided in Hawai‘i in 2008, though many consider this an undercount. Some estimate that as many as 60,000 people from the FAS (approximately one-fourth of the total FAS population) live in the US proper, Guam, and the CNMI.

Access to Health Care for Micronesians

But life is not easy here in Hawai‘i for migrants from the Compact Nations. Housing is expensive, and jobs have been hard to come by. Furthermore, access to health care has been difficult. Until July 1, 2010, people from the Compact Nations were able to enroll in Med-QUEST, the State’s managed care Medicaid program, while Medicaid is funded partially by states and partially by the US federal government, during the Clinton administration people from the Compact Nations were excluded from federal funding for Medicaid. Although migrants from the FAS have the right of free entry into the United States, the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 disallows federal funds from being expended for their participation in Medicaid. According to State of Hawai‘i rules, until July 1, 2010, they had been eligible for health insurance under Hawai‘i’s managed care Medicaid program, Med-QUEST, as long as they met the eligibility requirements for federal poverty levels. “Compact Impact” funding from the federal government to the State of Hawai‘i to offset health and educational...
costs have been inadequate, coming in at approximately $10 million each year. The COFA Task Force developed under the Hawai'i Attorney General’s office estimated “Compact Impact” costs at over $100 million in 2007.2 The State argued that this put the burden on the taxpayers of the State, which had to entirely fund Med-QUEST for people from the Compact Nations. These figures, however, fail to consider the contributions of Compact migrants including working people from the Compact Nations who pay income taxes.

**State Budgetary Constraints and the Executive Branch Response**

Since the economic downturn in 2009, the State of Hawai'i has had a budget shortfall. The response of the administration of Republican Governor Linda Lingle was pay cuts, furloughs, and layoffs for state workers. The public school system closed down on furlough Fridays, giving Hawai'i the shortest school year in the nation during the 2009-2010 academic year. The disenrollment of Micronesians from Med-QUEST was part of the State’s cost-cutting measures. In a measure intended to save $15 million dollars annually, in July 2009, the Hawai'i Department of Human Services announced that approximately 7,500 COFA migrants enrolled in Med-QUEST would be disenrolled beginning on September 1, 2009, and placed in a program with fewer benefits, called Basic Health Hawai'i (BHH).8

The State justified its actions with an appeal to anti-immigrant sentiments. Testifying before the State House, Director of Human Services Lillian Koller cited the Compact of Free Association, noting that “Any alien who has been admitted under the Compact or the Compact, as amended, who cannot show that he or she has sufficient means of support in the United States, is deportable.” going on to say, “Individuals on any type of public assistance, including Hawai‘i’s state-only funded medical assistance for COFAs, do not have sufficient means of support.”9 Responding to the State, two of the pro bono attorneys supporting the Micronesian community wrote:

> While the level of public benefits available to needy Hawai‘i residents in these difficult times is an open issue, the way in which we talk about these individuals should not be uncivilized. Callously referring to them in public testimony as deportable commodities that should be grateful for their mere continued presence in Hawai‘i de-humanizes these individuals, diminishes public discourse on a complex subject and evinces a shocking lack of sensitivity on the part of DHS [Department of Human Services]. Koller should know better.10

In its first iteration, BHH had no provisions for continued treatment for the estimated 130-160 patients on chemotherapy or 110 patients on hemodialysis.11 The announcement was in English only, some received notice merely days prior to implementation, and the medical community was not given guidance as to maintaining continuity of care. As health and legal providers, we saw first-hand fear and confusion, as well as resolve and resilience, in the Micronesian community as they faced these new and uncertain regulations.

**Initial Legal Challenges to BHH**

On August, 31, 2009, the day before the State was set to reduce healthcare coverage for COFA migrants, attorneys from the non-profit Lawyers for Equal Justice and the law firm Alston Hunt Floyd & Ing filed a legal complaint on behalf of residents of Hawai'i from the Compact Nations objecting to BHH on constitutional and procedural grounds. The next day, on September 1, 2009, US District Judge Michael Seabright issued a temporary restraining order to prevent the State from carrying out the change, citing a lack of adequate procedural protections. Thus BHH was halted for nearly a year during which time the State attempted to address its procedural defects. Despite the temporary judicial relief, confusion persisted in both the Micronesian and health provider communities. Health practitioners and service providers began hearing stories about patients wrongly denied prescriptions from pharmacies and about patients who simply stopped seeking primary and preventive healthcare because they did not know or understand that a legal injunction had been issued. In response to the legal ruling, the State disseminated draft rules and held the required public hearings. Then, on July 1, 2010, the BHH plan was implemented.

**Implementation of BHH and its Health Effects**

Basic Health Hawai‘i, as its name suggests, had rather limited coverage — 10 hospital days, 12 outpatient visits per year, and 4 outpatient medications per month. Furthermore, reimbursement for community health centers to provide services such as language interpretation was cut. Federal funds intended for emergency services were utilized to pay for chemotherapy and dialysis. While BHH was in effect during the latter half of 2010, the authors heard stories from patients and clients that a number of patients had stopped their medications or simply stopped obtaining care. Some fragile patients deteriorated, and ended up in the hospital with severe complications. Those who were not previously enrolled in Med-QUEST, such as those newly arrived from the Compact Nations could not obtain any coverage at all. One such patient with thyroid cancer ended up with a $23,000 hospital bill for a thyroidectomy. In that hospitals are unlikely to collect on such bills, a portion of the costs saved by the State via BHH were actually borne by hospitals.

**In Defense of Constitutional Rights**

In August 2010, Lawyers for Equal Justice and pro bono attorneys from Alston Hunt Floyd & Ing and Bronster & Hoshibata initiated another class action lawsuit against the State on behalf of COFA migrants to Hawai‘i. The plaintiffs challenged the constitutionality of the BHH plan because it cut health benefits to individuals solely based on their alienage and national origin. This, they argued, was a violation of the Equal Protection clauses of the Hawai‘i Constitution and the 14th Amendment of the US Constitution, which states that “No State shall…deprive any person of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws.” The suit also raised civil rights claims under the Americans with Disabilities Act.

As noted by Victor Geminiani and Deja Ostrowski of Lawyers for Equal Justice, the suit relied on declarations by patients and physicians. Patients emphasized their work histories in Hawai‘i and outlined the difficulties of obtaining necessary care under BHH. Working with pro bono attorneys, physicians documented the deterioration of health of individuals and noted that costs would increase as patients with advanced illnesses would eventually present for care requiring more intensive services.12

Finally, in the waning days of the Lingle administration, Judge Seabright granted the plaintiffs’ injunction and reinstated full Med-QUEST benefits for COFA migrants. In his December 13, 2010
decision, he acknowledged that without an injunction, “Plaintiffs will suffer irreparable harm...because they would be left without adequate medical coverage, which will force them to pay for treatment on their own or completely forego the treatment.” This significant legal victory to reinstate medical benefits had immediate and potentially life-saving impact. The legal opinion also affected other pending court cases on behalf of immigrants across the country. But the victory was not solely a legal one; rather, it was forged from social justice lawyering practices that embraced a broader vision of what a “win” means for lawyers, for health workers, and ultimately for the community.

**Advocating for Access to Health Care**

The BHH legal case spurred thinking about the different approaches to advocate for people from the Compact Nations to receive health care. Next, we propose additional collaborative, social justice dimensions to enhance traditional public health and judicial advocacy approaches. In particular, we suggest that reparations and community organizing perspectives enhance the current legal approaches to the COFA health issue. Finally, the health and human rights perspective is discussed.

**The Social Healing Through Justice Perspective**

Traditionally the reparations approach is defined as the righting of past injustices. We propose employing a modern reparations framework of “social healing through justice” developed by legal scholar Eric Yamamoto. Briefly stated, this framework “elevates the role of social healing” and links group and societal healing to “doing justice.” This framework embraces concepts of “reconciliation (rather than compensation)”; the need for group participation in genuinely addressing societal healing; “recognition, responsibility, reconstruction, and reparation;” and “material change in socio-economic conditions underlying the group relationship.” Of particular relevance here, Yamamoto states:

> People must recognize the humanity of others and the historical roots of group-to-group grievances. This includes articulation of the group harms and acknowledgment of the deeply embedded prejudices reflected in the stock stories we tell about others. The afflicting party must accept responsibility for healing group-based wounds, whether grounded in personal culpability, receipt of privileges and benefits, or a simple desire to build community. Acts of reconstruction are aimed at building a new productive relationship, including apologies and other acts of atonement, along with efforts to restructure social and economic institutions. Reparations encompass public education, symbolic displays, and financial support for those in need.

While rooted in legal theory, notions of healing and the need for material change to improve current (health) conditions should also resonate for medical and public health professionals.

This approach, of course, requires some familiarity with the history of the US relationship with Micronesia – starting with the Pacific War, through nuclear testing in the Marshall Islands during the Trust Territory, to its continued use for weapons development. Into the 1960s, the US government conducted human radiation experiments on Marshallese without their knowledge or consent. Of the Micronesian peoples, it is clearly the Marshall Islanders that have suffered the greatest injustices. Yet in the post-war period, all of the Trust Territory was entrusted to the United States with the understanding that it would develop the islands’ infrastructures, health, and education systems. Under the current Compact agreements, the United States continues to benefit from its unfettered use and control of the region militarily.

Because it was the United States as a nation that utilized and continues to utilize Micronesia for its strategic ends, many in Hawai‘i believe that the State has been unfairly shouldered with a national burden. However, a social healing through justice approach calls for engagement by all groups — victims, perpetrators, those harmed by and those benefiting from the injustices — in a process of recognition, responsibility, reconstruction, and reparation.

The modern reparations perspective would demand not only that we ensure the health of people from the Compact Nations in the United States, but that we continue to engage in healing all aspects of the legal, social and interpersonal relationships stemming from past political agreements. Many Micronesians think so themselves. At a rally at the State Capitol in August 2009, a Marshallese woman described being a child as nuclear fallout “rained down” on her, then declared, “The United States has an obligation after what they’ve done to us,” and “We have earned the right to be here. I have earned the right to Med-QUEST.”

A reparations approach that embraces “social healing through justice” elements moves us away from the traditional reparations argument that confines us to monetary compensation for the effects of nuclear testing in the Marshall Islands. Practitioners (including doctors and lawyers), policy-makers, and community members who wish to engage in a social healing through justice process should spend time learning and sharing the history of burdens and advantages — on both “sides” — and discussing the impact on the health, education, and employment of COFA residents in Micronesia and Hawai‘i. This approach would enhance subsequent litigation and legislative BHH advocacy by creating a framework to link history to current health issues, and to engage the greater community in social healing through doing justice.

**Political Education and Community Mobilization**

Appeals to the US legal responsibility for Micronesia under the Trust Territory or the Compacts carry little weight these days in Washington, DC. When he was in the House of Representatives, Hawai‘i’s current Democratic governor (since December 2010), Neil Abercrombie inserted into the House version of the health reform bill language reinstating Medicaid for people from the Compact Nations. It did not make it in the final version of the law, however. Given the current push to cut federal spending, we cannot expect much relief from the US Congress.

In Hawai‘i, funding for Med-QUEST for people from the Compact Nations competes with everything else that receives state funding. Although the citizens of Hawai‘i are generally welcoming of newcomers, in these times everyone is struggling to make ends meet. Faced with continuing budget constraints as governor, Neil Abercrombie has said that he will not take Med-QUEST away from Micronesians, but that his administration will appeal Judge Seabright’s decision because it involves entitlements.

Since the State will always pose competing financial and social interests against each other during lean economic times, and judicial oversight may only address the narrow legal issues raised, communities must also engage in community organizing and public
education to present what is at stake for the general public. During the BHH struggle, the Micronesian community in Hawai‘i did just that. They held rallies, testified at public hearings, hosted fundraisers and shared their stories in the media. They also engaged a larger group of non-Micronesian allies to frame their situation in its proper historical and political context.

In some respects, the Micronesian community in Hawai‘i engaging in key community organizing to bring context and a face to the narrow legal issues — in a manner reminiscent of the Japanese American redress movement, where community organizing and public education were not an afterthought but a key element of the legal redress strategy. Legal scholars Eric Yamamoto and Susan Serrano state, “the real bulwark against governmental excess and lax judicial scrutiny, then, is political education and mobilization, both at the front end when laws are passed and enforced and at the back end when they are challenged in courts.” Further, they state:

In today’s climate [post Sept. 11] of fear and anger, our first task in protecting both people and key democratic values is to be pro-active at the front end…. We need to organize and speak out…. We need to mobilize and raise challenges…. Through political analysis, education and activism, our job is to compel powerful institutions, particularly the courts, to be vigilant, to “protect all.” Our second task is to be assertive at the back end—to call out injustice when it occurs, to spell out the damage it does to real people in our midst and to our constitutional democracy, and to demand accountability to principles of equality and due process.”

In the real world, therefore, it was not treaty obligations or federal legislation that reinstated Med-QUEST for people from the Compact Nations. Rather, it was a legal appeal to constitutional rights, alongside community mobilization and collaborative practice.

**Health and Human Rights**

Judge Seabright’s decision, which references cases of immigrant rights in other states, reminds us that the struggle of the Micronesian community in Hawai‘i has parallels to that of immigrant communities across the nation. Anti-immigrant forces are wont to decry public assistance given to immigrants. Immigrants and their advocates point to the contributions that immigrants make to society — particularly to the fact that immigrants often perform the work that others do not want. In Hawai‘i, many Micronesians work as janitors, dishwashers, hotel housekeepers, parking lot attendants, and fast food servers. Their struggle for acceptance by the wider community parallels that of other ethnic groups that immigrated to Hawai‘i in generations past. Micronesian children go to school with everybody else’s children. Their parents want them to stay out of trouble and to have better lives than their own. It is only a matter of time before families become intertwined in the way that ethnicities have always mixed in Hawai‘i.

Whether or not federal funding for health care for Micronesians is forthcoming, the compelling reason for Micronesians to be included in Med-QUEST are the simple premises that health is a human right, and all humans should be included “under the rubric ‘human.’”

The first clause of Article 25 of the Universal Declaration of Human Rights, adopted by the United Nations in 1948, reads,

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

In the end, it comes down to this: What does it say about us who live in Hawai‘i to deny health care to people in our midst, to allow people in our midst to fall ill and die? While we need to continue to press the case that all people should have the human right to health — it is an uphill battle.

**Conclusion**

In conclusion, we suggest that those of us in law, medicine, and public health take a social justice approach — one that is geographically broad and historically deep. Serious study of large-scale historical and social forces will reveal that we have many commonalities. We should call for reparations where they are appropriate. We should work to spread the idea of health as a human right. We should utilize the legal and public policy frameworks alongside political education and community mobilization to ensure the people’s health. We should do all of this in the context of “doing justice.”

**Disclosure Statement**

The authors declare that they do not have any conflict of interest in the matters discussed in this article.

**List of Abbreviations**

BHH – Basic Health Hawai‘i (the State-funded program on which Micronesians in Hawai‘i were enrolled July-December 2010)

CNMI – Commonwealth of the Northern Marianas Islands

COFA – Compact of Free Association

DHS – State of Hawai‘i Department of Human Services

FAS – Federally Associated States

FSM – Federated States of Micronesia

Med-QUEST – Hawai‘i’s managed care Medicaid program for the non-elderly, non-disabled. ‘QUEST’ stands for: “Quality care, Universal access, Efficient utilization, Stabilizing costs, and Transforming the way health care is provided.”

RMI – Republic of the Marshall Islands

ROP – Republic of Palau

TTPI – Trust Territory of the Pacific Islands

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10. Ibid., A6.
17. Ibid.

Airai bai, Babaldeob (Palau)
Social Determinants of Health for Native Hawaiian Children and Adolescents

David M.K.I. Liu MD, PhD, JD and Christian K. Alameda PhD

Abstract

Introduction: Traditional Hawaiian thought places children in a position of prominence in the family. Yet in Hawai‘i, Native Hawaiian children and adolescents face significant inequity in health outcomes. From prenatal alcohol and tobacco use, late or no prenatal care, macrosomia as well as low birth rates, to exclusive breastfeeding rates at 6 months, and high rates of infant mortality, Native Hawaiians face inequities in pre and early childhood indicators. During childhood and adolescence, Native Hawaiians experience high rates of obesity, and physical, mental and sexual abuse. This review examines the determinants behind the health inequities encountered by Native Hawaiian children and adolescents, and contextualizes those inequities in a human rights-based approach to health.

Methods: a literature review was conducted for relevant research on Native Hawaiian and other indigenous children and adolescents. Existing data sources were also reviewed for relevant Native Hawaiian data.

Results: There is a significant dearth of data on the determinants of health for Native Hawaiian children and adolescents. Some prenatal data is available from the Prenatal Risk Assessment Monitoring System, while selected youth data is available from the Youth Behavioral Risk Factor system. Available data show significant inequities for Native Hawaiian children and adolescents, compared to other groups in Hawai‘i. Based on comparisons with other indigenous and marginalized peoples, the etiology of these disparities may be a lack of health equity, deriving from multigenerational trauma and discrimination as well as poverty and inequities of housing, education, environment, healthcare access, and social capital.

Conclusions: The significant barriers facing Native Hawaiian children and adolescents achieving their full potential constitute a challenge to the fulfillment of the human right to health. Future research needs to more fully articulate the linkage between the health status of Native Hawaiian children and adolescents, the determinants of that status, and the requirements of the human right to health. Needed particularly are longitudinal studies which provide data that may link multigenerational trauma and discrimination to poverty and other factors, ultimately producing healthy inequity for Native Hawaiian children and adolescents.

Introduction

Traditionally, the place of the child in Native Hawaiian culture was sacred: he lei poina ‘ōle ke keiki. A lei never forgotten is the beloved child.1 However, in current Hawai‘i, Native Hawaiian children and adolescents face a range of health inequities: how did these changes occur?

Prior to European contacts, Native Hawaiians were a healthy people.2 Subsequently, Native Hawaiian contacts with Europeans, beginning in 1778, had violent and long-lasting effect upon Hawaiian society.3 The violence permeated every level, from disruption of traditional ontology and epistemology and violent displacement with Christianity and other Western systems to the appropriation of lands, loss of traditional economy, and ultimately the loss of self-government.4 5 Because of these factors and introduced disease, depopulation was approximately 95%, and Native Hawaiians continue to experience a level of health significantly degraded from that of 1778.2 6

As Native Hawaiians became a minority in their own homeland, they were also marginalized in the political economy. From a position of preeminence in the Kingdom, Native Hawaiians have progressively lost representation in the Territory and then State.9 From an agricultural and aquacultural system able to support a population up to one million, including classes not engaged in food production, Hawai‘i is now 90 percent or more dependent on outsiders for sustenance.9 The Hawaiian culture has been commodified along with the land, so that it is currently largely associated with the tourism industry.10-12 The Hawaiian language, although one of two official State languages, is still not recognized in everyday, and particularly legal arenas. It is important to emphasize at this point, however, that there is a significant tradition of resistance and persistence among Native Hawaiians.13,14 It has never been a process of passive victimization to foreign politics, economics, cultures and disease. Instead, from the earliest days of encounters with the West, Native Hawaiians have resisted the violence of colonization and assimilation. Indeed, many interpret the foundation and elaboration of the Kingdom as the most basic effort of the ali`i (chiefs) to preserve and perpetuate the role of Native Hawaiians in their own governance.15,16 To the end, an overwhelming majority of Native Hawaiians strove to strengthen both the domestic and international strength of the Kingdom.14 The last Hawaiian monarch, Queen Lili‘uokalani, indeed, did not abdicate her throne, but temporarily yielded governance to the overwhelming military power of the United States, specifically remembering the experience of Kauikeaouli, Kamehameha III, who faced a similar situation with Great Britain, who in fact did restore self-government to the Kingdom in 1843.16 Although the United States to date has not corrected the self-admitted act of war that constituted the overthrow, Native Hawaiians continued to work to regain self-governance and perpetuate their culture and identity.13

Methodology

We conducted a review of literature through PubMed, as well as obtaining data from the PRAMS and YRBS. The keywords “Native,” “Hawaiian,” “child,” and “health” were searched. Because of the diversity and relative small number of studies, from qualitative to quantitative, no attempt was made to evaluate individual studies. For the PRAMS and YRBS data, data was analyzed using SPSS, and compared the results for Native Hawaiians to all other groups combined, excluding Native Hawaiians.

Results

Prenatal and Infant Health Indicators

One study examined perinatal and infant health indicators for Native Hawaiians and Caucasians.17 Hawaiian mothers were younger, more likely to be unmarried, and had higher parity. Hawaiian infants were more likely to be preterm. Infant mortality for Hawaiians was only significantly different for normal birthweight, full term babies. After controlling for age, parity, education and prenatal care, Native Hawaiian women were not significantly different than Caucasian...
women. The authors concluded that the mortality differential was due to poverty and environmental factors. Another study, examining gestational diabetes, found inequities for Native Hawaiian mothers. Native Hawaiian women who are pregnant are also statistically more likely to experience interpersonal violence before or during a recent pregnancy during the years 2004-2008. Native Hawaiian mothers are more likely to engage in binge drinking of alcohol, smoke in the three-month prior to pregnancy, and use illicit drugs in the month before pregnancy. Native Hawaiian mothers who are pregnant are also more likely to be obese than mothers of other ethnicities, increasing their risk for adverse pregnancy and neonatal outcomes, per data from PRAMS from 2000 to 2007.

Although Hawai‘i as a whole has breastfeeding initiation rates higher than the national average, Native Hawaiian women have breastfeeding initiation rates lower than both state and national rates, with Native Hawaiian women never initiating breastfeeding significantly more than women of other races and ethnicities since 2000. However, improvement is occurring for both groups, with no significant difference for 2006-2007. For Native Hawaiian women who do initiate breastfeeding, many do not maintain exclusive breastfeeding beyond 20 weeks.

Native Hawaiian infants slept on their backs significantly less than infants of other races and ethnicities. Both groups are improving since 2000 to 2001, but the inequity remains. Native Hawaiian mothers are also much more likely to use the Supplemental Nutrition Program for Women, Infants and Children than mothers of other ethnicities.

**Obesity**

One study in Hilo found that although Native Hawaiian males were significantly more obese than non-Hawaiians after age six, that degree of Hawaiian ancestry was not significantly related to adiposity. Degree of Native Hawaiian ancestry was significantly associated with body fat distribution, but not overall adiposity in an earlier study. And although education has been significantly associated with BMI in other populations, in the Hilo study it was only significant for fathers’ educations in third grade Hawaiian girls.

**Mental Health and Suicide**

In examining YRBS data from 2003 through 2007,

**Smoking Among Adolescents**

In Hilo, one study determined that in univariate analysis that Hawaiian primary ethnic identity was significantly associated with trying smoking and being a current smoker, this association disappeared with multivariate analysis. Instead, the most salient factors were peer and parental smoking, and attendance at a public school.

**Infectious Disease**

Native Hawaiian and Pacific Islander children have a much higher incidence of methicillin-resistant Staphylococcus aureus osteomyelitis and cellulitis.

**Mental Health**

Native Hawaiian adolescents are significantly more likely to have any DSM diagnosis. This difference was primarily driven by overanxiousness and obsessive compulsive disorder diagnoses. Gender differences also followed these patterns, with girls having more diagnoses than boys, with a similar distribution of individual diagnoses. Disruptive behavior comorbidities were higher for boys, while both Hawaiian and non-Hawaiian youth had higher than national average rates of substance abuse.

**Suicide**

Overall, suicide is the third highest cause of death for adolescents in the United States. It is the second leading cause of death for 15 to 24 year olds, and males in Hawai‘i complete suicide more often than females by a ratio of three to one, with Native Hawaiians having higher rates of suicide than other ethnic groups. Native Hawaiian youth aged 10 to 14, while constituting only 27% of that demographic, are 50% of completed suicides. Overall, Native Hawaiian youth have a higher lifetime prevalence of suicide attempts than other ethnic groups.

Common risk factors for economically disadvantaged groups include poverty, discrimination, high school dropout, pregnancy and single parent households. In Hawai‘i, Yuen et al identified Hawaiian cultural identification, depression, educational level and the educational level of the main wage earner. A different study identified substance abuse as a risk factor for suicidal ideation, attempts and completion. Liminal periods, particularly between middle school and high school and high school and adulthood were also periods of higher risk for suicide.

**Self-Perception**

In the area of self-perception, cultural loss is theorized to have traumatized the most vulnerable of the Native Hawaiian community – its children. Social determinants of health, such as a child’s school environment, family income, place of residence, community resources and activities, health care access, parental support, and community empowerment shape the way Hawaiian children see themselves. This self-perception provides the framework for the attitudes children develop regarding their health, and this self-perception often continues to adulthood.

Self-perception studies with children were first conducted in the early 1950s with African Americans in response to the desegregation movement. When African American children were asked to choose between a white doll and black doll on socially acceptable preferences, black children chose the white doll (Clark, 1950). Similarly, when Hawaiian children were asked to choose between White, Japanese, and Hawaiian photos, with respect to positive physical and social attributes, Hawaiian children selected the White and Japanese photos (Alameda, 1998).

**Providers**

As with many minority populations, the pediatric providers for Native Hawaiian children and adolescents are often not Native Hawaiian. Recent data indicated that only 0.6% of all board-certified pediatricians were Native Hawaiian or Pacific Islander (NHPI) in 2007. In previous years, however, NHPI pediatricians were aggregated with Asian pediatricians (AANHPI). Comparatively, 0.6% of patients were NHPI in 2007; in previous years, aggregated AANHPI patients constituted 5.3% (1993) and 6.7% (2000) of all patients seen. For all of the underrepresented pediatricians included in the surveys, they were statistically more likely to see patients from...
underrepresented groups than non-minority physicians, including Asian physicians.

**Discussion**

Contextually, several studies have emphasized that both risk and resiliency factors are at least additive, and may need to be analyzed in terms of levels, rather than the previous view of upstream and downstream.\(^3^4,3^5\) Thus, in examining the matrix of risk and resiliency, certain factors may or may not be more pertinent, given the diversity of the Native Hawaiian population: for Native Hawaiian children and adolescents with affluent, educated parents, it may be that their degree of cultural affiliation has more explanatory power than for children with less affluent, less educated parents. In other cases, poverty combines with limited economic opportunities structured by colonial legacies and the everyday oppression of perceived second-class status in one’s own homeland to increase the probability of negative health outcomes.

**Determinants of Health**

While there has been limited focused examination of the determinants of health for Native Hawaiian infants, children and adolescents, parallels can be drawn to the similar studies done for the children of other indigenous peoples. The social determinants of health are the factors contributing to the environment to which individuals receive exposure, and in return can influence development and health over the lifespan.\(^3^6\) Income has usually been recognized, along with education, as one of the two most powerful determinants of health. In examining national data, household income was negatively associated with childhood asthma, migraine and other severe headaches, and ear infections.\(^3^7\) Parental mental health was also a significant negative mediator of child health, as having a family with more children. But data on the SDOH and Native Hawaiian child and adolescent health is for the most part lacking, and it may be that the lack of published research on this subject contributes to the further marginalization of this population.\(^3^8\)

**Racism and Colonialism**

Along with social determinants of health such as poverty, educational opportunities, and housing, history may continue to affect the health status of Native Hawaiian children. Racism and colonialism can have both direct and indirect effects on health. Directly, racism and colonialism differentially structure the distribution of power, resources, and money. Indirectly, racism and colonialism contribute to chronic stress and increase allostatic load.\(^3^9,4^0\) Racism has been demonstrated to have deleterious health effects in a number of settings: racial inequities in health in Maori self-reported health,\(^4^1,4^2\) Aboriginal self-reported psychological and physical health,\(^4^3\) African American lack of health care trust, sleep quality, and fatigue,\(^4^4,4^5\) and Latino post traumatic stress disorder symptoms.\(^4^6\)

**Pathophysiology**

In order to understand the development of health inequities in Native Hawaiian children and adolescents, it is important to be able to trace the often barely visible or invisible trace of their genealogies. These genealogies connect the determinants of health with individual and family health outcomes, and often become erased in a strictly biomedical model, which could be seen to constitute a colonial enterprise to naturalize health inequities as genetic or cultural. Unfortunately, much of the research to recover these genealogies has yet to be conducted, so by necessity this review depends more on work done in other communities.

**Developmental Origins of Health and Disease and Epigenetics**

The theory of the developmental origins of health and disease (DOHD) posits that factors influencing a fetus and child will affect later childhood and adult health. There are ten generally agreed upon principles of DOHD, from positing critical periods of development for certain tissues, to the key role of the placenta in programming to the costs of fetal compensation and a differential of programming effects in males and females.\(^4^7,4^8\) Thus, factors such as maternal nutrition and psychosocial stress are mediated by the genome and epigenome to influence fetal programming, which in turn eventually effects the risk profile for coronary heart disease, diabetes, depression, and cancer. (Kajantie 2008) In areas such as the development of adult serious and persistent mental illness, it is the interaction of genes and environmental risk factors that can produce schizophrenia, depression, and dementia.\(^4^9\) Maltreatment in childhood can produce structural and functional changes in the brain and hypothalamic-pituitary-adrenal axis.\(^5^0\) Applying this theory to Native Hawaiian child and adolescent health, more research is required to both more clearly quantify the determinants that influence preconceptual, prenatal, and early child health, as well as to define the pathways between these variables and later health and/or disease.

**Allostatic Load**

Allostatic load is the sum total of stresses encountered over the life of an individual.\(^5^1,5^2\) In this way, it relates to Krieger’s conception of embodiment, that we carry our life’s experiences, from positive to negative, as our phenotype. Biologic markers measure allostatic load, and their levels can assess the impact of acute and chronic stress. High allostatic load, in combination with genetic and environmental factors can precipitate risky behaviors such as adolescent alcohol use.\(^5^3\)

**Chronic Stress**

Chronic stress functions to cause dysregulation through multiple pathways in development. Excessive stress can disrupt the normal development of the neuroarchitecture of the brain.\(^5^4\) Another pathway is through allostatic load, where the cumulative stresses through a lifetime contribute to disease. A third pathway is through the disruption of self-regulation and coping. Here, disrupts the orderly function of the hypothalamic pituitary adrenal axis (HPA), and may cause degeneration of areas of the prefrontal cortex and hippocampus. The socioenvironmental context in which a child develops heavily influences the ability of a child to regulate her emotions, and thus to moderate the effects of the HPA. If a child grows up in a household that is not nurturing, surrounded by aggression and/or a lack of affection, their ability to self-regulate is damaged, and they develop chronically negative emotional states.\(^5^5\) Thus, chronic stress may not only contribute to disease and ill health via higher allostatic load, but also disrupts areas of the brain responsible for self-regulation and coping.\(^5^6\)

Together, chronic stress and allostatic load beginning prenatally or during childhood may increase the susceptibility of individuals...
to disease as varied as adult onset arthritis, adolescent alcohol abuse, and depression and other mental illness.

**Multigenerational Trauma**

The theory of multigenerational, or historical trauma posits that significant negative life events are transmitted intergenerationally and thus may continue to affect future generations decades or even centuries after the inciting event. For Native Hawaiians, some cite originating trauma as the ‘aina, or breaking of the traditional spiritual system in 1819. It is important to note that a possible explanation for the persistence of historical trauma, in addition to the magnitude of the initiating events constituting the trauma(s), but that such events are not simply in the past. There are constant new, or similar events which may contribute to historical trauma. There are constant struggles to maintain the integrity of iwi kupuna (Native Hawaiian human remains), to preserve wahi pana (sacred sites), to recognize the equality of Hawaiian with English as an official language of the State of Hawai‘i. Some Native Hawaiians may see the largely ethnic differential of political and economic achievement in Hawai‘i as a reminder of a second or third class status, reinforcing historical trauma. So Native Hawaiian children and adolescents may be directly experiencing their own historical trauma, in addition to being the recipients of transmitted trauma from their families.

The impact of historical trauma may be community wide depression. This community wide depression then manifests itself both in risky health behaviors, as well as contributing directly to pathways which increase the risk of chronic disease. The risky behaviors, whether unhealthy diets, lower levels of physical activity, unprotected sex, or substance abuse, can either directly lead to higher morbidity and mortality, or indirectly contribute to higher morbidity and mortality through increasing the risk for the future development of disease.

**Resilience Factors**

Although Native Hawaiian children and adolescents face a multitude of challenges to their maintenance or achievement of good health, they also have a number of resilience factors. One recent study, examining risk and resilience factors for drug use among Native Hawaiian youth emphasized that risk and resiliency factors, rather than being a dichotomy, are negotiated, and importantly that familial and community networks (which were often overlapping or the same), could be simultaneously both risk and resiliency factors for youth drug use. Thus, while acculturative stress is a risk factor for Native Hawaiian youth with high degrees of Hawaiian cultural affinity, being a member of a family with high cohesion, organization, parental bonding and support is protective. Else et al (2006) posit that the dissonance between the internal cultural identity of Hawaiian males and their external identities, is a major factor in creating higher suicide risk.

**Limitations of This Study**

Although this study was designed to be as comprehensive as possible, it did not survey all graduate theses and dissertations, as well as unpublished work. Equally important, outside the arenas of substance abuse and depression, there is a lack of studies exploring the connections between determinants of health and Native Hawaiian child and adolescent health. Thus, this study is heavily reliant on research performed outside of Hawai‘i, and on other populations. Generalizations from these studies to Native Hawaiians may be of reduced validity.

**Conclusion**

There are significant gaps in the data available on the health of Native Hawaiian children and adolescents. In particular, the role of social determinants of health in their health is largely lacking, as well as research identifying the pathways between the social determinants and individual health outcomes. Shifting a focus away from the individual and family to structural determinants, while difficult, changes the discourse from one of essentially blaming the victim to one that recovers the political, economic, and cultural genealogy of health and illness. As more research delinks the degree of Native Hawaiian ancestry from negative health outcomes, more focus can be brought on how the perceived and experiential role of being Native Hawaiian is articulated with health and illness. As the American Academy of Pediatrics has stated, “[h]ealth disparities in children . . will remain all too prevalent until [SDOH] are addressed through a national agenda on child health equity — an agenda informed by the global children’s rights movement . . . pediatrics and pediatrics must expand beyond a focus on health care and health disparities to engage the broader context of health equity.”

While many current programs and policies aim to address individual behaviors and risk factors, it is possible that future studies will indicate that the appropriate nexus for locating interventions in the health of Native Hawaiian children and adolescents is in the social determinants of health, particularly in addressing the pervasive influence of racism and colonialism on Native Hawaiian children and adolescents. If causation is established between these structural factors and the health of Native Hawaiian children and adolescents, structural, in coordination with individual and family level interventions will be necessitated. Thus, although it is important to continue to research dietary and physical activity interventions, the political/economic genealogy of reduced access to traditional foods and lifestyle will need to be addressed, in order to tailor policies and programs that enable community and societal level changes. These changes may address areas as diverse as land tenure, water rights, food safety, and maritime shipping policies. Similarly, given the significant role of education in shaping an ethnically hierarchical society, addressing Native Hawaiian child and adolescent health may require wide scale changes to the public education system, such as increasing the numbers of Native Hawaiian educators, more equitably distributing educational resources, and changing the governance of the education system. Finally, and perhaps most importantly, if, going back to Maslow’s hierarchy of needs, if self-determination for Native Hawaiians is not fully actualized, it may be that health inequities will remain significant.
The authors report no conflicts of interest.

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Children on Tol, Faischuuk
An Innovative Approach to Developing a Cultural Competency Curriculum; Efforts at the John A. Burns School of Medicine, Department of Native Hawaiian Health

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Abstract

Introduction: Initial efforts to teach cultural competency at the University of Hawai‘i John A. Burns School of Medicine began in the late 1980s through the Native Hawaiian Center of Excellence. With the formation of the Department of Native Hawaiian Health in 2003, cultural competency training was added as a key area of focus for the department. A multidisciplinary team was formed to do the ground work. Physicians (Family Medicine and Internal Medicine) and an administrator (MBA now at Queen Medical Center) from the Department of Native Hawaiian Health were joined by a cultural anthropologist (Department of Family Medicine and Community Health), a social worker (UH Myron B. Thompson School of Social Work), and a retired DrPH/Registered Dietician from the State Department of Health to form the cultural competency curriculum team. All but one of the team members is Native Hawaiian.

Discussion: As cultural competency training is a relatively new, rapidly developing field, there is no consensus on how to teach it. The department decided early on to focus on a variety of methodologies using Native Hawaiian health as the curriculum’s foundation. Many different paths were taken toward the development of the present curriculum which utilized different components within the medical school’s curriculum. This paper describes the process and development of a cultural competency training curriculum at the University of Hawai‘i medical school. Recent literature recommendations by experts in the field reinforce the current curricular content that resulted from this developmental process.

Introduction

There has been a national compendium of standards around the topic of using cultural competency training as a way to address the health disparities confronting our nation’s minority populations. In addition, health related regulatory agencies are now requiring cultural competency training for healthcare providers. This has also resulted in efforts to develop cultural competency training in medical schools.

There are a multitude of definitions of “cultural competency” developed over the past decade or so. A definition used by the federal Health Resources and Services Administration centers on a process that adapts according to the needs of individuals and organizations. It includes, as originally defined by Cross and colleagues, “a set of congruent values, behaviors, attitudes and policies that come together in a system, agency, or among professionals that enable them to work effectively in cross-cultural situations.”10 Most definitions assume an understanding of the diversity of patient populations.

Herein are included a few examples of the myriad of standards and recommendations related to the requirement for, and content of, cultural competency training. The National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS standards), issued by the US Department of Health and Human Services, Office of Minority Health in March 2001, were established to ensure that all people entering the health care system receive equitable and effective treatment in a culturally and linguistically appropriate manner. These standards were proposed as a means to correct inequities and to be inclusive of all cultures.3 The Institute of Medicine (IOM) in 2002 concluded that “(a)lthough myriad sources contribute to these disparities, some evidence suggests that bias, prejudice, and stereotyping on the part of healthcare providers may contribute to differences in care.” Consequently, they recommend “integrate cross-cultural education into the training of all current and future health professionals.”4 The Liaison Committee on Medical Education (LCME) requires the inclusion of cultural components of care in medical education.5 Organizations such as the California Endowment published recommended standards for the content of cultural competence education in the areas of attitudes, knowledge, and skills.6 Jordan J. Cohen, the President of the Association of American Medical Colleges (AAMC), summed it up in 2003:

“One of the most difficult challenges facing medical education is how to inculcate the knowledge and skills required for culturally competent patient care. Given the rapidity of demographic changes in our society, virtually every future physician will have responsibility for caring for a more diverse group of patients than is the case today. The needed competencies cannot be adequately acquired from books and lectures alone; what’s required is emersion (sic) in learning environments in which sufficient numbers of students (and faculty) from diverse racial and ethnic backgrounds interact on a continuous basis.”7

A concern is raised that cultural competence tends to focus on the “other” at the expense of what the practitioner brings to the patient-physician relationship. A better option may be the recently-coined term, “cultural humility,” which focuses instead on the development of a respectful partnership with the patient. In order to be culturally humble, the practitioner must commit to be self reflective, self critical and culturally inquisitive in the service of establishing non-paternalistic clinical relationships with patients, their families and communities.8,9 While the authors support the philosophical shift in the term “cultural humility,” this paper will use the more commonly known term, “cultural competence/competency.” This is also the term originally used for the project.

The Need for Cultural Competency Training in Hawai‘i

Cultural competency training is also needed in Hawai‘i, with its ethnically diverse population.10 Many of these diverse populations suffer from health disparities.11,12 Native Hawaiians, the host culture, have some of the worst health statistics of all ethnic groups in the state of Hawai‘i. They have the highest mortality rates for heart disease, cancer, stroke, accidents and diabetes.13,14 Life expectancy for Native Hawaiians continues to be the lowest of all groups and has even plateaued in contrast with longevity gains being made by other ethnic groups.15

Initial efforts to address Native Hawaiian health and health disparities through cultural competency training for physicians and medical students began in the late 1990’s with the establishment of the Native Hawaiian Center of Excellence (NHCOE) at the University of Hawai‘i (UH) John A. Burns School of Medicine (JABSOM). The
NHCOE, under the guidance of Dr. Benjamin Young, discovered that many faculty and community physicians were unaware of Native Hawaiian health disparities. NHCOE addressed this knowledge gap by sponsoring continuing medical education (CME) conferences with cultural competency training. Topics included Native Hawaiian health disparities, social determinants of health, teaching, research, and traditional healing.

In 2001, in collaboration with the ‘Ahahui o nā Kauka (Association of Native Hawaiian physicians) and Protect Ka ho‘olawe ‘Ohana, the NHCOE organized the first Kaho‘olawe island cultural immersion experience for Native Hawaiian and other interested physicians. This was in response to requests from Native Hawaiian physicians for the opportunity to learn about their own culture. The structure of the weekend allowed physicians to immerse themselves in land-based activities that promoted indigenous healing. The concept of the ‘āina (land) as a healing agent was very moving, and the participants continue to talk about that experience today.

Discussion/Description of Project
Formation of the Department of Native Hawaiian Health, 2003
In October 2003, the Department of Native Hawaiian Health (DNHH) was established within JABSOM as the only medical school department solely dedicated to indigenous health in the United States. In February 2004, a community strategic planning meeting was held to establish the vision, mission and objectives for this newly established department. In keeping with traditional Hawaiian values that honor the wisdom of the elders and community leaders, invited participants included kupuna (elders), traditional healers, other health care professionals, and community representatives. Participants strongly recommended that all JABSOM medical students undergo cultural competency training.

Formation of the Cultural Competency Development Project, 2004
As a result of this meeting and with the encouragement of then Dean Cadman, the DNHH began the process of developing a cultural competency curriculum for JABSOM and thus, the Cultural Competency Curriculum Development Project ("C3") was born. By this time, the NHCOE had also been absorbed into the DNHH which allowed for increased collaborative work in the area of cultural competency. While much was being published about cultural competency in healthcare during this period, a literature search of national medical training programs acknowledged that cultural competency was not being widely taught in medical schools.

Formation of the Cultural Competency Curriculum (“C3”) Development Team
The cultural competency curriculum development team ("C3") was purposely multi-disciplinary; guided by the Native Hawaiian ‘ōlelo no‘eau (proverb) that instructs, “‘A‘ohe pau ka ‘ike i ka hālau ho‘okāhi” (all knowledge is not taught in the same school). The original members of this committee were comprised of a diverse and experienced group of healthcare professionals, some of whom were also cultural practitioners: two primary care physicians and an administrator from the DNHH, a social worker from both the JABSOM Department of Psychiatry and UH School Social Work, a retired DrPH and dietician from the State of Hawai‘i Department of Health, and a cultural anthropologist and researcher from the JABSOM Department of Family Medicine and Community Health. A kupuna physician and another primary care physician are recent additions.

Development of the Curriculum
Early discussions centered on curricular objectives. The team recognized that there were many diverse ethnic populations in Hawai‘i, such as the recent immigrant population of Micronesians, also suffering from significant health disparities. However, the consensus of the group was to focus on addressing the health and health disparities of Native Hawaiians, the host culture. Specifically, the curriculum would do this by enhanced training of students and physicians who interact with Native Hawaiian patients. Should the curriculum prove successful, it could then be broadened to include other ethnic and social groups.

The first step in the development of the curriculum was to look at strengthening the “culture” in cultural competency training. Hawaiian issues relating to well-being, cultural practices, and spirituality needed to be an integral part of the training. To address this, the team knew it needed to go back to the culture for guidance. They asked for advice from Native Hawaiian kupuna and community members, medical students and physicians (the latter participated in at least one of three Ka ho‘olawe immersions) in the form of focus groups. The results helped guide the formation of the curriculum.

Initially, C3 focused on faculty training, as faculty behavior is frequently modeled by medical students. It would be ideal if both faculty and medical students could be trained concurrently, but there were limited resources available at that time. Various teaching and assessment strategies for the faculty were proposed including web based teaching, small group discussions, and role playing, self-reflections, self-assessments, pre and post tests, and CME courses. We initially partnered with the Hawai‘i State Department of Health, Office of Health Equity as they were also developing cultural competency training. This proved challenging due to timeline differences.

There was no budget allocated for any of these proposed initiatives. Serendipitously, the Project Director received monies from the UH Kualii Council (Native Hawaiian faculty and staff and representatives of Native Hawaiian serving programs) for culturally competent initiatives for medical students. As a result, the team’s focus changed from faculty to medical student training. Faculty development would have to wait.

As with all under-funded innovative projects of this type, progress depends on the passion and commitment of those tasked with making it happen. Many members of the C3 team initially volunteered their time in the development and implementation of the curriculum, including spending entire weekends in project activities.

Cultural Immersion
Cultural immersion programs have great potential as a method of consciousness-raising among medical students to counter the effects of non-conscious inherited racism and biases, and the impact of these beliefs on health care. Cultural immersion is based on the principle that immersion in another’s culture, practices, and language is an effective means of learning about oneself “in” another culture. The team studied the week long immersion experience of 3rd year medical
students from the University of Otago in Aotearoa (New Zealand) to different remote predominantly Maori rural communities.22 Because of its potential as a great learning experience, the C3 team chose to start with a medical student immersion. The model, though not the venue, was the cultural immersion programming conducted a few years earlier for physicians on Kaho’olawe island. In attempting to duplicate the essence of the Kaho’olawe experience, the Wai‘anae Coast on the island of O‘ahu was chosen as the immersion site. Its population is predominantly Native Hawaiian and the community is rich in cultural resources. Since 2006, six medical student immersions have been conducted. Approximately 25% of each first year JABSOM class participated after a random selection process. Immersions focus on (1) increasing students’ capacity for empathy by exposing them to a different worldview, (2) developing critical self reflection/self awareness, (3) experiencing traditional Hawaiian cultural practices, and (4) exploring traditional and contemporary Native Hawaiian values and beliefs, focusing on the culture’s strengths. Cultural immersion programming is guided by the Hawaiian ʻōlelo no‘eau, “Ma ka hana ka ‘ike” (In the doing, one learns).39

Colloquia
In 2006, after discussions with, and support from, JABSOM’s Office of Medical Education, a 4-hour mandatory cultural colloquium (lecture) was incorporated into the Community and Populational Health Colloquial Series for first year medical students. This provided the opportunity to address Native Hawaiian cultural issues with the entire class. With slight variation over the years, core topics continue to include Native Hawaiian health disparities with emphasis on its relationship to the history of Hawai’i, cultural historical trauma and indigenous healing, patient-physician relationship, culture of western medicine, experiential exercises that promote self-awareness, and Native Hawaiian traditional healing practices.

Lectures and Problem Based Learning (PBL)
Further expansion of cultural competency training curriculum included an introduction to Native Hawaiian health lecture, patient-physician panels and traditional healing practices. In 2007, the team revised a problem-based learning (PBL) case that highlighted cultural learning issues. By 2008, further colloquia time allowed for richer content that included social justice issues, more traditional healing practices, and role-playing exercises. As of the 2010-2011 academic year, first year medical students complete 9.5 hours of mandatory cultural competency training. However, the two and a half day cultural immersion program, while a voluntary experience for students, remains the heart of the C3 curriculum.

Elective
In early 2009, an elective in Native Hawaiian health focusing on traditional healing practices was initiated. The following school year, this elective combined with another DNHH elective in research methodology to become a year-long “selective” course in Community Health Course, “Native Hawaiian Health, Past, Present and Future.” The course features traditional Native Hawaiian concepts and practices around health and healing, addresses Native Hawaiian health disparities through research and community initiatives, and encourages students to develop a research project benefiting Native Hawaiian health.

Other Initiatives
The positive effects of the cultural immersion program resulted in the institutionalization of the immersion weekend by the Family Medicine Residency Program. It has funded cultural immersion weekends for all of their interns over the last four years. These were especially important, as many of the interns are not from Hawai’i and have no experience with Native Hawaiian patients. Due to intern request, the team also provided seminars on topics such as traditional Native Hawaiian healing practices, traditional diet, cultural historical trauma, and indigenous healing. The C3 team has also piloted cultural standardized patient cases with the Family Medicine residents. The Family Medicine residency had already implemented standardized patient cases utilizing other ethnic groups such as the Filipino and Micronesian population.

The C3 Project has engaged in collaborative activities with the indigenous health programs of the University of Otago in Christchurch, New Zealand and University of Melbourne, Australia, since an international medical conference in 2006. Faculty attended each other’s immersions in 2009. Discussions and feedback have positively enriched all programs. Furthermore, in Spring 2011, the C3 team joined the UH Myron B. Thompson School of Social Work Hawaiian Learning Program faculty and students on their weekend cultural immersion, paving the way for future partnerships.

In 2010, the Department of Surgery, in collaboration with the Department of Native Hawaiian Health and other University partners initiated an annual Cross-Cultural Health Care Conference. See Table 1 for the chronological development of the cultural competency curriculum.

Initial C3 efforts in training faculty have begun and include faculty immersions and culturally based activities. New initiatives were started utilizing culturally-based standardized patient cases for medical students. Opportunities for additional multi-disciplinary collaborative efforts with international colleagues continue. Planning is underway for curricular involvement in the second and fourth year of medical school and focus groups of senior students to reflect on our past efforts.

Assessment of the Curriculum
The C3 team is assessing the effectiveness of its efforts utilizing multiple evaluation strategies. Assessment tools include pre- and post-tests for the immersion, post-curricular qualitative and quantitative evaluations for workshops, immersions and electives, and a JABSOM standardized patient assessment tool. Data collection is ongoing and preliminary results are being evaluated. However, more data is needed to achieve statistical strength. On-going evaluation of the curriculum is challenging as much of the curriculum is guided by indigenous world views and processes, many of which don’t lend themselves to a western evaluative framework. Finally, funding constraints has impacted the evaluation process.

Funding
Funding for the C3 curricular initiatives was piecemeal in the beginning. The initial funding from the UH Ku‘ali‘i Council, was stretched out over three and a half years. Smaller grants were obtained from the UH SEED (Student Equity, Excellence & Diversity) program and the JABSOM Office of Medical Education. The Family Medicine Residency is continuing to fund the intern immersions. In 2009,
the team was very fortunate to secure monies from a newly funded NHCOE to support current programs and new initiatives. As many of the efforts have been dependent on grants, future funding will continue to be a challenge.

**Conclusion**

In 2004, there was limited cultural competency training taking place in JABSOM and no real infrastructure to support its development. As with most unfunded, but critical initiatives, this project depended on the passion and resourcefulness of those tasked with implementing them, as well as the goodwill of the community, whose members have contributed time, resources, and expertise in order for this project to succeed. This cultural competency initiative has been strongly influenced by: C3 team availability for teaching and planning, limited instruction time within the overall JABSOM curriculum, budgetary challenges, and serendipity. The C3 team was influenced by the national cultural competency standards of the time, but also relied heavily on focus group data to inform curricular development. Many aspects regarding the process of teaching the curriculum came from the culture itself. In addition, all curricular initiatives were subjected to evaluation, which also influenced curricular development.

A 2010 article by Betancourt and Green discussed the evolution of cultural competence. The DNHH current and proposed cultural competency curriculum is congruent with many of the key principles and recommendations proposed in their article. The article describes that the “categorical approach” has evolved to “an approach focusing on the development of a set of skills and a framework that allow the clinician to assess—for an individual patient—what sociocultural factors might affect that patient’s care.” Many of these skills are taught throughout our curriculum, including: eliciting a patient’s understanding of his/her illness, skills for assessing decision-making preferences and the role of family, techniques for ascertaining the patient’s perception of biomedicine, and his/her use of complementary and alternative medicine, and bringing an awareness of issues of mistrust and prejudice of the provider and of the impact of race and ethnicity on clinical decision making. These skills are needed if clinicians are to deliver the highest-quality care to all patients.23

It’s been a fascinating journey developing this cultural competency curriculum. There is still much to do. The team will do its part to decrease Native Hawaiian health disparities through physician training by continuing to address national standards and guidelines while honoring the Native Hawaiian voice. Although still called the “cultural competency curriculum,” the team uses the term “cultural humility” in its teaching. It is the belief of the C3 team that many of the lessons from the curriculum are generalizable to other populations. For example, lessons around “cultural humility” apply to all patient-physician interactions. The team believes that many of the basic processes and themes utilized by the C3 curriculum at JABSOM can be adapted for other medical schools.

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References

Hokule’a rigging
Abstract
Background: Culturally competent health care providers are needed to eliminate healthcare disparities. In the State of Hawai‘i, Native Hawaiians suffer some of the worst health disparities. Prior to implementing a cultural competency curriculum to address these disparities, the John A. Burns School of Medicine’s Department of Native Hawaiian Health Cultural Competency Curriculum Development team asked Native Hawaiian patients about their experiences and recommendations.

Methods: We conducted four focus groups of Native Hawaiians to obtain recommendations on physician training, to be incorporated into the curriculum. Participants came from both rural and urban areas. Classical qualitative analysis of data identified recurrent themes.

Results: Five primary themes, arising in all four groups, were: (1) customer service; (2) respect for the patient; (3) interpersonal skills; (4) thoroughness of care; and (5) costs of medical care. Secondary themes, occurring in three of the four groups, were: (1) cultural competency training; (2) the training of medical office staff; (3) continuity of care; and (4) the role of the patient. Participants specifically requested that medical students receive cultural competency training about the host culture, its history, values, and traditional and alternative healing practices.

Discussion: The emphasis participants placed on the need for cultural competency training of physicians supports the need to address the role of culture in medical education. Although most of the issues raised are not unique to Hawai‘i, participants’ recommendations to teach students about the host culture and traditional healing practices identify important themes not usually found in medical school curricula.

Introduction
With the increasing diversity of the population in the United States, health care providers are challenged to provide culturally competent care. Many US minority populations suffer from health disparities.1 In 2002, the Institute of Medicine recommended that cross-cultural care training be included in medical schools as an approach toward eliminating these health disparities.2 The Office of Minority Health (OMH) as well as regulatory agencies such as the Liaison Committee on Medical Education (LCME) have called for guidelines but no national consensus on either the content or assessment of a curriculum that addresses culturally competent care.3-5 There was a specific paucity of literature directly addressing culturally competent or cross-cultural training appropriate for Native Hawaiian patients. While the literature uses multiple varying terms to address the area of “cultural competency” training such as cultural sensitivity, cross-cultural care, or cultural humility, in this paper we will retain the nationally accepted term “cultural competency.” Research with Native Hawaiians was reviewed that examined outreach, screening, or treatment programs that elicited the desires of patients and the need for culturally competent care.6

A focus group study of cancer survivors found that patients valued the “important role of culture in understanding health beliefs, attitudes, and behaviors.”7 The authors stated that “providers need to learn about the values and traditions of the cultural groups with which they work, to assess their importance to individual patients and to help interpret these values in ways that promote proactive health behaviors.”8 Focus groups of Native Hawaiian men revealed that many mistrusted their doctors and had negative personal interactions with physicians (focus on finances rather than care, being rushed and/or made to wait, ignored, discriminated against, not listened to, being unfamiliar with the physician) which prevented them from wanting to seek medical care.9 In addition, physicians themselves acknowledged the need for culturally competent training to address Native Hawaiian health needs.10 These findings of course are not unique to Native Hawaiians and support the overall dissatisfaction of patients’ care in the United States.11

Methods
Deciding that additional input from Native Hawaiians was needed to guide the development of the curriculum, the C3 team conducted focus groups to address training issues around cultural competency and Native Hawaiian health.21 Focus group methodology was chosen as the best and most “culturally acceptable” way to address the issues.22 Other researchers working with Native Hawaiians have found that Native Hawaiians “prefer to share their experiences orally and face to face (compared with surveys or telephone interviews) allowing them to gauge the researcher’s intent, sincerity, and trustworthiness as information is exchanged.”23

Recommendations for Medical Training: A Native Hawaiian Patient Perspective
Martina L. Kamaka MD; Diane S.L. Paloma MBA; and Gregory G. Maskarinec PhD

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Institutional Review Board (IRB) approval from both the University of Hawai‘i as well as the Native Hawaiian Health Care Systems (NHHCS) was obtained prior to conducting our focus groups. Researchers sought a range of Native Hawaiian opinions so participants were recruited from a rural, neighbor island community (Moloka‘i), chosen due to the high percentage of Native Hawaiian residents living there, as well as from O‘ahu (suburban and urban Honolulu). Moloka‘i participants were recruited through the Native Hawaiian Health Care System, Na Pu‘uwai. On the island of O‘ahu, participants were recruited from the Pearl Harbor Hawaiian Civic Club (Honolulu area). Non-Native Hawaiian spouses may join the civic clubs so they were included in the study if they chose to participate.

Focus groups took place in the community where they resided (Moloka‘i) or met regularly (civic club). Facilitators used three guiding questions for the focus groups: (1) Can you tell me about an experience with a doctor or a doctor’s office? (2) If you could change the way that doctors treat you, what would you change? and (3) If you were training doctors, what do you think would be important to teach them? Sessions lasted approximately two hours. Each focus group had a facilitator, someone capturing the key comments on a flip chart, and a scribe who took notes and recorded the session. All sessions were tape-recorded. Participants filled out written consent forms and all responses were de-identified. Participants were given a gift certificate to a local pharmacy for their participation. All but one member of the research team was Native Hawaiian and four of the six were part of C3.

**Participant Demographics**

Thirty-four (34) individuals participated in one of four focus groups. Data from 32 participants was collected as two participants did not complete their forms. Characteristics of the focus group population can be seen in Table 1. Eight (8) participants were from Moloka‘i (25%) and the rest from O‘ahu. Ninety one percent of the participants were Native Hawaiian. All Native Hawaiian participants, including those with mixed ethnicity, identified primarily with being Native Hawaiian. Participant age range was from 25 to 92. The Moloka‘i group was older (62.5% were over 65 years of age); 42% of the total number of participants were over the age of 65. There were almost twice as many women participants as men. Private insurance (Kaiser, HMSA, or Tricare) covered 80% of the participants while 10% had Medicare coverage, 3% had Medicaid and 7% did not have any insurance. This is similar to the Behavioral Risk Factor Surveillance System (BRFSS) data from the State of Hawai‘i in which 94% of Native Hawaiians had insurance coverage while 6% did not. An area of difference with the BRFSS is that 26% of our participants did not have a primary care doctor whereas only 12% of the BRFSS respondents did not have a “personal” physician.

**Evaluation**

Audio recordings were transcribed verbatim and then each member of the C3 team read and analyzed the data, relying on the team’s diversity (public health, medical, non-medical) and experience to reduce the risk of bias. Participants were de-identified prior to analysis. Multiple comments on the same topic by the same participant were counted as one response. Classical qualitative analysis was utilized to elicit primary and secondary themes. Primary themes were those discussed in all four focus groups. Secondary themes were those mentioned in 3 out of 4 of the focus groups.

| Table 1. Characteristics of Focus Group Participants (N=32) |
|-------------|-------------|----------------|
| Age (years) | n            | %              |
| 18-29       | 3            | 9.5%           |
| 30-49       | 8            | 26%            |
| 50-65       | 7            | 22.5%          |
| 65-80       | 11           | 35.5%          |
| >80         | 2            | 6.5%           |
| Gender      |              |                |
| Men         | 11           | 34%            |
| Women       | 21           | 66%            |
| Ethnicity   |              |                |
| Hawaiian/Part Hawaiian | 29 | 91% |
| Caucasian   | 1            | 3%             |
| Filipino    | 1            | 3%             |
| Japanese    | 1            | 3%             |
| Residence   |              |                |
| O‘ahu       | 24           | 75%            |
| Moloka‘i    | 8            | 25%            |
| Educational Attainment | | |
| Some High School | 3 | 9% |
| High School Graduate | 12 | 38% |
| Some College/Tech School | 9 | 28% |
| College     | 8            | 25%            |
| Employment  |              |                |
| Working (for wages) | 15 | 49% |
| Retired     | 14           | 45%            |
| Student     | 1            | 3%             |
| Homemaker   | 1            | 3%             |
| Unemployed  | 0            |                |
| Self-employed | 0        |                |
| Insurance   |              |                |
| Private (HMSA, Kaiser, Tri-Care) | 23 | 80% |
| Medicare    | 3            | 10%            |
| Medicaid    | 1            | 3%             |
| None        | 2            | 7%             |
| Primary Care Doctor | | |
| Family Physician | 10 | 32% |
| Internal Medicine | 10 | 32% |
| Clinic (not always the same) | 4 | 13% |
| Other       | 1            | 3%             |
| No primary care Doctor | 6 | 20% |

*Age range 25-92 years of age, †One participant did not answer, ‡Three participants did not answer*
Results
The team identified five primary and four secondary themes. The primary themes identified were: (1) customer service related issues; (2) respect/caring for the patient (trust issues, sensitivity to fears); (3) interpersonal skills of the provider (listening, communicating); (4) thoroughness of care (knowledge of patient, follow-up); and (5) issues around costs of medical care.

Primary Theme 1: Customer Service Related Issues Around Long Waits and Rushing
The most common concern raised was frustration with having to wait so long in physician offices. Participants described waiting for hours and then only being seen by the doctor for a few minutes. Patients felt that their time was as important as the physicians. One participant shared an experience in which she had to leave work, plan for travel time, arrived at the appointment 15 minutes early, as requested, only to have to leave after waiting for 90 minutes without being seen because she had to pick up her children. “Wasted time, wasted day.” Participants were also concerned with delays in getting test results back and difficulties with scheduling timely appointments.

A common comment was “stop rushing.” “I know you’re talking money... and patients still need that care, that sharing needs more time.” Participants wanted the doctors to take more time to learn about them and to follow up appropriately. “More time shows more care.”

Primary Theme 2: Respect/Caring for the Patient
This theme centered on how the participants felt when interacting with physicians. Participants wanted physicians to treat them with respect, caring, understanding and patience. They wanted physicians to take the time to establish trust, be sensitive to fears, be respectful of personal space and be aware of patient’s resistance, especially as it relates to a dislike of taking medications and of doctors coming to a new location (eg, rural location) to make an extra effort to get to know the patients. Building relationships is critical. “…who you know makes a difference.” In other words, if they know you, they are more likely to share information with you.

Participants commented included: “talk to the patient,” “explain what you’re doing,” “give information,” and “teach us.” Participants wanted procedures (and reasons for them) explained thoroughly. Patients felt “satisfied” when they were “learning something.” Advice needed to be tailored to the patient. Dietary recommendations should consider who cooks and the culturally appropriate foods available. Exercise recommendations need to consider the patients’ environment and access. Participants stated that the use of humor or forceful language could be helpful in the right context.

Participants appreciated doctors who were up-front with prognosis but always offered hope as well. This allowed patient and family to prepare and yet, “mind/brain can do a lot and you might be proven wrong.” Patients also indicated that they didn’t always know how or what to ask, so they wanted physicians to encourage them by asking good questions and giving a lot of information. This would “…let us decide what to do with the information.”

Physician to physician communication was another important issue. Participants appreciated a doctor who knew to ask for help or a referral. It made them feel like the doctor really cared and wanted to do the right thing. They did not, however, want to be the “go between,” the person who transmitted the information between the consultants and their doctors to communicate directly with each other.

Primary Theme 4: Thoroughness of Care
Another recurring theme was to “be thorough in your evaluations and testing” and history taking. This includes addressing family concerns. Giving the patient full attention was a clear message. Several stories were shared of critical errors being made due to lack of thorough history taking or follow-through. They wanted physicians to acknowledge patient fears (eg, needles and blood draws, bad diagnoses) and try to address them honestly and with respect. Patients were frustrated by delays or a lack of follow up on test and procedure results. Some were frustrated to find out that certain tests weren’t needed but performed anyway (unnecessary labs were discarded) and others were aware of mistakes and “poor techniques” (unsanitary procedures).

Primary Theme 5: Costs of Medical Care and Medical Systems
Participants were very concerned about the costs associated with medical care. All groups seemed to think that doctors were losing their sense of priorities. Priority should be to help patients and their...
families and not cost savings. They gave examples of first encounters with medical offices centering on the questions of what insurance coverage the patient had, and offices that prominently displayed signs “payment due at time of appointment.”

Participants resented being charged for supplies not used and consultant visits in which the consultant didn’t even bother to talk to or examine them. They appreciated doctors who asked about medication coverage or who used samples to figure out appropriate medications before writing the prescriptions. Drugs are too expensive to fill for “let’s try this prescription” scenarios. “When they send you to the drugstore…it hurts.” Participants resented the focus on money. They felt that doctors are paid well so they should give “good customer service.” “Medical costs going up, going up, going up but nobody says medical care is getting better, better, better.”

With medical systems, various concerns were raised. For rural communities, access to specialists and certain programs was very limited. As an example of rural health challenges, if only one person runs the program and if that person can’t do it, the community “comes to a standstill.” In suburban or urban situations, a variety of insurance plans, multiple locations for visits or tests and miscommunication between doctors or with staff can all present challenges. Computerization was seen as helpful as was one central location for physician visits, tests, record keeping and pharmacy. Participants expressed a desire for the family medicine-like model where doctors were personable and took care of the whole family. “Doctors knew you, your family, your history, your background” and “where you were coming from.” One participant stated outright, “I want a family doctor.”

Secondary Theme 1: The Need for Cultural Competency
Participants agreed that medical students and other health professionals needed cultural competency training. One touching story had to do with the cultural clash that occurred with a kupuna (elder) dying at a local hospital. The large family wanted to gather around to tell stories and play music, but the nurse insisted the room stay quiet and calm. The nurse did not understand the importance of music and family presence in comforting the patient. Participants wanted students to be exposed to alternative and traditional medical practices such as la’au lapa’au (herbal medicine). They wanted physicians to be open to patient use of these types of treatments. In addition, physicians needed to be more sensitive to cultural values (eg, attitude toward bodies and body parts, family involvement, incorporation of cultural values in treatment plans). To force Native Hawaiian patients to conform with contemporary American values was viewed as being disrespectful. Participants mentioned the needs for modifying and adapting care such as modifying height and weight charts. There was a desire to “treat different groups differently.” They were especially concerned about “non-local” doctors (doctors who come from places outside of Hawai’i) who they perceived as treating patients differently. They viewed local doctors as being more compassionate, more sensitive, less business-like and showing more aloha. Participants thought the non-local doctors needed to learn about the host culture (“good and bad”).

Secondary Theme 2: The Need for Medical Office Cultural Competency Training
The office staff was seen as a critical component of the patient-physician interaction. They expected the staff, which represents the doctor, to be friendly, helpful, well trained and supportive of the doctor. One patient described complaining of chest pain to the front office staff and being told, “we busy, go home.” Participants were frustrated with difficulties in scheduling appointments and felt that staff could do a better job of letting patients know when the doctor is running late. They felt medical staff should also get cultural competency training. Medical offices could be made more comfortable for patients and children.

Secondary Theme 3: The Need for Continuity of Care
Accessibility to their doctors was a major concern. Not only was it hard to schedule timely appointments but many physicians don’t take “new patients.” Participants found that they needed to change doctors frequently due to physician relocation (sometimes without notice to the patients). In addition, many doctors failed to communicate changes in acceptance of insurance plans.

Secondary Theme 4: Role of Patient in Their Own Healthcare
Three out of the four focus groups discussed the need for patients to take responsibility for their own health care. They felt patients needed to start preventative measures early, and learn to communicate more effectively with the doctors. “It’s a two way street…patients need to be accountable too.” “Doctors can only do so much.”

Discussion
Much of what was shared by our focus group participants is not surprising. Themes centering on communication, showing care and respect, as well as concerns about costs are daily conversations and frequent topics in the national media. Many of these themes have surfaced in other recent studies of Native Hawaiian patients. For example, a recent study looking at heart failure found that Native Hawaiians expressed a mistrust of physicians and western-based medical care. Patients commented that “their physicians ‘don’t care’ about them, are ‘too busy’ to listen to their concerns” and did not communicate well (were not honest and did not provide good medical information or patient education). Another study using patient surveys looked at Native Hawaiian patient attitudes and perceptions of what constitutes culturally sensitive health care provider traits and behaviors. They found that patients wanted family-centered, holistic, respectful and accepting health care with providers who could communicate openly and honestly. The authors felt strongly that “it is imperative that healthcare providers understand not only the culture but the cultural history of any patient.” As with the general population, Native Hawaiian patients seem most concerned about the interpersonal relationship they have with their physicians.

Those themes related to secondary theme number one (cultural competency training) were particularly relevant to the C3 team. Participants specifically requested cultural competency training and introduction to alternative healing practices for medical students. This was also found in the recent study by Kaholokula et al., “Native Hawaiians also expressed a preference for traditional Hawaiian healing practices.” Our results specifically point to the need to address Native Hawaiian history and cultural values as well as traditional Hawaiian healing practices.

Following the focus groups, the team had to decide how best to incorporate these topics within the curriculum. We realized that
cultural topics do not lend themselves well to didactic lectures and therefore adopted a wide variety of teaching methodologies including cultural immersions, small group discussions and experiential learning. Traditional healers and cultural experts were integrated into the curriculum. Initial efforts have resulted in the annual inclusion and expansion of cultural competency curriculum initiatives in JABSOM’s medical curriculum.

The team believes that many of the topics found in the focus groups can be generalized to other health disparate populations. With additional funding and faculty support, the needs of the other ethnic groups will be addressed.27,28

Study Limitations
Participant numbers were relatively small. The team could not be sure that these focus groups represented a true reflection of the Native Hawaiian community. We tried to address this by utilizing Native Hawaiian participants of both genders from both rural and urban settings with a wide variation in age. Insurance demographics were similar to those found on the State BRFSS (BRFSS limitations include missing those who are homeless or without phone service). Another limitation is the subjective nature of focus group data and the influence of group members on each other. To minimize the possible subjectivity of the analysis, all C3 team members independently scored data. Despite these limitations, “qualitative methods are useful and necessary in developing culturally informed interventions…especially for understanding ethnic populations.”24

Eighty percent of our participants had private insurance; seven percent (2 individuals) had no insurance. Many of the participants’ comments related to cost/insurance related issues and it may be inferred that they reflected the limited diversity of insurance carriers. Our focus group population mirrors the fact that there is one dominant insurance carrier in the state.

Although many of our focus group themes were not unique, literature regarding Native Hawaiian preferences toward cultural competency training remains limited. The use of focus groups proved invaluable to help clarify the needs and prioritize the components of the DNHH cultural competency curriculum. Significantly, the data identified a curricular goal not usually recognized by medical schools: the need to teach students about the host culture, its history, values, and traditional healing practices.

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References
Imi Hoʻola Program: Producing Primary Care Physicians for Hawai’i and the Pacific

Chessa C. DeCambra MBA and Winona K. Lee MD

Abstract

Background: The impact on health care delivery due to the impending shortage of primary care physicians is of national concern. To meet the growing health care needs of Hawai’i and the Pacific, the Imi Hoʻala Post-Baccalaureate Program (IHP) provides educational opportunities for students from disadvantaged backgrounds to pursue careers in medicine. Students selected to participate in the IHP have demonstrated a commitment to serve in areas of need of Hawai‘i and the Pacific. IHP alumni enter the John A. Burns School of Medicine (JABSOM) as first year medical students. Following graduation, these students enter a variety of residency training programs.

Purpose: The purpose of this study was to determine whether IHP alumni who successfully graduate from JABSOM choose primary care as their specialty of choice.

Methods: A retrospective review of IHP alumni from 1973 – 2010 was conducted. All IHP alumni who graduated from JABSOM and are currently in practice were included in the study.

Results: Of the 213 IHP graduates, 71.6% (n=152) are primary care physicians currently in practice.

Conclusions: The majority of IHP alumni are currently serving as primary care physicians. Selection criteria, educational curriculum, and experiential nature of the program may contribute to Imi Hoʻala’s success in producing primary care physicians.

Introduction

By 2025, The United States is projected to face a shortage of 65,800 primary care physicians.1 Under the new Affordable Care Act, increased demand for the newly insured will create additional tension on an already stressed health care system. Increased demand for primary care services due to aging baby boomers and rising prevalence of chronic diseases coupled with decreased supply due to physician retirement and fewer graduates entering primary care residencies contribute to this impending crisis.2 Despite the need for more primary care physicians in the health care workforce, the number of medical students choosing this specialty nationwide is on the decline. Recent surveys show that only 16-18% of medical students are planning to go into primary care.3

In an effort to meet the healthcare needs of Hawai‘i and the Pacific, the Imi Ho‘ala (Those Who Seek to Heal) Post-Baccalaureate Program at the John A. Burns School of Medicine (JABSOM) was established more than 30 years ago. The Imi Ho‘ala Program’s (IHP) goal is to contribute to diversity of the health care workforce and produce physicians committed to practice in under-served communities in Hawai‘i and the Pacific. Up to 12 students from economic, social, and/or educationally disadvantaged backgrounds are selected for the program each year. The curriculum emphasizes the integration of concepts in the sciences and humanities and further develops students’ communication, critical thinking, and learning skills. Upon successful completion of the program, students enter JABSOM as first-year medical students.

Few studies have shown whether post-baccalaureate programs positively contribute to the number of medical school graduates who eventually become primary care physicians. The purpose of this study is to determine whether IHP alumni who successfully graduate from JABSOM choose primary care as their specialty of choice.

Methods

This study is a retrospective review of IHP alumni from 1973 - 2010, who have graduated from JABSOM and are currently in practice. All physicians, except for those listed as residents, fellows, or no longer in practice, were included in the study. Gender, ethnicity, and medical specialty data was provided to IHP by program participants either during the IHP admissions process or at the time of JABSOM graduation and stored in the IHP database. Primary care specialty included family medicine, family practice, internal medicine, internal medicine/pediatrics, internal medicine/flexible residency, obstetrics/gynecology, pediatrics, primary care, and primary care/internal medicine. This study is a report on educational developments, not on human subjects research.

Results

Of the 213 IHP graduates, 71.6% (n = 152) practice primary care. Of the 152, there were a total of 79 females (52%) and 73 males (48%). Ethnicity categories did not indicate a clear majority and included 53 Hawaiians, 46 Filipinos, 27 Pacific Islanders (Chamorro, Kosraen, Marshallese, Palauan (Belauan), Pohnpeian, Yapese, Samoan), 14 Asians (Chinese, Japanese, Korean), 8 East Asians (Cambodian, Taiwanese, Vietnamese), 3 American Indians, and 1 Caucasian.

Discussion

The study’s findings indicate that the majority of IHP alumni not only choose primary care, but are also currently in practice. These findings are most likely related to (1) selection criteria for admission, (2) program curriculum, and (3) experiential learning opportunities. The IHP is an institutionalized approach to increase the enrollment of disadvantaged students at JABSOM. Students must meet the required selection criteria of disadvantaged status in order to qualify for the Program and demonstrate a strong commitment to serve in areas of need in the State of Hawai‘i and the U.S.-Affiliated Pacific Islands. Many of the students who participate in the IHP originate from rural areas and express an early interest in returning to their home community to practice rural medicine. The study’s findings suggest that the IHP may self-select students who would naturally gravitate to the generalist/primary care specialties.

Once enrolled in IHP, it is the program’s belief that the curriculum, specifically the Scientific Basis of Medicine (SBOM) course, encourages students’ initial inclination towards general/primary care specialties. As one of the core courses in the IHP curriculum, SBOM introduces students to the global view of health and disease, explores the roles of health professionals working in various health-care settings, and provides awareness of health-care delivery resources in Hawai‘i. Using a combination of group discussions, visual media, and guest speakers, SBOM aims to improve personal
and professional student growth. Guest speakers include physician role-models who exemplify professional traits and practice in rural communities, who offer real-world perspectives on health, culture, and health disparities that may have been directly observed by the students in their home communities. For many students, this legitimizes their personal experiences with health care in Hawai‘i and the Pacific and builds upon their interest and motivation to practice rural medicine in these areas.

In hopes of further reinforcing and sustaining student interest in practicing medicine in rural communities, IHP provides students with two distinct experiential learning opportunities on the neighbor islands. During the academic school year, students participate in a service learning project in the Kalaupapa settlement on the island of Moloka‘i and a week-long rural community medicine shadowing experience on one of the main Hawaiian islands. As part of the SBOM curriculum on leprosy, the Kalaupapa Service Learning Project provides students with the opportunity to interact with remaining patients in the settlement and receive exposure to practicing primary care in a rural setting. During the rural community medicine shadowing experience, primary care physicians (many of whom are also IHP alumni) provide shadowing opportunities in community clinics or private practice and share with IHP students their outlook on primary care and possible career trajectories. These experiences foster greater understanding of what practicing primary care in a rural setting is like from a provider’s point of view and assists students in reflecting on their own abilities and desires to return to their home communities. Having these primary care physicians serve as positive role models and as future mentors are a vital part of the IHP students’ learning experiences.

In conclusion, the study found that the majority of IHP alumni chose primary care medical specialties and IHP does contribute to the number of JABSOM graduates who eventually become primary care physicians. Future studies are planned to examine if student-specific factors, such as socio-economic background and rural community of origin are predictive of a student’s eventual practice specialty choice. Program specific elements of the IHP curriculum could also be examined to further explain how the IHP positively impacts students’ perceptions on primary care and rural medicine.

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References
Palliative Care and Traditional Practices of Death and Dying in Wa’ab (Yap Proper) and in the Outer Islands of Yap

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Abstract

Background: Death remains one of the most important and significant activities in Yap, an event that involves the entire island. A death of a Yapese not only unites the family, it initiates a complex series of reaffirmed kinship ties, rituals and exchanges that refocus the entire community and create new social identities for the participants. How these ties, exchanges, and identities are changing due to new economic challenges and new social pressures were the focus of this preliminary study, which sought to document the resiliency or fragility of traditional structures, measured in the efforts around death and dying in Yap and to identify ways that the health care system can intervene to improve palliative care.

Methods: 226 persons (49 on Wa’ab - Yap Proper - and 177 on the Outer Islands) participated in 16 focus groups, of which eight were on Wa’ab and eight on four Outer Islands: Fais, Falalop, Fetherai, and Mogmog. We additionally conducted 6 semi-structured open-ended key informant interviews, added to capture more of Yap’s enormous sociocultural diversity.

Results: The islands of Yap, particularly the Outer Islands, continue to support one of the world’s best traditional palliative care involving the immediate family, more distant relatives and in many cases the entire community. However, participants showed considerable concern for ways that this system is weakening and offered numerous suggestions for improving and strengthening palliative care in Yap.

Discussion: Although caution must be exercised not to undermine the existing system, six recommendations on how the health system can intervene can be identified. These involve identifying a key resource person on each island; supplying small, practical “comfort care” kits; making more pain medication available; conducting regular home visits; improving patient-physician and physician-family communication; designing a suicide intervention strategy; and documenting existing variations of how the dying are cared for on the other Outer Islands of Yap.

Background

Yap, the western-most state of the Federated States of Micronesia (FSM) is located in the western Caroline Islands midway between Guam and Palau. Yap has a population of approximately 11,200. 65% of the population resides on Wa’ab (Yap Proper), which consists of four islands connected by roads, waterways and channels, and includes the town of Colonia, Yap’s capital, whose population is about 1000. The population density is 243 per square mile and the median age is 20.9.

Stretching 600 miles east of Wa’ab are 78 outer islands, of which 22 are inhabited. Including the outer islands, the state of Yap covers approximately 500,000 square miles of ocean yet consists of only 45.8 square miles of land area.

Yapese is spoken by the inhabitants of Wa’ab, while the distinct Micronesian languages of Ulithian, Woleaian, and Satawalese are spoken in the Outer Islands; communication between the two groups most often takes place in English (understood by all islanders). According to the 2000 census, there were a total of 2,030 households in Yap, with a median of 5.4 persons per household. Some cash income was reported by 1,578 households (77.7%), with a mean household income of $8,300. Yap’s literacy rate is 92%. Life expectancy at birth is 66.5 for males, 67.6 for females. In 2004, per capita expenditure on health was US$180, an increase from US$116 in 2002.

Yap Memorial Hospital in Colonia is the only hospital in Yap and is directly accessible only to those residents who live in Wa’ab. Residents who live on the Outer Islands find access difficult due to limited transportation and rely on 17 Outer Island dispensaries and on traditional practitioners. A field ship sails about every 6 weeks when in service. Other cargo ships that can also carry passengers sail...
infrequently. Only three of the Outer Islands (Woleai, Ulithi, Fais) have runways. These are serviced irregularly by Pacific Missionary Airways (PMA), which offers reduced fee medical evacuations.

The Outer Islands of Yap have been largely left to their own devices by the health services system. Not only are there cultural, social, political, and linguistic divides between the main islands and the Outer Islands, but the distance between islands and the poor transportation back and forth frustrate most attempts to provide help for the islands. Given the clear preference of outer islanders to die on their own island, ways to improve the situation certainly deserve attention.

A death of a Yapese not only unites the family, it initiates a complex series of reaffirmed kinship ties, rituals, and exchanges that refocus the entire community and create new social identities for the participants. However, new economic challenges in the form of a cash economy, heavier reliance on imported food, increasing use of tobacco and alcohol, new religious sects (including Mormons, Bahais, and various Christian fundamentalist groups), and the increasing possibility that death may take place in Yap Hospital rather than at home, or even at a hospital in Manila, Guam, or Honolulu, all place stress on the rituals and exchanges that traditionally characterized death in Yap. Yap (like all of Micronesia) is undergoing an epidemiological transition, in that the islands continue to face problems with infectious diseases, including tuberculosis, Hansen’s disease, dengue, cholera, filariasis, STIs, and a recent outbreak of Zika virus, while now experiencing a huge rise in chronic diseases including diabetes, hypertension, cardio-vascular diseases, and cancers. Maternal child health issues include pregnancy complications, low birth weight, high infant mortality rates, and low immunization rates. Malnutrition problems co-exist with chronic diseases linked to obesity. These problems all add stress to the traditional systems of care and exchange.

How traditional ties, exchanges, and identities are changing due to new economic challenges and new social pressures was the focus of this study. We sought to document the resiliency or fragility of traditional structures, measured in the efforts around death and dying in Yap and to identify ways that the health care system can intervene to improve palliative care.

**Methods**

Discussions were initiated between Yap Comprehensive Cancer Control Program (Yap CCCP), the leadership of the Wa’ab Community Health Center (WCHC), Yap Department of Health Services (Yap DHS), and the Governing Board of Yap Area Health Education Center on how best to address the community-perceived need of improved palliative care. Exploring existing beliefs about death and dying utilizing focus groups was agreed upon as an appropriate strategy. The proposal was presented to the Council of Pilung and Council of Tamol (the Councils of Chiefs of Wa’ab and of the Outer Islands), as well as to the Yap Cancer Coalition, the Yap Medical Association and Yap Nurses Association. Once adjusted to include their recommendations, the proposal was submitted to the Pacific Center of Excellence for the Elimination of Disparities (CEED) which requested further modification that limited the number and scope of focus groups and reduced the budget while also requesting a review of a draft Pacific Palliative Care Curriculum prepared by Kokua Mau in Honolulu (see article in this issue). Approval from the University of Hawaii’s IRB was obtained (CHS 18261) and the research was undertaken in April and May 2010.

Facilitators for the focus groups were identified and trained. The facilitators organized, scheduled, and conducted focus groups composed of representative adult volunteers, who were asked their opinions on four related topics:

1. What is a good death?
2. What examples can you give of a bad death?
3. How can the health care system improve to help make bad deaths better ones?
4. Are there traditional practices of which we should be aware before advocating any changes?

Groups included a youth group, a cancer survivor group, a group of widows, a group of community leaders, two community groups on Yap, physicians of Yap Hospital, and groups divided by gender on four outer islands. Altogether 226 persons (49 on Wa’ab and 177 on the Outer Islands) participated in 16 focus groups, of which eight were on Wa’ab and eight were on four Outer Islands: Fais, Falalop, Fetherai, and Mogmog. We additionally conducted 6 semi-structured open-ended key informant interviews. These informant interviews were added to capture more of Yap’s enormous sociocultural diversity.

**Results**

The islands of Yap, particularly the Outer Islands, continue to support one of the world’s best traditional palliative care systems (known on Ulithi and Fais as hachou—care for the dying, with cognates in the other languages and dialects of the Outer Islands), involving the immediate family, more distant relatives, and in many cases the entire community. However, participants showed considerable concern about the way this system is weakening and offered numerous suggestions for improving and strengthening palliative care in Yap.

Traditional practices release the immediate family from their daily chores to allow them to tend full time to the dying (shifts are assigned throughout the night, a process known as yach metmat lobong). Attendants are expected to be quiet, subdued, and cheerful, taking care not to excite the dying patient. Food, supplies, and labor are provided by the extended kin network and wider community. Special food offerings and daily garnals of flowers are brought to the dying person, and efforts are made to resolve all family disputes and inheritance issues while the dying person can still participate in the discussions. As one elder explained: “When we take it [food and supplies] to the sick person’s house, then we have to call out the names. We have to make a relationship on the person’s father’s side and on the person’s mother’s side.” That is, the visitor’s genealogy and relation to the patient is explicitly articulated as part of the visit. Christian families perform bedside prayers and sing hymns, and all community members are expected to visit the dying person. Whenever possible, relatives from other islands also visit the dying and bring supplies to the family.

In some communities, a “question medicine” is prepared to give to the patient, to determine whether or not they may survive or cannot. Divination by palm knot tying is still sometimes practiced for this purpose, too, and knot tying is also used to identify who is...
the right person to do local medicine. A yes or no question is posed, then knots are tied in four coconut fronds and the numbers in each counted, with the final number providing the code for the answer to the question.

At a typical funeral, distant relatives announce their kinship ties to the deceased, orally tracing the lineage through both parents of the departed, ties that in some cases are otherwise nearly forgotten and sometimes require genealogical consultations to prepare. On some of the more remote islands “wailing,” is still performed at the funeral, ritual lamentations addressed directly to the newly dead, although this practice is actively discouraged by Christian religions. Coffins are laden with lavalavas (locally woven cloth worn as a skirt) and monetary offerings. In many communities, the grave site is watched for three days in expectation of signs that the spirit of the departed is still hovering there, and conversations with the dead take place. Personal property of the deceased not disposed or willed before death is burned, to dissuade the spirit of the departed from remaining near the home.

After a death, the family remains at home for four days. Catholic Yapese conduct a nine day novena at their home, with all work obligations suspended; more distant relatives tend their fields and perform other chores for the family. Work on some taro fields or on small non-inhabited but cultivated atoll islands closely associated with the deceased may be suspended for up to six months as a sign of respect. After the funeral, the name of the deceased is no longer uttered, until a suitable descendant is born to whom the name is given, along with expectations that the newborn will grow up to develop the same character as his namesake.

While there were many points brought-up in the discussions on death and dying, some of the more pertinent points to improving palliative care include:

1) To some Yapese, pain while dying is desired. Although not as prevalent as the almost universal opinion that experiencing pain during labor and delivery is a necessary part of being a complete woman, it was considered to be a strong argument against pain medication. All agree there is no local medicine used only to control pain. Much more than a simple test of strength or will power is involved, but the issues of ethical subjectivity and moral identity involved are too complex to fit within the current paper.

2) Family members never want to give up hope of cure. They always want something done for the patient that is working for a cure (usually this is local medicine). Acceptance of imminent death can and does occur, despite the continuation of local medicines targeted to cure the disease.

3) Autopsies are culturally unacceptable.

4) Never speak the name of the dead. “To discuss death, you are calling upon death.”

5) Local medicine is almost always being given, regardless whether the patient is at the hospital or at home. Local medicine practitioners generally hold much better rapport with the patient and their families than do western trained physicians.

6) Yapese both on Wa‘ab and on Outer Islands would prefer to die at home.

7) A good death occurs when one dies having met obligations, fulfilled responsibilities, and resolved disputes. A quick death is not always a good death.

8) There are active systems of traditional palliative care in Yap. These traditional systems include respite care, hygiene practices, feeding, and even estate planning.

9) A residential palliative care facility such as a hospice house would be inappropriate for Yap, as it would indicate that the family is not meeting their obligations to their loved one. This point was agreed upon in every group despite awareness of situations of neglect in which families were unable to meet those obligations.

10) Yap has a very complex system regulating actions after a person’s death. This includes notification of the death, funerals, and dividing the estate. Systems vary significantly between the different cultures of Yap. New disputes tend to arise after the funeral, criticizing the way the dead was prepared, the way people were notified, that people who thought they should be involved were left out.

**Discussion**

Although caution must be exercised not to undermine the existing system, six recommendations on how the health system can intervene can be identified.

1) A key resource person should be identified, most likely a member of the Outer Island dispensary staff or the Wa‘ab Community Health Centers, to receive basic palliative care training. These individuals can then show families the safest and most suitable ways to care for the dying; particular instruction should include how to move the patient safely, how to prevent falls, wound care, bathing, hygiene, how to feed the patient, and help the patient sit up, simple methods that might relieve breathing difficulties or swallowing difficulties, and discuss ways to address dehydration, constipation, and incontinence. Laminated flip-charts would be suitable to teach local families basic care procedures.

This effort will require a glossary of appropriate words to be prepared, given, for example, that there is no local word for “incontinence” or “constipation,” and that the same word is used not only for dementia and delirium but also for schizophrenia, psychosis, and other mental conditions, simply meaning “crazy.”

2) If possible, a small, practical “comfort care” kit should be assembled and given to the families when they receive the training outlined above. This kit could include very basic supplies such as a bar of soap, a towel and wash cloth, a razor, reusable pampers, rubber gloves, a sheet, hydrogen peroxide, and chlorine bleach to disinfect bedding. Gradually, if resources permit, it might be possible to expand these basic supplies to include a set of more durable equipment, including a bed, walking cane, wheelchair, commode, but the reuse of these items might be problematic. Now that the hospital in Yap is manufacturing oxygen, it may be possible to have oxygen available on the Outer Islands, and this should be included in planning.
(3) Somehow, pain medication must be made available to those dying at home, but Yap’s health services will have to decide the most practical way to address this serious need. With the morphine supply at Yap hospital sometimes running out, and none available on the Outer Islands, the timely supplying and stocking of pharmaceutical supplies throughout Yap still needs to be improved.

(4) Regular home visits, such as those conducted by physicians from the CHCs for the mentally ill, should be instituted, with families fully informed of their availability, for the terminally ill, which could address issues of dehydration, delirium, breathing difficulties, and other palliative care issues requiring more than the family’s basic intervention. This could be combined with the practical at home teaching suggested above.

(5) Doctor-patient, doctor-family communication and communication between all members of the health team, especially doctors and nurses, with patients and their families, needs to be improved urgently. Outer islanders invariably reported unsatisfactory visits to Yap Memorial Hospital, with poor communication clearly the source of much of the dissatisfaction. Elders in Yap with long experience with the hospital also report that the situation is deteriorating. With the one remaining Yapese doctor at the hospital preparing to move to the CHCs, this problem may require more than additional training of staff. Yap Hospital may need to designate persons fluent in Yapese, Ulithian, Woleaian, and Satawalese to be responsible for communicating with patients (not just the terminally ill) and their families, as a first step to addressing this worsening situation.

(6) Suicide Intervention. An expert such as Fr. Fran Hezel should be contacted to assess whether there are ways to design culturally appropriate workshops on suicide prevention and on family counseling following suicides, as deaths from the pandemic of suicide continues to plague Yap. Again, a glossary of terms used to speak of “suicide,” for which there is no single one-word translation in any of the four local languages, might be a useful first step to prepare for such a workshop. It is noteworthy that the absence of a single term for suicide (as affirmed by the co-authors of this paper), unlike in Chuukese or Pohnpeian, suggests that suicide may be a more recent phenomena in Yap than in other parts of Micronesia.

Given that Yap has 22 inhabited outer islands whose inhabitants speak three distinct languages (Ulithian, Woleaian, and Satawalese) with many dialects, and given that both contemporary and traditional attitudes, beliefs, and practices vary enormously from island to island, an effort should be made to extend this project to the 18 islands our research team was unable to visit. A sample of interviews of individuals from Ifaluk, Elato, and Lamotrek confirms this variation and it needs to be thoroughly documented.

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References

Local Food Policies Can Help Promote Local Foods and Improve Health: A Case Study from the Federated States of Micronesia

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Abstract
The Federated States of Micronesia (FSM) and other countries throughout the Pacific are facing an epidemic of non-communicable disease health problems. These are directly related to the increased consumption of unhealthy imported processed foods, the neglect of traditional food systems, and lifestyle changes, including decreased physical activity. The FSM faces the double burden of malnutrition with both non-communicable diseases and micronutrient deficiencies, including vitamin A deficiency and anemia. To help increase the use of traditional island foods and improve health, the Island Food Community of Pohnpei has initiated a program in the FSM to support and promote local food policies, along with its Go Local awareness campaign. Such local food policies are defined broadly and include individual and family commitments, community group local food policies and policies established by government, including presidential proclamations and increased taxation on soft drinks. The aim of this paper is to describe this work. An inter-agency, community- and research-based, participatory and media approach was used. Partners are both non-governmental and governmental. The use of continuing awareness work along with local food policy establishment and the acknowledgement of the individuals and groups involved are essential. The work is still in the preliminary stage but ad hoc examples show that this approach has had success in increased awareness on health issues and improving dietary intake on both an individual and group basis. This indicates that further use of local food policies could have an instrumental impact in FSM as well as other Pacific Island countries in promoting local foods and improving dietary intake and health, including the control of non-communicable diseases and other dietary-related health problems.

Introduction
The Federated States of Micronesia (FSM), as well as throughout the Pacific, is experiencing an epidemic of non-communicable diseases, including diabetes, heart disease, and cancer.\(^1-3\) One in three Pohnpei adults is now diabetic.\(^2\) In addition, the FSM has serious problems of vitamin A deficiency and anemia.\(^1-3\) Over half of FSM children suffer from vitamin A deficiency.\(^3\)

The major contributing factors to this situation are lifestyle changes, including less physical activity; the growing trend towards the consumption of imported refined foods; such as white rice, flour, sugar, fatty meats, and other imported processed foods and the neglect of the traditional food system, including the physical activity involved in growing, harvesting, preparing, and consuming local island food.\(^3\)

Many people have indicated that there is a misperception held by many people that local food, in particular, the local staples of breadfruit, taro, and banana, are “just starch” and that this is related to the shift to turning away from local food. However, local food is not just starch. For example, giant swamp taro, Cyrtosperma merkusii, is rich in fiber, which protects against diabetes; and provides essential minerals, including calcium for building bones and teeth, iron for building strong blood, and zinc for fighting infection; and essential vitamins. Recent studies on FSM giant swamp taro show that there are many yellow-fleshed varieties that are particularly rich in provitamin A carotenoids, as well as essential minerals.\(^4,5\) The studies on the yellow-fleshed banana varieties are also rich in provitamin A carotenoids, and special mention is made of Utin Iap and Karat, which were once neglected but after the promotion of their nutrient content are now being revived.\(^4,5\)

Due to the urgency of the situation in the region, the Pacific Island Health Officers Organization (PIHOA) has proclaimed a Regional State of Health Emergency due to the epidemic of non-communicable diseases in the United States-affiliated Pacific Islands.\(^6\)

In order to help address the problems in Pohnpei and promote local foods, the Island Food Community of Pohnpei (IFCP) was founded in 2003\(^6\)and chartered in 2004. In 2005, it initiated a campaign known as “Let’s go local!” a campaign to promote local island food for their “CHEEF” benefits: Culture, Health, Environment, Economics, and Food security.

As part of a global health program led by the Centre for Indigenous Peoples’ Nutrition and Environment (CINE), the IFCP carried out a successful intervention promoting island food.\(^8\) At the end of a two-year intervention in the target community, Mand of Madolenihmw Municipality, the community’s diets showed significant improvements along with a positive change of attitude toward local food in the community.\(^8\)

Although the major part of this campaign started in 2004 with the establishment of the Island Food Community of Pohnpei, the work started in 1998 after the analysis of Karat, other bananas and giant swamp taro. The Micronesian community became excited about the results of these analyses, which showed how rich they were in nutrient content. It is estimated that over 50,000 people have been reached through this campaign since that time, through newspaper, radio, television, video, email, workshops, poster campaigns, and face-to-face encounters. Many of these people were also reached many times through different methods and media.

Awareness has been a major thrust of this campaign, but the IFCP also focuses on local food policies as another powerful tool to help increase the use of local food and increase physical activity. The aim of this paper is to describe this work and impact to date.

Methods
An inter-agency, community and research-based, participatory and media approach, using ethnography, is used as the cornerstone of all our work. A social ecologic approach\(^7\) was followed.

Many agencies, governmental and non-governmental, are involved in the planning and initiating local food policies, which helps provide support for the program as well as to expand it. The FSM National, as well as state government agencies were included, in particular those of health, education, agriculture, and resources and development. Non-government agencies included environmental groups, church, women and youth groups, as well as the private sector and businesses. Individuals from those agencies were selected as members of task forces, the IFCP board, and carrying out projects for promoting local food production and consumption. Individuals and institutions were recruited for membership in the Island Food Community of Pohnpei.
Working with communities is a particular focus. Research is used to analyzing local foods to establish the values of their nutrient content, and the scientific justification of their value towards health contributions. Also research is used in assessing community dietary and nutrition status for project evaluation. Data on process indicators are collected regularly for assessment of progress on local food policy establishment and maintenance. Such process indicators include, number of newspaper articles published, number of radio press releases broadcast, number of Island Foods GO LOCAL Email network messages and number of members receiving these emails, number of workshops and school visits held, number of films made and times shown on local television, and number of participants. Ad hoc quotes are collected from community members as to their impressions of local food, barriers to promoting these foods as well as successes in promoting these. Data on dietary intake are collected by use of a 7-day food frequency questionnaire, designed and tested for use in Micronesia, in community surveys. These surveys also collect information on varieties of food crops planted and knowledge of local foods, their nutrient content, and health. These data are used for baseline information and evaluation of project impact.

A participatory approach is used in initiating the idea of local food policies, involving people in the planning process, thereby increasing support. The media, including radio, newspaper, email, and newsletters, are used in sharing about the news of local food policies, acknowledging those who establish such policies, giving the idea to others, and helping the idea of local food policies to spread. The ethnographic approach, including interviews, informal focus group discussions, observation, literature review, and photography, is used to gain understanding of the situation and plan strategy more effectively.

Results
Local food policies have been established at the personal and family levels, community levels, and government levels. All are important and help to inspire other individuals and groups in establishing such policies.

Personal and Family Level
Personal commitments to eating local food and stopping or limiting the consumption of imported foods have created awareness and sparked others to follow. Rice is imported and is mainly white non-enriched rice, low in fiber and other nutrients, but energy-dense and is thought to have contributed much to the non-communicable disease burden in FSM. A founding member of IFCP stated at the IFCP Foundation Meeting in 2003 that he had tried an experiment and had gone one year without eating rice, despite his desires for eating that food, and that this had had a positive impact in his family and community for promoting local food. His statement led another founding member and IFCP board member officer to stop eating rice for health reasons and to promote local foods. He said after he stopped eating rice, “Now I feel better.” After several years of eating this way, he was so moved when one of his grandchildren said that he also wanted to stop eating rice and to “go local.” As a testimony, he then brought his grandchild and five other family members to an IFCP board meeting so that the story could be told. IfcP board members were also moved and applauded this progress.

Another personal story was told in 2007 by a top Pohnpeian government leader during a government workshop at Pohnpei Agriculture where the topic of local food promotion was raised. He stated, “I too have a story to tell. I stopped eating rice myself, as long as I am on-island where I can get local food, and now I feel better.” He also told that two of his daughters followed him and stopped eating rice. He agreed that his story be reported in the local newspaper.

Community Level
At its very establishment in 2004, IFCP members agreed that only local foods would be served at IFCP events and this included the exclusion of rice. At that time, it was quite unusual to have a group event and not serve rice. Members brought forth questions as to whether people would complain. However, no one complained and members and guests often commented about how they looked forward to the IFCP meals with totally local foods. As for drinks, either drinking coconuts or water were served. Soft drinks were not accepted.

From 2005 to 2007, Mand Community took part in the CINE-supported global health project mentioned above and had many community meetings and workshops. At all the community meetings, only local dishes were served. Community members were warmly encouraged for bringing traditional dishes and there was strong feedback from the community that they enjoyed these foods. A film was made of traditional foods and Mand Community members gathered together to demonstrate making traditional mahr (fermented breadfruit) recipes using a traditional umu (oven) and other local traditional delicacies.

In 2010, three communities established bans on using soft drinks at their community events. These included Mand Community in Madolenihmw, the Pingelap Peoples’ Organization, Inc, and the Kosrae Kolonia Congregational Church.

The leader of Mand Community joined a workshop in Thailand in 2009 on supporting traditional food systems and improving health as part of the CINE global health project. On his return to Pohnpei, he shared at an IFCP board meeting his personal belief that not enough is being done to promote local foods. Separately, he and the IFCP Research Advisor discussed about various actions that could be taken and the Research Advisor pointed out the evidence that the consumption of soft drinks has caused major health problems worldwide. Soft drinks contain no vitamins or minerals, and are the only food item that has been significantly associated with overweight. As soft drinks have basically nothing healthy to offer and are associated with overweight, they are a good item to avoid. The Mand Community leader decided that he would put the matter to his community and let them vote on it. Later he reported that the vote was unanimous in banning soft drinks from use in their community events. As he explained to others “we want our community to be healthy, so we don’t want to have our community consuming something that would keep us from being healthy.”

The news of Mand Community’s decision spread quickly, not only through the “coconut wireless” but also through the media as press releases were announced in the radio and newspaper. Following the decision by Mand Community, the Pingelapese Peoples’ Organization, Inc (PPOI), announced that it had decided to ban soft drinks from their events. This was also reported in the local media.
Another group, the Kosrae Kolonia Congregational Church, banned soft drinks from their church events in 2009. The pastor in charge there explained that he had asked church members to follow this practice in order to improve health and to provide a good example to their children. In 2011, the IFCP asked if the pastor would like to have a story on this for the newspaper and he wholeheartedly agreed. He said, “Wouldn’t it be great if the other churches would follow?”

**Government Level**

In 2005 Karat was proclaimed as the Pohnpei State Banana, based on its traditional value and exceptionally rich nutrient content. As the banana has been neglected in recent years, this gave it important prestige and is an example of how a government proclamation can serve to promote local foods. This was a Pohnpei State Government Proclamation, signed by Governor David in 2005.17

A bold step was taken in 2010 with the FSM Department of Health and Social Affairs banning all imported foods from their offices. The FSM Secretary of this department pointed out that people can still leave the office to eat such foods outside but that their office should lead in setting the example for healthy eating and thus should not allow imported foods in the office. The information was shared first informally and later the story was released in the Go Local Email Network18 and local newspaper.19

A powerful step was also taken on June 7, 2010, with the FSM President encouraging the use of local food at all FSM Government events in a Presidential Proclamation.20 The policy included this statement:

“Now therefore, I proclaim that the National Government of the Federated States of Micronesia is committed to a policy that encourages enhanced local food production, consumption of local produces and import substitution to the fullest extent possible, and practices based upon sustainable use of food resources. In all government events and festivities and official ceremonies, utilization of local food is encouraged to create people’s awareness on the continuing need to adopt a healthy and balanced lifestyle. All the departments and agencies in the National Government are to give effect to this mandate.

The discussions for this started as part of the discussions of the World Food Day activities in 2009 and continued during the discussion in preparation for the FSM Food Summit in 2010. The FSM Department of Resources and Development carried out the final follow-up with the FSM President’s Office to finalize the proclamation.

Another government level type policy is that of increasing import taxes on food items. The IFCP and a small working group with members representing the FSM State and National health government agreed to focus on increasing the import tax on soft drinks. Other Pacific Island nations already had established such taxes and the outcomes had been positive toward health improvement.21

There are two good reasons for increasing taxes on soft drinks: firstly, such a tax could decrease soft drink consumption and lead to health improvements and secondly, the revenue from such a tax could generate revenue for health improvement programs.22 The IFCP led efforts on this, along with staff from the FSM Department of Health and Social Affairs and Pohnpei State Department of Health. Discussions were initiated informally with the Pohnpei State Lieutenant Governor at the FSM Food Summit about the possibility and he was in favor of the step. A formal letter was then submitted to him with the scientific information regarding the health problems associated with soft drink consumption. The information was forwarded to the Pohnpei Attorney General’s Office, which then wrote the bill to be submitted to the State Legislature. At the time of writing this paper, the bill has been developed but is still being considered by the Legislature. Public talks have been made to point out the importance of this for health improvements. It is stressed that if the price of soft drink is considerably more than the price of a coconut, then there would be a greater incentive for purchase of drinking coconuts.

**Lessons Learned So Far**

A number of lessons have been learned so far. In order to establish local food policies, a certain level of awareness is first needed in order to motivate the initiation of policies. For example, it was learned that many people did not know about the nutritional values of local food, especially giant swamp taro. People have been using it to feed their pigs. However, on learning of its nutritional values, they indicated that they will start eating it and feeding it to their families.

One lesson learned related to raising awareness was that a community- and inter-agency-based approach is important. Another was “Walking the Talk”: if workshops are held to promote local foods and health, it is essential to serve local foods, and not to present a “mixed message” by serving imported foods. Repetition cannot be underestimated: messages needed to be repeated many times. Mass media (radio, newspaper, email, videos, television) help in reaching many people at one time and also in repeating messages, as these are often sent multiple times.

Our slogans “Let’s go Local” and “Go Yellow” (for the yellow-fleshed nutrient-rich varieties) helped our awareness campaign greatly, providing branding and unity. Social marketing tools, such as promotional Go Local pens, pencils, t-shirts, stickers, posters, brochures, and newsletters, were very useful in capturing attention and passing on messages. Face to face encounters were also important in creating awareness. Community people wanted scientific findings on their own local foods. Food analysis was critical to establishing the nutrient content and value of local food. Assessment and evaluation of the work was important to show progress. Finally, but not at all the least, frequent acknowledgement of individual and agency involvement increased motivation and interest.

**Conclusions**

Personal and family commitments to local food, as well as community and government and non-government level food policies can all have important impact to promoting local food. One such policy can “spread” by motivating another group to follow the same direction and also adopt a similar policy. Awareness of the importance of the commitment or policy is needed. Use of the media, including radio, newspaper and email, are also essential in spreading the news, helping motivate the development of further policies, providing acknowledgements, and motivating groups to keep up with their good work. This case study in the Federated States of Micronesia could provide insight for similar work in other Pacific Island countries with similar health problems.
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Needs and Experiences of Samoan Breast Cancer Survivors in Southern California

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Abstract
Objective: Breast cancer rates are increasing among Samoan and other Pacific Islander women, yet studies of their social support needs are nearly non-existent. The purpose of this paper is to report on the cultural dimensions of social support among Samoan breast cancer survivors in Southern California.

Methods: Data for this paper came from a larger one-and-a-half year study of the social support needs of Samoan breast cancer survivors and their family and friends. In-depth, retrospective, qualitative interviews were conducted with a purposive sample of 20 Samoan survivors who were recruited from an existing social support program as well as the general community.

Results: We documented important informational needs and behaviors, social support needs and experiences, and spirituality issues for the Samoan breast cancer survivors.

Conclusions: Our findings underscore the need for culturally-specific social support services for Samoans, as well as the necessity of community-based participatory research to define and explore social support and other survivorship needs in this understudied population. Recommendations from the community report-back, stressed the importance of expanding community Samoan cancer social support groups through collaborations with Samoan leaders and churches.

Introduction
There are an estimated 9.8 million cancer survivors in the United States, approximately 2.2 million (22%) of whom are breast cancer survivors.1 The psychosocial needs of breast cancer patients and survivors are well-documented in the literature.2,3 Unfortunately, little research exists on the needs of ethnically diverse women with breast cancer, many of whom have unique fears relating to family and caregiving, coping, and spirituality.4,5 One significantly unstudied population in cancer survivorship is Samoan Americans. Of the nearly half a million Pacific Islanders (PIs) in the United States, Samoans comprise the second largest population after Native Hawaiians. In 2004 there were 60,520 Samoans living in the United States, over 80% of whom resided in California.6,7 Breast cancer is the leading site for cancer among Samoan women in California, comprising approximately 27% of cancer cases.8 Both national and local data suggest that PI breast cancer rates are increasing, and that the cancers are found at later stages of diagnosis compared to white women.9,10 Studies of the psychosocial needs of Samoan breast cancer survivors, however, are nonexistent. The purpose of this paper is to describe the findings from an exploratory study of the social support needs and experiences of Samoan breast cancer survivors in Southern California.

Methods
Partnership
Data for this paper come from a larger 1.5 year, cross-sectional retrospective study of breast cancer experiences among Samoan survivors, and their family and friends, in Southern California.11 We engaged in a community-based participatory research effort between two entities: the Samoan National Nurses Association (SNNA) and the California State University, Fullerton (CSUF). SNNA is a nonprofit organization founded in 1996 by a group of Samoan nurse professionals to promote health education and services, including monthly cancer social support groups, for the Samoan community. CSUF is a teaching university, and members of both SNNA and CSUF had successfully collaborated on two past CBPR efforts, with the principles and activities described in previous publications.12,13 In addition, a Community Advisory Board (CAB) comprised of eleven leaders (including ministers, social workers, health professionals, and breast cancer survivors) was convened by SNNA and met quarterly with community and academic researchers to inform, review, and approve all aspects of the study implementation and evaluation.

Participants
Eligibility for study participation included adults 18 years or older, of Samoan descent, and having been diagnosed with breast cancer and completed treatment for that cancer. We recruited 20 Samoan breast cancer survivors using stratified purposive sampling to include those who participated in SNNA’s monthly social support group program (n=10), and those who did not. The latter women were found through announcements of the study at outreach activities, through personal contacts (such as family, friends, and church members), and through community referrals. SNNA staff approached each woman individually to introduce the purpose of the study, and ask for their participation in one face-to-face interview; women who agreed were scheduled for an interview at a location convenient to the interviewee (usually the woman’s home).

Interview Questions
The interview guide was developed based upon existing literature and social support theory,14 as well as from consultation with experts in multiethnic breast cancer survivorship.2 Two focus groups (one with SNNA staff and the other with Samoan community leaders) were conducted with 13 individuals to explore their views about what topics (particularly cultural) should be included in the survivor interviews. Lastly, the CAB revised and approved the final interview guide, which included questions about needs during diagnosis, treatment, and post-treatment, as well as impacts on feelings of sexuality and body image, relationships with significant others, and spirituality/relationships with God and church. The guides were translated into Samoan by a bilingual nurse at SNNA, reviewed by one CAB member, and discrepancies were discussed and resolved by the two. Instruments and procedures were approved by an IRB at CSUF, and written informed consent (in English and Samoan) was obtained from each survivor prior to the start of the interview.

Procedures
Four bilingual SNNA staff, each of whom was born in Samoa and...
had over 20 years of clinical and community experience in the continental US, were recruited and trained by study research staff on qualitative interview methods. These training sessions were held over two days for a total of 8 hours, and covered how to put participants at ease, why and how to ask open-ended questions and probes, how to address issues such as reticence or distress, and how to obtain informed consent. Each interview was conducted in the language of preference of the survivor, tape recorded, and lasted approximately 2 hours. At the conclusion the survivor received a small monetary honorarium as a token of appreciation.

**Data Management and Analyses**

All interview recordings were transcribed and translated verbatim by the study team. A set of transcripts were read by the entire study staff, with major coding schemes developed during a total of five meetings with study staff and consultants. All transcripts were then analyzed by one researcher using Atlas.ti to identify and code emergent themes, with weekly meetings between the university researchers to refine codes and ensure appropriate application to the transcripts. Once preliminary analyses were complete, summaries were created and shared with study staff and CAB members for comments and reflections. A final report-back session was held with study participants and approximately 30 other community members at a local restaurant in order to obtain further feedback regarding study findings, generate overlooked areas for analysis, and discuss implications for future services.

**Results**

Of the 24 survivors who were invited to participate in this study, 20 agreed to participate for a response rate of 83.3%. As shown in Table 1, survivors were generally born in Samoa, married, and had a high school diploma or less. Some survivors told study staff that they felt a responsibility to participate because they belonged to a rare group of Samoan survivors and had an important story to tell. Several also shared with us that their life experiences did not adequately prepare them to deal with their breast cancers, and that through discussing their emotional experiences they would hopefully help themselves and others in the future.

**Informational Needs and Practices During Diagnosis and Treatment**

Many survivors discussed problems stemming from their perceived lack of education and familiarity with cancer. One survivor whose highest level of education was a high school diploma told her interviewer, “I didn’t go to school that taught anything about a woman’s body. So I think [breast cancer] happened because I didn’t take care of myself.” Survivors also talked about how little cancer is discussed in Samoa, and how they perceived it to be automatically fatal. One survivor shared, “I kept asking, what is cancer? Can anybody explain to me exactly what cancer is all about? I know for a fact that during that time back home, they never heard of cancer. But right here in America, there’s a lot of people that go through and die from cancer.”

For women diagnosed in Samoa, their lack of knowledge may be exacerbated by the lack of infrastructure to be screened and treated in a timely manner. A survivor shared her experience after being screened in Samoa: “[The doctor] did a biopsy and sent the speci\-men to Hawai‘i, and it was almost three months after the biopsy was done and I still hadn’t received a word from the doctor. And the next thing I know, the janitor from [the hospital] told me that I have breast cancer.” A few other survivors shared frustrations with getting information from their doctors. In one case, a survivor described that after having a negative experience with her doctor during diagnosis in the United States, she ran into a friend who also served as a nurse at the hospital. Luckily, the friend not only recommended a different doctor but was able to make an appointment for the woman to see him. These kinds of informal connections were commonly used among Samoan survivors to access information that influenced their diagnosis and treatment decisions.

Support groups play an important role, with many survivors crediting SNNA’s monthly cancer support group program for providing information during and after their treatment. For all of the women (n=10) who participated in SNNA’s support groups, being with people who were the same ethnicity is part of the benefit, as in the words of one younger, married survivor who said, “With my own I can kind of adjust and kind of weigh out some of the things

<table>
<thead>
<tr>
<th>Table 1. Demographic Characteristics of Samoan Survivors (N=20)</th>
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<tbody>
<tr>
<td><strong>Age</strong></td>
</tr>
<tr>
<td>30-49 years</td>
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<tr>
<td>50+ years</td>
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<tr>
<td><strong>Born in Samoa or American Samoa</strong></td>
</tr>
<tr>
<td>Born in Samoa</td>
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<tr>
<td><strong>Marital Status</strong></td>
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<tr>
<td>Married</td>
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<tr>
<td>Widowed/Divorced</td>
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<tr>
<td>Single</td>
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<tr>
<td><strong>Highest Level of Education Attained</strong></td>
</tr>
<tr>
<td>High school or less</td>
</tr>
<tr>
<td>Some college or more</td>
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<tr>
<td><strong>Health Insurance</strong></td>
</tr>
<tr>
<td>None</td>
</tr>
<tr>
<td>Private/Medicare</td>
</tr>
<tr>
<td>Medicaid</td>
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<tr>
<td><strong>Number of Children</strong></td>
</tr>
<tr>
<td>None</td>
</tr>
<tr>
<td>1-2</td>
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<tr>
<td>3+</td>
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<tr>
<td><strong>Years Since Diagnosis</strong></td>
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<tr>
<td>&lt; 5 years</td>
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<tr>
<td>6-10 years</td>
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<tr>
<td>11+ years</td>
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<tr>
<td><strong>Stage of Breast Cancer</strong></td>
</tr>
<tr>
<td>Early (Stage I or II)</td>
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<tr>
<td>Middle (Stage III)</td>
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<tr>
<td>Late (Stage IV)</td>
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<tr>
<td><strong>Social Support</strong></td>
</tr>
<tr>
<td>Member of SNNA’s cancer support group</td>
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<tr>
<td>Not a member of SNNA’s cancer support group</td>
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</table>
someone may say, versus being somewhere openly put on the spot. I think I am more comfortable here.” Additional benefits were the ability to talk about their treatment processes, and maintaining the motivation to follow-up with treatment regimens. For women who were not participants in the SNNA program (n=10), some still found support groups that helped them better understand their disease and treatment options. A younger divorced survivor described looking for information with her sister for more information by stating: “I found [the support group] through my medical team at Torrance Memorial. They referred me to a couple of cancer support groups and I studied, I read, I attended a lot of meetings and that’s how I found out a lot more and more about cancer and [now] understand it.” However, it appeared that fewer of these women relied on family members or friends for support, suggesting that they either did not need support or were unable to find needed support for their concerns. Younger survivors appeared to be more comfortable than older ones in using support groups, regardless of language spoken.

Traditional Samoan treatments were not widely used among the survivors. “My grandma … knew the best fofos (massage),” stated one relatively younger survivor. “But she…just told me to keep going to the doctor. She more or less told me that fofos is for something else and that ‘this kind of sickness is for you to go to the doctor. That’s what the doctor is for.’” According to another older survivor, Samoan treatments could also be harmful, stating, “I’m afraid the more they massage [the breast] when they manipulate the tissues so much, it kind of spreads [the cancer] around.” In only one case did the survivor use Samoan treatment, after receiving radiation for her early stage cancer.

Social Support Needs
Over three-quarters of the survivors talked about how losing their breast was not the major concern of theirs. According to a younger, married survivor diagnosed with stage IV breast cancer, “I told [the doctor] you took my breast away. I don’t really need it now, I can go without it. It doesn’t make me less of a woman than I am now, so fine.” Similarly, an older widow of four explained that she was less concerned about the cancer and more concerned about the loss of her hair. “You know, so I thought that’s the only way I can get on, get rid of this cancer. Then I was thinking, oh my God, when I have a surgery I’m going to have chemo. What will happen if my hair all falls out?” Only one younger Samoan survivor described the change of her breast appearance as important. According to her, “[The doctor said] oh you’re beautiful. But when I see myself in the mirror and I think about the things that I went through, I can’t see what is so beautiful. For me being alive is beautiful, but just the physical part is what I have to get over.”

Breast cancer influenced the ways that survivors were able to fulfill their roles as mothers and spouses. According to one widowed survivor, being a mother and attending her only child’s graduation was more important than getting immediate treatment for her stage III breast cancer. She shared, “I asked if we can postpone [the surgery] until after…my oldest son’s graduation. My brother said, ‘your surgery will be done and you will make it for your son’s graduation. The longer it will not be done the bigger it gets. We will schedule your surgery before the graduation and I promise you will go.’ So I said okay.” The survivors, however, discussed the need for assistance with routine chores such as doing the laundry, washing dishes and cooking meals became challenging for many because of the fatigue from chemotherapy. Many women shared that they were not prepared to adjust their life from being the major source of caretaking for the family, to being the one who needed support and care from spouses and children. Most appreciated it when others offered to help, although the survivors also recounted the burden they felt by imposing on others. Dealing with her stage IV cancer diagnosis soon after her husband’s death, this mother of nine said, “I went through all [with] the support of my children and I didn’t want to be a handicap to them, or like even going to my appointments, the doctor said I’m not to drive…but I managed to drive with my left hand. So this is how stubborn we are sometimes.”

Financial concerns were also important. Sixty percent of the survivors were working full-time when they were diagnosed with their breast cancers, and many shared the pressure they felt to go back to work in order to support their husbands, children, and / or larger community responsibilities. Women talked about how money was a stressor, often because they were an important source of financial support for their families. In the words of one middle-aged mother of two who felt comfortable sharing her financial problems: “[During treatment] I guess, I was going through a lot…and I was really kind of forced … back to work, cause at the time my family needed support from me work wise because now my husband was gone and financially that put us in a bind.”

Other important areas of assistance included language, transportation, and child care. For instance, several Samoan-speaking survivors relied on family to interpret with doctors. As briefly stated by one Samoa-born survivor of stage III breast cancer, “I did not fully understand what [the doctor] was telling me, but my daughter was the one I spoke to and she explained what the doctor was telling me.” Similarly, survivors described spouses and older children as taking care of younger ones, with distance (eg, in the case of the survivor who was diagnosed in Samoa but received treatment in Hawai‘i) posing an added challenge.

As we expected, survivors experienced many different kinds of emotions throughout their diagnosis and treatment processes, including depression associated with the fear of dying (during diagnosis) and fear of recurrence (after treatment was completed). In addition, some women described the strain breast cancer treatment put on their relationships with their family members. In the case of a young married woman who lived with her parents and other siblings: “I had this one cousin who…was there to advise my parents on things that they can help me. Because, you know, we as Samoans, [parents] sometimes kind of talk down to you, and say ‘maybe you shouldn’t have done that,’ or ‘if you would have listened.’ But they didn’t do that, because they were advised by my cousin who was close to me at the time. She talked to them, and so we had a [positive] time because my parents were understanding, and they knew what I was going through.”

Another problem a few survivors discussed was the influence of breast cancer on their relationships with their spouses. The younger survivor, who thought her spouse felt guilty when they had sex, stated, “For a while he thought he did something that caused me to get cancer. I said ‘no, I don’t think so,’ but it changed a lot. Our intimacy with each other wasn’t the same… it felt different. He was afraid he might hurt me or something.”
Social Support Experience
With regards to who helped the survivors cope with their many stressors, the Samoan survivors we interviewed talked at length about the emotional support they received from their family members. Most often, survivors told only their spouses or children about their diagnoses and treatments, and these family members helped the survivors cope. “I feel my family should know about it. I need them to pray for me.” Not all family and community members, however, were able to provide the support that the survivors wanted. In the case of many who lived in Samoa, breast cancer treatment meant traveling and living abroad for extended periods of time apart from their families. She said, “I was lonely because my husband was in Samoa and only my kids were here. Every time he called from Samoa I get home sick; it was really hard to stay here and go through all this without my spouse…. Of course my kids were here but it wasn’t the same.” In another survivor’s case, the spouse was with her but was not as supportive. She shared, “Because I was trying to get comfortable with the whole idea of the way that I look underneath…. I just kind of felt uncomfortable. And then, for me when I look at him, he felt uncomfortable. We never talked about it…. I wish there was somebody that can talk to us.”

A few survivors, however, believed that strong Samoan women should be self-reliant and take care of themselves, including cancer. In one Samoan-born survivor’s words, “I didn’t feel like I needed somebody, even my kids…. I’ll be strong enough to do my own things, you know, in order for me to have somebody help me out or anything like that.” Part of the reason was because women did not want to burden others with their own problems. According to the survivor who had previously described her role as the family breadwinner, “I don’t want no one to think, ‘Oh I need to go and help her do this, do that,’ I don’t want that. I don’t want no one. I don’t want to burden.” Some believed that their cancer was a private matter that others should not know. According to one survivor, this meant not telling her family: “It was my decision to remove my breast and I didn’t even think about telling my daughter or kids.” None of the women who described the desire to be self-reliant shared any depressive thoughts or feelings during their diagnosis or treatment experiences, suggesting that the cultural value of self-sufficiency may be viewed as a cultural asset rather than a negative coping mechanism for women.

Spirituality
All of the survivors referred to spiritual strength throughout their cancer experiences. For some, the spirituality helped them to find meaning and reason for what was happening to them. “I was strong and fearless because I wanted to live for my kids and use my life for Christ.” For others, spirituality helped them cope with the challenges they faced. For instance, a young woman expressed how she dealt with her diagnosis of stage III breast cancer: “My courage came from God. That’s basically what helped me through a lot of different obstacles I was going through, is the courage to let go and you know there were just things you can’t fix.” Spiritual strength came not only from the survivor’s prayers, but also from feeling the support from their family and friends. According to an older, widowed survivor, “The most helpful thing to me…was my children’s prayer and support for me. You know, because all these things, my surgery and everything, there’s no one [else in] my fam-
ily [who] knows about it.” A previous publication describes these results in more depth.11

Conclusion
This was the first study to explore and document the social support needs and experiences of Samoan breast cancer survivors. First, we found a lack of knowledge regarding cancer in the Samoan community, particularly among women who were more recent immigrants from Samoa, which has been previously described among the general Samoan population in the past.15 Clearly, however, the need for information becomes paramount for women faced with making crucial treatment decisions without understanding the basics of breast cancer disease and progression, and we found evidence that programs such as SNNA serve as trusted sources of needed information and assistance. Second, we found that many survivors prioritized their family roles and obligations many times over the timely receipt of treatment for themselves. In some cases, it was not until trusted sources (such as family and SNNA) underscored the importance of treatment in order for survivors to continue fulfilling their roles did they agree to be treated. While some women described the comfort they received from supportive spouses and/or children, some also described their desire to remain self-sufficient (often in order to remain the family care-taker rather than the care-receiver). Also, sexual issues of intimacy were discussed by several women, with younger age a possible indication of higher body and sexual intimacy needs. Lastly, spirituality was a source of support for all of our study participants, underscoring the important potential role the church plays for not only Samoans but many other ethnic populations.16 All of these themes point to the need for culturally appropriate and timely support from trusted family and community sources to minimize distress for future Samoan breast cancer patients.

In a community where breast cancer is a highly stigmatized disease, the fact that Samoan survivors shared the breadth and depth of their experiences regarding sensitive subjects was a testament to the CBPR process and the trust they felt toward the SNNA interviewers. Despite this significant study asset, however, we faced many challenges in planning and implementing the study design. Designing the questionnaire proved to be challenging due to the highly sensitive nature of discussing sexual relationships, and the CAB provided invaluable guidance on how to ask this of women in culturally appropriate ways. Another challenge was recruitment of a purposive sample of Samoan survivors, particularly the 10 women who did not participate in SNNA’s cancer support group, and the interviewers had to draw upon their considerable knowledge of the community in order to assure survivors of their privacy and confidentiality. Scheduling also proved a challenge, and the interviewers estimated that it took an average of four hours per survivor to contact, schedule, and conduct each interview in a private atmosphere. Lastly, we realize that our sample was biased toward survivors who could be called “thrivers,” since so many of them were long-term survivors who had successfully completed their treatments.

Despite these challenges and limitations, however, we feel very fortunate to have learned so much about the cultural dimensions of social support needs for Samoan survivors. For instance, at the community report-back session, both study participants and general community members expressed their overwhelming support for not only continuing SNNA’s cancer support groups, but expanding them
by working closely with Samoan churches and other community organizations. This may be particularly important for survivors who do not naturally become members of SNNA’s support group because of their own interests. In these cases, the churches can help promote the importance of support groups. For instance, the minister of a Samoan church recommended that church leaders make announcements to their congregations about the service and the need to support Samoan cancer survivors. Based upon this and other recommendations, study staff have proposed the creation of a community navigation program in collaboration with such organizations. We hope this study spurs more research on, and services for, survivorship among Samoans and other ethnic-specific populations.

The authors report no conflicts of interest.

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References

Cancer Mortality Following Polychlorinated Biphenyl (PCB) Contamination of a Guam Village

Robert L. Haddock DVM MPH; Grazyna Badowksi PhD; and Renata Bordallo MSW

Abstract
Beginning more than 10 years after the release of polychlorinated biphenyl (PCB) contamination in the favored fishing grounds of Merizo village, an increase in the proportional cancer mortality rate was observed among residents of the village. This increased rate continued for approximately 20 years after which it returned to near island-wide Guam levels. Although the temporal association between PCB contamination of the environment of this village and an increase in cancer mortality is intriguing, it does not necessarily demonstrate a cause and effect relationship.

Objective: To investigate a possible temporal relationship between PCB contamination of the Cocos Lagoon and cancer deaths in the adjoining village of Merizo.

Methods: Data utilized in the study included deaths recorded by the Guam Cancer Registry (years 2000 to 2007) and data collected from original death certificates (years 1968-1999). To check whether there was a significant difference in the proportion of deaths due to cancer in Merizo compared with the rest of Guam, deaths were grouped in four 10-year periods, 1968-1977, 1978-1987, 1988-1997, and 1998-2007, and the Pearson Chi-Square test was calculated for each period separately.

Results: While the number of new cancer cases recorded in the village of Merizo were insufficient in number to draw a statistically significant conclusion when single year incidence rates were compared to the rest of the island, a proportional mortality study showed a distinct increase for the village of Merizo compared to other villages for the period 1978-1997.

Conclusion: While it is not possible to conclude with certainty that PCB contamination of the Cocos Lagoon was responsible for the observed increase in the proportion of cancer deaths in Merizo village beginning during the 10-year period 1978-1987, that increase and the subsequent decrease as PCB levels also decreased presents the possibility that these trends may be related.

Introduction
In 1945 the United States Coast Guard (USCG) established a Long Range Navigation (LORAN) Station on Cocos Island, an islet of approximately 100 acres 2 miles off the southern tip of Guam and bordering an extensive lagoon which provides a favored fishing ground for nearby villagers. Soils on Cocos Island are predominantly well-drained coral sand deposited by wave action. Slightly more than a mile long and with an elevation of generally less than 10 ft., the island is highly susceptible to erosion due to wave action.

In 1962 Typhoon Karen destroyed the LORAN Station and spread its contents far and wide. In 1963 the site was declared surplus to military needs and returned to the Government of Guam for use as a public park. A study conducted in April 2005 during which island soil, lagoon sediment and lagoon biota samples were collected from the station site and near-shore waters found elevated concentrations of polychlorinated biphenyls (PCBs), lead and cadmium in soils and sediment samples collected from several discreet locations along the shoreline adjacent to the former LORAN Station. PCB concentrations exceeding the EPA Residential Preliminary Remediation Goal (PRG) of 0.22 milligrams per kilogram (mg/kg) were found in six surface soil samples. Concentrations ranging from 0.23 to 1,080 mg/kg were found in lagoon sediment samples, and five subsurface soil samples contained concentrations ranging from 0.25 to 29.65 mg/kg. Biota samples collected included 12 commonly consumed fish. Eleven of the 12 samples had PCB levels in excess of the EPA Recommended Screening Value for Recreational Fishers of 0.02 mg/kg (concentrations ranged from 0.06 to 5.3 mg/kg). The sampling also detected concentrations of lead exceeding the EPA Residential PRG of 400 mg/kg in three island surface samples, with concentrations ranging from 466 to 2,120 mg/kg. Cadmium concentrations exceeded the PRG of 37 mg/kg in a single surface sample (concentration of 136 mg/kg). Unfortunately no previous testing had been conducted so it is not possible to say with certainty whether this contamination occurred as a result of Typhoon Karen or earlier activities at the site. During 2007 almost 400 cubic yards of soil from the most heavily contaminated island areas were removed and shipped to an EPA-approved toxic waste disposal site in Beatty, Nevada and by 2010 PCB levels in fish samples had been much reduced from a mean of 10,000.35 µg/kg in 2005 to 245.32 µg/kg in 2010.

Methods
To examine the hypothesis that cancer mortality rates among Merizo villagers were influenced by the presence of PCB contamination in their environment, deaths due to cancer and to all other causes for Merizo and all other villages were grouped in four 10-year periods (1968-1977, 1978-1987, 1988-1997, and 1998-2007) and the Pearson Chi-Square test was calculated for each period separately. To compare the risk of dying due to cancer in Merizo with the rest of Guam, the odds ratio together with 95% confidence intervals were calculated. All analysis was done using PASW Statistics 18 software.

Results
In the years 1968-2007 there were 21, 292 total deaths on Guam. The cause of each death was categorized as due to a cancer, or non-cancer, ie, other. Our purpose was to determine whether there was a significant difference in the proportion of deaths due to cancer in Merizo compared with the rest of Guam in the years after the hurricane. Since Merizo is a small village with a small population (2,163 in the year 2000 census), it was impossible to compare the proportions annually. For the statistical test to have sufficient power to be able to detect a difference but still allow us to see changes occurring over time, the data were grouped in four 10-year periods: 1968-1977, 1978-1987, 1988-1997, and 1998-2007, and Pearson Chi-Square test was calculated for each period separately.

The counts together with percentages are in the Table 1. We can see that in the years 1968 to 1977, Merizo and the rest of Guam had almost the same proportion of deaths due to cancer, 9% and 9.4% respectively. However, in the following twenty-year period the proportion of deaths due to cancer was significantly higher in Merizo; 23.7% in Merizo versus 14.1% for the rest of Guam in the years 1978 to 1987, and 27% in Merizo versus 16.7% for the rest of Guam in the years 1988-1997. P-values for Pearson Chi-Square tests
Table 1. Cross-tabulation for Village Cause of Death by 10-year Periods

<table>
<thead>
<tr>
<th>Years</th>
<th>Village</th>
<th>Merizo</th>
<th>Count</th>
<th>Cancer</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1968-1977</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>7</td>
<td>71</td>
<td>78</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>% within Village</td>
<td>9.0%</td>
<td>91.0%</td>
<td>100.0%</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td></td>
<td></td>
<td>375</td>
<td>3624</td>
<td>3999</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>% within Village</td>
<td>9.4%</td>
<td>90.6%</td>
<td>100.0%</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td></td>
<td></td>
<td>382</td>
<td>3695</td>
<td>4077</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>% within Village</td>
<td>9.4%</td>
<td>90.6%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>1978-1987</th>
<th>Village</th>
<th>Merizo</th>
<th>Count</th>
<th>Cancer</th>
<th>Other</th>
<th>Total</th>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>23</td>
<td>74</td>
<td>97</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>% within Village</td>
<td>23.7%</td>
<td>76.3%</td>
<td>100.0%</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td></td>
<td></td>
<td>602</td>
<td>3663</td>
<td>4265</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>% within Village</td>
<td>14.1%</td>
<td>85.9%</td>
<td>100.0%</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td></td>
<td></td>
<td>625</td>
<td>3737</td>
<td>4362</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>% within Village</td>
<td>14.3%</td>
<td>85.7%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>1988-1997</th>
<th>Village</th>
<th>Merizo</th>
<th>Count</th>
<th>Cancer</th>
<th>Other</th>
<th>Total</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>34</td>
<td>92</td>
<td>126</td>
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<tr>
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<td></td>
<td></td>
<td>% within Village</td>
<td>27.0%</td>
<td>73.0%</td>
<td>100.0%</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td></td>
<td></td>
<td>959</td>
<td>4796</td>
<td>5755</td>
</tr>
<tr>
<td></td>
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<td>% within Village</td>
<td>16.7%</td>
<td>83.3%</td>
<td>100.0%</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td></td>
<td></td>
<td>993</td>
<td>4888</td>
<td>5881</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>% within Village</td>
<td>16.9%</td>
<td>83.1%</td>
<td>100.0%</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>1998-2007</th>
<th>Village</th>
<th>Merizo</th>
<th>Count</th>
<th>Cancer</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>30</td>
<td>112</td>
<td>142</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>% within Village</td>
<td>21.1%</td>
<td>78.9%</td>
<td>100.0%</td>
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<tr>
<td></td>
<td>Other</td>
<td></td>
<td></td>
<td>1358</td>
<td>5472</td>
<td>6830</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>% within Village</td>
<td>19.9%</td>
<td>80.1%</td>
<td>100.0%</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td></td>
<td></td>
<td>1388</td>
<td>5584</td>
<td>6972</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>% within Village</td>
<td>19.9%</td>
<td>80.1%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Table 2. Risk Estimate for Cancer Mortality, Merizo and All Other Guam Villages

<table>
<thead>
<tr>
<th>Years</th>
<th>Value</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>1968-1977</td>
<td>Odds Ratio for Village (Merizo / Other)</td>
<td>.953</td>
</tr>
<tr>
<td>1978-1987</td>
<td>Odds Ratio for Village (Merizo / Other)</td>
<td>1.891</td>
</tr>
<tr>
<td>1988-1997</td>
<td>Odds Ratio for Village (Merizo / Other)</td>
<td>1.848</td>
</tr>
<tr>
<td>1998-2007</td>
<td>Odds Ratio for Village (Merizo / Other)</td>
<td>1.079</td>
</tr>
</tbody>
</table>

Discussion

The establishment of the Guam Cancer Registry was authorized by law in 1998 and after that date health care providers were required to provide cancer incidence data. Prior to that date, however, reliable cancer information was accessed primarily from death certificates. For this reason this longitudinal study was restricted to using cancer mortality data.

While a 1962 typhoon was responsible for destroying the Cocos Island LORAN station and spreading contaminants throughout the Cocos Lagoon, subsequent severe typhoons in 1976 (Pamela), 1992 (Omar), 1997 (Paka), and 2002 (Chatta’an and Pongsona) may have resulted in the dispersal and dilution of this contamination. This may account for the fact that contamination levels were observed to have decreased substantially even before the remediation efforts of 2007. Even normal currents and wave action may play a part in dispersal of contaminants. It is worthy of note that PCB contamination has not been detected in sediment or aquatic life samples collected on the south side of Cocos Island which directly faces the Philippine Sea and is protected from wave action by only a narrow strip of barrier reef.

It is an unfortunate fact of life that today trace amounts of PCBs may be found almost everywhere there is human activity and some PCB contamination of the Cocos Lagoon may occur as run-off from the adjacent highway and associated businesses. Guam’s sanitary landfill, however, is some 25 miles distant and impacts a drainage area on the opposite side of the island.
The migration of neighbor-island residents to Guam, particularly if they were from the areas downwind of the American atomic bomb tests of the 1950s-1960s (especially the Republic of the Marshall Islands and the Federated States of Micronesia), might be suspected as a cause of increased cancer rates on Guam but none of the 87 cancer deaths among Merizo residents diagnosed between 1978 and 2007 were from these areas (79 were Guam Chamorros, 3 were Filipino and 5 were Caucasian).

Although this study does not conclusively link PCB contamination of Cocos Lagoon to an increase in cancer mortality among the residents of Merizo, the temporal relationship is intriguing and certainly justified public health concerns and the effort to mitigate this environmental hazard. It is also of interest to note that in the analysis of historical mortality data it was observed that the proportion of deaths due to cancer for all Guam rose significantly from 9.4% in 1968-1977 to 19.9% in 1998-2007 (Figure 2). While this trend deserves further study, it may be related to a decrease in the number of island deaths caused by infectious diseases and an increase or stable number of deaths due to non-infectious chronic diseases including cancer.

**Disclosures**

No conflicts of interest are reported by the authors.

**Acknowledgment**

The Guam Cancer Registry is a joint activity of the University of Guam and the Guam Department of Public Health and Social Services and is supported by NIH grant no. 5 U54 CA143728-02.
Higher Percent Body Fat in Young Women with Lower Physical Activity Level and Greater Proportion Pacific Islander Ancestry

Nate Black MS; Vanessa Nabokov MS; Vinutha Vijayadeva PhD, MPH; and Rachel Novotny PhD, RD

Abstract
Samoan women exhibit high rates of obesity, which can possibly be attenuated through diet and physical activity. Obesity, and body fatness in particular, is associated with increased risk for chronic diseases. Ancestry, physical activity, and dietary patterns have been associated with body composition. Using a cross-sectional design, the relative importance of proportion of Pacific Islander (PI) ancestry, level of physical activity, and macronutrients among healthy women in Honolulu, Hawai‘i, ages 18 to 28 years was examined. All data were collected between January 2003 and December 2004. Percent body fat (%BF) was determined by whole body dual energy x-ray absorptiometry (DXA). Nutrient data were derived from a three-day food record. Means and standard deviations were computed for all variables of interest. Bivariate correlation analysis was used to determine correlates of %BF. Multiple regression analysis was used to determine relative contribution of variables significantly associated with %BF. Proportion of PI ancestry was significantly positively associated with %BF (P=0.0001). Physical activity level was significantly negatively associated with %BF (P=0.0006). Intervention to increase physical activity level of young Samoan women may be effective to decrease body fat and improve health. CRC-NIH grant: 0216.

Introduction
Pacific Islanders (PI) in the United States are a high risk population for lifestyle-related chronic diseases due to high prevalence of obesity and its sequelae. Indeed, the prevalence of obesity among one PI group living in Hawai‘i, Samoans, is among the highest in the world, and is associated with a possible genetic predisposition to obesity, modernization of diet, adoption of a cash economy, as well as sedentary lifestyle. In general, Samoan women exhibit higher rates of obesity than Samoan men, which is likely attributable to physical activity disparities associated with traditional gender roles rather than differences in diet patterns.

The severity of obesity in Samoan women can possibly be attenuated through diet and physical activity, especially through adherence to traditional diet and activity patterns. However, the majority of Samoans live in highly modernized areas of the Samoan islands and abroad, where traditional diet and activity patterns are being displaced. The effects of modernization on the traditional Samoan lifestyle are threefold: first, wage-earning Samoans have increasingly participated in the physically demanding traditional subsistence activities of farming, fishing, and hunting. Second, as a result of the first, consumption of traditional foods has decreased. Third, wages earned have been used to purchase non-traditional foods like rice, flour, and tinned meats. As more Samoans become modernized, it will be increasingly important to discover modern lifestyle characteristics (eg, diet and physical activity) which, through broader application, might attenuate the severity of obesity in Samoans distanced from their traditional lifestyle.

The objective of this study is to examine the relative importance of the proportion of PI ancestry, level of physical activity, and macronutrient intake to %BF among young Samoan women in Honolulu, Hawai‘i, between the ages of 18 to 28 years.

Methods
For this cross-sectional study, a convenience sample of 55 predominantly young Samoan women was recruited at university campuses in Honolulu, Hawai‘i. Data from 48 women (87%) who completed food records were included in this study. There were no significant differences in age, proportion of PI ancestry, height, weight, body mass index (BMI), %BF, or years of education between included and excluded women (data not shown). Participants were eligible for inclusion in the study if they were O‘ahu residents; women; between 18 to 28 years of age; a minimum of 50% Samoan ancestry; not pregnant or lactating; had body weight less than 300 lbs, which reflected the upper limit of the dual energy X-ray absorptiometry (DXA) equipment; and had no previous cardiovascular disease or diabetes diagnoses.

Written informed consent was obtained from each participant prior to testing. Permission to use human subjects was obtained from the Hawai‘i Pacific Health Institutional Review Board and from the Committee on the Use of Human Subjects at the University of Hawai‘i at Manoa.

Participants’ age and years of education completed were self-reported in whole years. Ancestry was determined using the BLEND method as previously reported. In short, participants’ ethnic proportions were computed as the summation of the reported biological parent’s ethnic proportions divided by two. Several PI ethnic groups were reported (Fijian, Hawaiian, Maori, Niuean, Samoan, Tokelauan, Tongan), and subsequently combined to yield one PI ethnic group, though the majority were predominantly Samoan. PI proportion was treated as a continuous variable in the regression model.

Height was measured in centimeters with a digital stadiometer (Measurement Concepts, North Bend, WA) and weight in kilograms with a digital scale (Seca, Hanover, MD) according to standard protocol. BMI was calculated as kilograms per meter squared (kg/m²).

Body composition was determined by whole body dual energy x-ray absorptiometry (DXA, GE Lunar Corporation, Madison, WI). Subjects were given pregnancy tests prior to DXA scanning (Accuchek, F. Hoffman-La Roche, Ltd., Basel, Switzerland; QuickVue, Quidel Corporation, San Diego, CA).

Nutrient data were derived from a three-day food record, consisting of one weekend day (Saturday) and two weekdays (Thursday and Friday), and analyzed using the Cancer Research Center of Hawai‘i food composition database. Measuring spoons and cups were provided for all participants to help assess the quantity of food eaten. During clinic visits, the study coordinator examined all diet records with participants to verify reporting accuracy. Total energy (kcal), carbohydrate (g/d), fat (g/d), protein (g/d), and fiber (g/d) were calculated as averages of the three days’ measures. Percent energy contributions of carbohydrate, fat, and protein were calculated as the dividend of mean energy from a given macronutrient and total energy times 100.
Physical Activity: Physical Activity Rating (PAR) was established using the National Aeronautics and Space Administration Physical Activity Rating Questionnaire (NASA PAR-Q), as previously described. The NASA PAR-Q is an eight-point scale used to describe participants’ current levels of physical activity, with 0 indicating the lowest level of activity and 7 the highest. The scale lists amounts, types, and intensities of physical activities to guide participants in selecting an appropriate number on the scale. In the present study, participants were instructed to indicate the level which most closely corresponded to their physical activity levels for the preceding four weeks, and the study coordinator was available to explain the scale instructions and questions for individual participants, if needed.

Statistical analysis: SAS System for Windows, version 9.0 (SAS Institute, Inc., Cary, NC) was used for all statistical analyses. Means and standard deviations were computed for all variables of interest. Bivariate correlation analyses were used to determine correlates of %BF. Multiple regression analysis was used to determine the relative contribution of variables influencing %BF. Variables considered in the multiple regression model included age, years of education, proportion of PI ancestry, PAR level, dietary energy, and mean intake of dietary carbohydrate, fat, protein, and dietary fiber.

### Results

On average, the women in this study were young, college-age adults, and of PI ancestry (predominantly Samoan, a Polynesian ethnic group), who had completed almost two years of college-level education. (Table 1)

According to the Centers for Disease Control and Prevention (CDC) and World Health Organization (WHO) BMI cut-off points, 21% of these women were overweight and 56% were obese. When considered in light of suggested Polynesian-specific BMI cut-off points 27% of these women were overweight (BMI range of 26-32 kg/m²) and 46% were obese (BMI > 32 kg/m²); however, they had an average percent body fat of 42.8 ± 6.8%, confirming a high level of body fatness.

On average, the women of this study were sedentary as indicated by a low PAR score (2.5 ± 2.1), which is equivalent to regular participation in recreation- or work-related moderate physical activities of a cumulative duration ranging from 10-60+ minutes per week.

The reported average percent of energy intake for carbohydrate (48.4 ± 7.7%) and for protein (13.9 ± 3.3%) fell within the Acceptable Macronutrient Distribution Ranges (AMDR) of 45% to 65% and 10% to 35%, respectively. Percent energy from fat (37.7 ± 6.4%), however, exceeded the AMDR range of 20% to 35%. Also, 20 of 48 of the women in this study did not meet the weight-based recommendation for protein for adults of 0.8 grams of protein per kilogram body mass per day (data not shown).

Of the variables considered in the bivariate correlation analysis, only PI ancestry and PAR were significantly correlated with %BF (r = 0.54, P < 0.0001 and r = -0.50, P = 0.0003, respectively). Age, years of education, dietary energy, and mean intake of dietary carbohydrate, fat, protein, and dietary fiber were not significantly correlated with %BF (data not shown) and so were not included in the final regression model.

The final regression model of correlates of %BF (Table 2) among these predominantly Samoan women accounted for 43% of the variance. The major limitation of this study was the low number of participants. However, despite this fact, both PI ancestry and PAR were significant correlates of %BF, suggesting a real effect, though the regression equation may be unstable and the variance (R²) somewhat overestimated.

### Discussion

The contribution of proportion PI ancestry in this sample of predominantly ethnic Samoan women had the largest impact on %BF prediction. An increase from 50% to 100% PI ancestry resulted in an increase of BF by 9.0 percentage points (data not shown). This contrasts with the findings of Brown and colleagues who reported that BMI and waist circumference were not correlated with a higher proportion of Hawaiian/PI ancestry in admixed, multiethnic populations, after controlling for educational attainment. However, Brown and colleagues’ measurements do not distinguish body fat and muscle.

This study also confirms the previous observation that modernized Samoan women are quite sedentary. Samoan women may attain their highest obesity rates when they couple sedentary traditional occupational activities with heavy involvement in a cash economy. However, cross-sectional research has shown an association between decreased severity of obesity in Samoans and regular physical activity and exercise, especially through traditional physical activities such as farming and gardening. Additionally, intervention studies are needed to establish the potential for obesity prevention and treatment through physical activity and exercise in this population.
suggest that physical activity coupled with nutrition intervention can halt weight gain in urbanized Samoan populations similar to the participants in the present study.  

In this study, physical activity level was significantly negatively associated with %BF, with a 1.3% decrease in %BF for every unit increase in PAR, indicating that among Samoan women living in Hawai‘i between the ages of 18 to 28 years, even a modest amount of regular physical activity may attenuate the severity of obesity. This is in agreement with the finding that young Samoan women in the independent nation of Samoa who participated regularly in physical activity in the form of traditional farm work exhibited lower BMI and %BF.  

The relationship was similar but did not reach significance in the corresponding group living in American Samoa. The use of a more objective measure of physical activity (eg, accelerometer, pedometer, doubly-labeled water) in conjunction with the subjective PAR would have provided a more accurate assessment of participants’ habitual physical activity and may have strengthened the negative association between physical activity and %BF.

Generally PI are leaner (more muscular) at any given BMI than Caucasians. Thus the use of %BF as measured by DXA and PI-specific BMI cut-off points allow for ethnic-specific interpretations of the findings of this study. The results of this study corroborate previous observations that Samoan women exhibit high rates of obesity, placing them at increased risk for obesity-related chronic diseases. It was previously reported that among the women of this study that the CDC/WHO BMI and waist circumference cut-off points were linearly related to blood glucose, cholesterol, and lipid values, and were predictive of blood glucose and lipid levels associated with increased risk for chronic diseases. Thus, despite the existence of Polynesian-specific BMI cut-off points, the CDC/WHO BMI cut-off points may still be useful in assessing the risks of diseases among this population of young, predominantly Samoan women.

There was no association of mean energy intake with predicted %BF, corresponding to the observation of Bindon and colleagues that previous studies of Samoans have failed to show an association between obesity and energy intake. However, as Galanis and colleagues have noted elsewhere, high energy intakes among Samoans correspond with their high prevalence of obesity. The difficulty of establishing a firm relationship between energy intake and obesity among Samoans may stem from the inherent limitations of dietary assessment. In the present study, the lack of association between energy intake and %BF could be attributable to underreporting, though measures were taken to increase and verify the accuracy of the diet records. Reported energy intakes often underestimate actual energy intake, but assuming a normal population and unbiased reporting, the ranking of energy levels would still be expected to show association and thus have no effect on outcomes. However, reporting has been found less reliable among women and people who are obese, both characteristic of the participants in the present study. Therefore, these results may have been biased towards no effect with respect to energy intake.

The results of dietary analysis in this study indicated a largely appropriate dietary macronutrient composition, though high in dietary fat. However, 42% of the women in this study did not meet the weight-based recommendation for protein for adults, underscor-
living in Hawai‘i were not assessed in the present study, it is probable that they are similar to their highly modernized counterparts in New Zealand. Given the well established relationship between modernization and obesity among Samoans, and the possibility that Samoan women may increasingly turn to diet and exercise for weight loss to conform to a slimmer than traditional body size, there is an ever increasing impetus to discover and implement culturally appropriate intervention methods to stem the tide of the growing obesity epidemic among PI.

The results of this cross-sectional study identify physical activity as a possible ameliorating influence on the severity of obesity in young, predominantly Samoan women. Given the high rates of obesity among Samoan women, additional experimental investigation is warranted to establish the effectiveness of physical activity intervention in this population.

**Disclosure Statement**

None of the authors identify a conflict of interest.

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- R.J. Fisher Middle School, Los Gatos, CA (V.N.)

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Losap Island, Upper Mortlocks (Chuuk)

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46
An Assessment of the Pacific Regional Cancer Coalition: Outcomes and Implications of a Regional Coalition Internal and External Assessment

Angela U. Sy DrPH; Karen A. Heckert PhD, MPH, MSW; Lee Buencondejo-Lum MD; Johnny Hedson MBBS, MMed(Surg); Suresh Tamang MBA; and Neal Palafox MD, MPH

Abstract

Significance: The Pacific Regional Cancer Coalition (PRCC) provides regional leadership in the US Affiliated Pacific Islands (USAPI) to implement the Regional Comprehensive Control Plan: 2007-2012, and to evaluate its coalition and partnerships. The Pacific Center of Excellence in the Elimination of Disparities (CEED), aims to reduce cancer disparities and conducts evaluation activities relevant to cancer prevention and control in the USAPI.

Purpose: The PRCC Self (internal) and Partner (external) Assessments were conducted to assess coalition functioning, regional and national partnerships, sustainability, and the role of regionalism for integrating all chronic disease prevention and control in the Pacific.

Methods: Self-administered questionnaires and key informant telephone interviews with PRCC members (N=20), and representatives from regional and national organizations were administered (N=26). Validated multi item measures using 5-point scales on coalition and partnership characteristics were used. Chronbach's alphas and averages for the measures were computed.

Results: Internal coalition measures: satisfaction (4.2, SD=0.48) communication (4.0, SD=0.50), respect (4.1, SD=0.60) were rated more highly than external partnership measures: resource sharing (3.5, SD=0.74), regionalism (3.9, SD=0.47), use of findings (3.9, SD=0.50). The PRCC specifically identified its level of “collaboration” with external partners including Pacific CEED. External partners identified its partnership with the PRCC in the “coalition” stage.

Principal Conclusions: PRCC members and external partners are satisfied with their partnerships. All groups should continue to focus on building collaboration with partners to reflect a truly regional approach to sustain the commitment, the coalitions and the programming to reduce cancer in the USAPI. PRCC and partners should also work together to integrate all chronic disease prevention and control efforts in the Pacific.

Background

The US Affiliated Pacific Islands

The US Affiliated Pacific Islands (USAPI) are comprised of three freely associated states (the Federated States of Micronesia [FSM], the Republic of Palau and the Republic of the Marshall Islands [RMI]), two US territories (American Samoa and Guam) and the Commonwealth of the Northern Mariana Islands (CNMI). The area has been described as many small inhabited islands scattered over 2.5 million square miles in the Pacific Ocean comparable in area to that of the continental US.

Significant geographic and cultural barriers to health care exist in the Pacific, resulting in poor health in many underserved island communities. For example, life expectancies in the USAPI are 9 to 12 years shorter than in the United States. Factors that contribute to health disparities in the region are many. Among these factors are an insufficient number of trained health care providers in rural areas, skepticism towards western medicine, and myths and misconceptions about health practices and health concerns. Those with the least resources often live in extremely remote outer islands and are unable to travel to urban medical centers on the central island, and such isolation results in little, if no, access to healthcare.

Cancer in the USAPI

Cancer is the second leading cause of death in the USAPI. Available data from the USAPI show remarkably higher cancer mortality compared to the United States. Between 1998-2001, American Samoa, with a population of 65,500, had 152 deaths due to cancer. In the United States with a population of about 300 million, the number of deaths due to cancer was 562,875 in 2007. In 2002, the Marshall Islands, with a population of 52,000, had 11 deaths due to breast cancer while in the United States, the number of deaths due to breast cancer was 40,410 in 2005. Lack of prevention and treatment options along with a culturally incompatible western, American based model of health care for Pacific Islanders, contribute to the excessive cancer burden in the USAPI. Cancers that are potentially curable such as breast and cervical cancers are found in advanced stages because of a lack of resources to provide adequate prevention and screening services.

The Pacific Regional Cancer Coalition

In June 2004, the Department of Family Medicine and Community Health (DFMCH), John A. Burns School of Medicine, University of Hawai’i received a Centers for Disease Control and Prevention (CDC) National Comprehensive Cancer Control Planning grant as the bona fide agent for the USAPI jurisdictions and territories. The Pacific Islands Health Officers’ Association (PIHOA) is a non-profit association representing the health interests of the USAPI jurisdictions and territories. The Pacific Island Health Officers’ Association (PIHOA) is a non-profit association representing the health interests of the USAPI jurisdictions. For the past 20 years, PIHOA has served as the regional health policy body for the US affiliated Pacific Islands. PIHOA has associate, affiliate, and honorary members representing federal agencies and programs from around the Pacific region.

The DFMCH and PIHOA are Pacific regional partners who share resources and expertise to address the cancer burden in the USAPI (Figure 1). This partnership resulted after many years of concerted effort and commitment by key organizations.

The Pacific Regional Cancer Coalition was formed to address the cancer burden in the USAPI region. For regional meetings and decision-making, the PRCC is comprised of the CDC Comprehensive Cancer Control (CCC) program coordinators and chairs of each USAPI jurisdiction’s CCC coalitions, and members of the Cancer Council of the Pacific Islands (CCPI). The CCPI provides the overall direction for regional CCC efforts, and the CCPI members from each USAPI jurisdiction are part of their jurisdiction CCC coalitions and steering committees. PIHOA serves as overall advisory to the CCC process (Figure 1).
The CCC program is “an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation, and palliation.” Partnerships or coalitions are formed to develop and implement CCC plans in geographic regions throughout the United States including in each of the USAPI jurisdictions.

The PRCC has identified four goals to address cancer prevention and control in the USAPI: (1) Strengthen and expand regional collaboration, planning, and advocacy affecting all aspects of cancer control; (2) Diagnose cancer as early as technically possible within the region; (3) Improve the capacity to treat cancer effectively in the USAPI region; and (4) Collect, analyze, and report accurate cancer related data across the region.

Community Coalitions
Public health professionals engage the active participation of community representatives through community coalitions to achieve primary prevention and health promotion objectives. Coalitions are “groups of individuals, factions, and constituencies who agree to work together to achieve a common goal.” Coalition members and partnering organizations collaborate in formal, organized ways to address issues of shared concern by implementing interventions aimed at changing individuals and environments. To effect changes in community health, coalitions aim to foster community capacity, the ability of a community to identify, mobilize, and address public health problems.

The ability of a coalition to function depends on the participation of coalition members. Coalitions share existing and potential resources available from its members and partners. Coalition members work together and provide their commitment, expertise, and other assets to reach their community health promotion goals.

Coalition assessments help a coalition determine its progress according to its objectives and whether the coalition remains on track and may be sustained in the future to address the community’s health priorities. A coalition assessment is a type of evaluation because systematic information is provided to strengthen the partnership during implementation. The collection of outcome data may also be included to assess the extent of change among participants or within systems. The development of community coalitions generally takes place over time according to phases that are conducive to measurement, for example: (1) processes that maintain the partnership infrastructure and function, (2) the implementation of activities and programs intended to accomplish a partnership’s goals, and (3) changes in health status or the community directly attributable to the work of a community coalition. Data to be collected to evaluate each phase of a coalition would involve: (1) conducting a member survey to assess satisfaction with how a coalition functions, (2) evaluating a program or activity that the partnership conducts, and
Community coalitions and community-based participatory approaches are the cornerstone of the CDC Racial and Ethnic Approaches to Health (REACH) US and CCC programs. REACH US and CCC programs require grantee states to implement an assessment of strengths and weaknesses of their community coalitions during their five-year cooperative agreements. Both CDC programs also promote adherence to Partnership Principles. The literature on community coalitions and collaboration offers various methods for coalitions and/or partners to either self-assess their role and functioning and/or to assess the viability of their relations with other partners and stakeholders.

A number of CCC and REACH US grantees have adopted recommendations and tools from the literature to carry out their own assessments, for example B-Free CEED (Center of Excellence in the Elimination of Disparities) at New York University. The PRCC is a regional coalition representing multiple sectors among USAPI organizations. The PRCC is unique among CCC and REACH US supported community coalitions, and the unique features of this regional coalition needed to be adequately addressed in the design of the assessment tools. For example, the concept and practice of “regionalism” was defined and valid questions for assessing the PRCC members’ and partners’ perceptions of regionalism and PRCC’s role and/or function in this regard were developed. “Regionalism” was defined in this project as the extent that regional organizations and partnerships that address concerns in the USAPI region perceive their efforts to be directed toward common goals. In a geographically expansive environment with extremely limited resources, the concept and active practice of regionalism may be as critical as community capacity to effect and sustain changes throughout the Pacific region.

**Purpose**

The purpose of the PRCC self-assessment (internal) and regional and national partner assessment (external) was to evaluate the progress and potential for regional coalition and partnership building of the PRCC and its regional and national partners. This partnership assessment addressed goals of CDC-funded programs in the USAPI that work in partnership to address cancer prevention and control in the Pacific: (1) CCC and REACH US Coalition and Partnership Principles, (2) Regional CCC 5-year Plan, 2007-2010, and (3) regional objectives for the Pacific Cancer Programs. The PRCC evaluation examined the partnership characteristics and processes that would maintain the coalition infrastructure and functioning. The regional coalition assessment was comprised of an internal self-assessment of the PRCC membership and an external assessment of the partnering relationships with the PRCC’s regional and national partner organizations.

**Methods**

A CCPI self-assessment and partnership assessment ad hoc workgroup was formed with representation from the PRCC, the Pacific Center of Excellence in the Elimination of Disparities (CEED), and the three CCPI executive officers. Pacific CEED is a REACH US funded program addressing breast and cervical cancer prevention and control in the USAPI and the evaluation of such initiatives (Figure 1). The CCPI executive officers also selected CCC coordinators to provide feedback on measures and questions to help develop the assessment tools.

**Sample and Recruitment**

All members of the PRCC (N=27) from each USAPI were invited to participate in the PRCC self-assessment. PRCC members were initially invited to complete the self-administered questionnaire electronically via a letter from the CCPI president. Ultimately, most PRCC members were recruited and completed the self-administered questionnaire at a semi-annual CCPI meeting held in Honolulu.

Representatives from nine Pacific regional and national partner organizations (N=36) were invited to participate in the PRCC partner assessment via email invitation from the CCPI president. The partner organizations were American Cancer Society, Asian and Pacific Islander American Health Forum, C-Change National, CDC REACH US, Intercultural Cancer Council, Pacific CEED, Pacific Regional Central Cancer Registry, Pacific Island Health Officers Association, and University of Guam.

**Data Collection**

The PRCC self-assessment involved a self-administered questionnaire followed by telephone interviews. PRCC members who had completed their questionnaires were scheduled for a 15-minute telephone interview via an email request with the interview guide attached. The response rate for the PRCC self-administered questionnaire was 70% (n=20), and the response rate for the follow-up telephone interviews was 27% (n=3).

The PRCC partner assessment involved an online self-administered Survey Monkey questionnaire. Two reminder emails were sent before the response deadline. The response rate for the partner assessment survey was 55% (n=20).

**Measurement and Instrumentation**

Measures were obtained from validated scales and measures on coalition functioning and levels of collaboration. Measures related to coalition functioning and satisfaction were obtained from a national REACH US coalition evaluation led by Nancy Van Devanter, DrPH from the New York University B-Free CEED. The PRCC assessment workgroup added measures not used for the REACH US coalition evaluation to address the unique regional status in the Pacific of the PRCC. The additional coalition and partnership measures were derived from Butterfoss’ Coalition Effectiveness Inventory and Bright’s Community Organizational Assessment Tool. A 5-point Likert scale from “strongly disagree” to “strongly agree” provided the response options for these additional measures. Levels of Collaboration Scale (Frey, et al) was also included to assess the degree of collaboration between the PRCC and its partners. Response options ranged from “no interaction” reflecting that coalition members and partners did not think that they collaborated at all with particular a partner organization to “collaboration” reflecting that coalition members and partners felt that they were highly collaborative with a particular partner belonging to one regional or national system.

Table 1 describes the measures used in the questionnaires and their sources.
The PRCC self-assessment survey contained 47 close-ended items. The PRCC partner assessment survey contained 38 close-ended items, and 6 open-ended questions. Questions concerning internal coalition satisfaction and functioning were not included in the partner survey because respondents were being surveyed about their partnering relationship with the PRCC, i.e., external assessment.

The PRCC telephone interview guide was developed to obtain descriptive data to supplement the PRCC self-assessment questionnaire. The interview guide contained 18 open-ended questions developed with feedback and approval from the CCPI president. Questions addressed the role of the PRCC member, perceptions on the PRCC, communication with partners, goals achievement, partnership with PRCC member’s own jurisdiction, and participation in CCC evaluations.

**Data Analysis**

Data from the surveys were entered into SPSS. Items for each scaled measure were aggregated to create a single measure. Chronbach’s alphas were computed for each aggregated measure to indicate the strength of its internal consistency or reliability with a value of “1.0” representing perfect reliability of single items aggregated to create one measure. Means of the scaled measures were computed.

**Results**

Results from the PRCC self-assessment (internal), PRCC partner assessment (external), and comparison results of these two assessments are presented in Tables 2-4. Figures 2-5 provide the graphed results, including results on levels of collaboration. Overall, the coalition and partnership measures indicated strong internal consistency. The PRCC self-assessment contained 9 multi-item scaled measures on coalition and partnership functioning. Chronbach alphas ranged from a 0.670 for “decision making” to 0.912 for “satisfaction” (Table 2 and Figure 2). The PRCC partner assessment contained 6 multi-item scaled measures with Chronbach alphas ranging from 0.690 for “use of findings” to 0.840 for “resource sharing” (Table 3 and Figure 3).

**PRCC Functioning and Satisfaction**

For the PRCC self-assessment, the lowest ratings were for “decision making” (mean=3.5, SD=0.63) and “resource sharing” (mean=3.5, SD=0.74) (Table 2 and Figure 2). The PRCC members who were interviewed explained that decision-making was a challenge due to diversity.

“I think the greatest struggle is how to balance all this while developing and implementing programs, how to accommodate all the choices and address the needs of the diverse member jurisdictions, considering the mismatched differences. A good open and honest communication is very important. Sometime we have to make very difficult decisions.”

The interviews also discussed that obtaining resources was seen as a challenge since the ability to acquire resources is required in order to achieve cancer prevention and control goals that have not been met.

The highest ratings were for “communication” (mean=4.0, SD=0.56) and “respect” (mean=4.0, SD=0.60). The PRCC interview results indicated that respondents thought that communication and respect were strong. Respondents explained areas where they thought the PRCC excelled.

“[The PRCC excels at] respect for other different coalitions within the region and within different jurisdictions.”

“[The PRCC excels at] coordinating with partners to help to integrate and coordinate the efforts. With the limited resources, communications are the key.”

**PRCC Partner Characteristics and Satisfaction**

For the partner assessment, the lowest ratings were for “use of findings” (mean=3.9, SD=0.57) and “regionalism” (mean=3.9, SD=0.50).
Table 3. Mean Scores for External Partner Assessment

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n</th>
<th>Mean</th>
<th>SD</th>
<th># of items</th>
<th>alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction</td>
<td>10</td>
<td>4.2</td>
<td>0.48</td>
<td>4</td>
<td>0.690</td>
</tr>
<tr>
<td>Resource Sharing</td>
<td>10</td>
<td>4.0</td>
<td>0.63</td>
<td>8</td>
<td>0.849</td>
</tr>
<tr>
<td>Partnership</td>
<td>10</td>
<td>4.0</td>
<td>0.52</td>
<td>8</td>
<td>0.764</td>
</tr>
<tr>
<td>Sustainability</td>
<td>10</td>
<td>4.0</td>
<td>0.56</td>
<td>3</td>
<td>0.758</td>
</tr>
<tr>
<td>Use of Findings</td>
<td>10</td>
<td>3.9</td>
<td>0.47</td>
<td>5</td>
<td>0.699</td>
</tr>
<tr>
<td>Regionalism</td>
<td>10</td>
<td>3.9</td>
<td>0.50</td>
<td>5</td>
<td>0.705</td>
</tr>
</tbody>
</table>

This may be related to responses on open-ended questions that report the partner representatives did not think collecting, analyzing, and reporting on cancer data either has been accomplished or was still in progress. Partners who commented on the extent that the goal, “Collect, analyze, and report accurate cancer related data across the region” has been accomplished as a result of their partnership with the PRCC explained that this goal was either in progress or has not been accomplished. Regionalism may have been rated lower because PRCC members do not think that the regional goals to diagnose and treat cancer have been achieved yet.

The highest rating was for “satisfaction” (mean=4.2, SD=0.48) (Table 2 and Figure 2). Partners indicated that they accomplished several cancer prevention and control projects, and this may be attributed to their satisfaction with their partnership with the PRCC. PRCC partners noted a variety of projects accomplished as a result of their partnership with the PRCC. Many of these projects also address the cancer prevention and control continuum.

“Establishment of functional cancer control coalitions and cancer control program coordinators in each of the jurisdictions”

“We have been able to provide in person capacity building assistance and trainings to American Samoa, Guam, and CNMI”

“Development of a Pacific Regional Cancer Registry”

“Introduction of quality improvement components into local cancer program activities”

“Through our collaboration with PRCC, there have been cancer survivors highlighted in our Book of Hope and then many of the PIJs [Pacific Island jurisdictions] are now in process of developing their own versions of the Book of Hope.”

Levels of Collaboration Between Partners

Levels of collaboration were measured between the PRCC and its partner organizations, and partner organizations’ perception of collaboration with the PRCC. Figure 4 depicts the PRCC members’ response regarding the extent they collaborate with their regional and national partners. Members of PRCC identified that two partner organizations were in the “collaboration” phase with them. Figure 4 depicts the responses of the PRCC partners regarding the extent to which they collaborated with the PRCC. Partners of PRCC as an aggregate rated the level of collaboration with the PRCC in the “collaboration stage” defined by “Shared ideas, shared resources, frequent and prioritized communication, all members have a vote in decision making.”

Comparison of Internal and External Coalition Assessment Measures

Table 4 compares the results of coalition measures that were used for both the internal and external assessment. Four measures of coalition characteristics were common for both the PRCC and its partners. Overall the PRCC partners rated their partnership characteristics higher than the PRCC members rated themselves.
**Table 4. Comparison of Common Coalition Measures Between PRCC and PRCC Partners**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>PRCC Members (internal)</th>
<th>PRCC Partners (external)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td># Responses</td>
<td>Mean</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>20</td>
<td>3.7</td>
</tr>
<tr>
<td>Regionalism</td>
<td>20</td>
<td>3.6</td>
</tr>
<tr>
<td>Sustainability</td>
<td>17</td>
<td>3.6</td>
</tr>
<tr>
<td>Resources</td>
<td>19</td>
<td>3.5</td>
</tr>
</tbody>
</table>

**Discussion**

**Coalition and Partnership Measures**

The lower Chronbach’s alpha values were likely the result of items that required responses in the negative direction, eg, “It takes too long for the PRCC to reach a decision” while most response categories were positively scaled, ie, strongly disagree-strongly agree. Although measures were obtained from validated sources, some groups may not respond well to reversed patterns in a survey. PRCC members are bilingual or multilingual with English as their second or third language.

“Satisfaction” had the highest Chronbach’s alpha for the PRCC self-assessment, and lowest for the PRCC partner assessment. An example of a question measuring “satisfaction” within the PRCC was “I am satisfied with the types of projects/proposals that the Pacific Regional Cancer Coalition has proposed.” An example of a question measuring “satisfaction” of external national and regional partners was: “I am satisfied with the progress that has been made with the PRCC to implement the CCC program.” Validated measures to evaluate satisfaction of external partnerships were not found in the literature. The Chronbach’s alpha for the “satisfaction” measure on the partner assessment was low because the validated internal measures for “satisfaction” was adapted to attempt to address satisfaction with the external partner.

**Recommendations**

The PRCC will undoubtedly continue to focus on both internal coalition strengthening, especially decision making, and ways to foster direct communication given that face to face and even telephone contact is not always reliable. Externally the PRCC may continue direct communication given that face to face and even telephone contact is not always reliable. Externally the PRCC may continue to focus on building its external partnerships and resource sharing to continue to build the PRCC’s capacity to treat cancer in the region. PRCC partners may also focus on working with the PRCC to foster a truly regional initiative. The PRCC and its partners should also work together to integrate all chronic disease prevention and control efforts in the Pacific.

The coalition assessment methodology may be applied again in a few years. The sample sizes for the PRCC interviews and the partner assessment should be increased. Most of the Pacific Islands jurisdictions are one day and several hours ahead of Honolulu, and arranging telephone calls is challenging. The coalition assessment workgroup agreed on this approach because there was no opportunity to conduct in person interviews during the time when this assessment was being conducted.

The extent that key informant interview results are representative of the PRCC is unknown because only three interviews were conducted. A purely qualitative evaluation comprised of interviews of a larger sample of PRCC members is recommended at an opportuity when members may be interviewed in person instead of over the phone, eg, biannual face to face meetings. This qualitative evaluation will add further context and description to the quantitative findings on PRCC members’ perception of their coalition and partnerships, and ability to address cancer prevention and control goals in the Pacific.

The development of community coalitions, their accomplishments, and impacts in a community takes place over time according to phases. This assessment documented the process of coalition functioning of the PRCC and partnership building with its regional and national partners. The next phase of assessment would be to document the implementation of PRCC activities and programs intended to accomplish its goals on cancer prevention and control. Results from this latter evaluation will ultimately inform the final assessment phase, ie, the extent that the PRCC has achieved changes in cancer related outcomes.

**Conclusions**

The results of the PRCC self-assessment indicate that the coalition is functioning well internally. Also, PRCC partners are satisfied with their partnership with the PRCC and their accomplishments as a result of the partnership. This assessment has informed PRCC members of the progress of their partnerships and next steps to continue to strengthen and maintain regional partnerships to reduce cancer in the Pacific.

This is the first coalition and partnership assessment of the PRCC. The results show that overall the instrumentation and measures were reliable. This evaluation demonstrates that a unique regional coalition which aims to address cancer across a vast, geographically dispersed region may be adequately assessed to provide findings on progress. Results will be used to provide recommendations to strengthen the regional coalition by fostering regionalism and to sustain the regional cancer prevention and control initiatives.

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References
The Training and Education Program of the University of Guam/University of Hawai’i Cancer Center Partnership

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Although funding from United States and international health organizations is contributing to infrastructure development and health systems strengthening in the Pacific region, Guam and the neighboring US-Affiliated Pacific Islands (USAPI) have historically lacked the infrastructure (eg, cancer screening and treatment facilities, scientific laboratories, long-standing cancer registries) and trained personnel (eg, researchers, clinicians, data registrars) necessary to conduct effective cancer research. Weaknesses in the regional educational pipeline (K-12), particularly in mathematics and science, contribute to the low numbers of Americans of Pacific Island ancestry in master’s and doctoral degree programs across the country. Relatively low faculty salaries, geographical isolation, limited funding, outdated facilities, institutional barriers, and outmigration further challenge efforts led by academic and leading research institutions to establish research training programs and research partnerships in the region. Despite the many challenges, however, it is clear that research and research training must be part of the solution if the Pacific region and Pacific Islanders are to realize improved health, less suffering, and fewer deaths in the 21st century.

The University of Hawai’i Cancer Center (UHCC) and the University of Guam (UOG) have shared a commitment to serve the needs of populations and communities in the Pacific region through improving cancer research, care, training and education, and outreach to ultimately reduce cancer health disparities in the region. Funding from the National Cancer Institute’s (NCI) Center to Reduce Cancer Health Disparities supports the long-standing partnership of the two institutions, initiated in 2002 to increase the number of minority scientists of Pacific Islander ancestry engaged in cancer research while building capacity at the University of Guam to conduct cancer research, and to sharpen the focus at UHCC in addressing cancer health disparities relevant to the Pacific region. Towards this objective, the UOG/UHCC Partnership supports a Training and Education Program. The aims of the Training and Education Program include:

(1) Train minority Pacific Islander students in cancer research at the MS level at the University of Guam and at the PhD level at the University of Hawai’i;
(2) Stimulate cancer research efforts at the University of Guam through mentorship and faculty development; and
(3) Develop a cancer health disparities track in the Micronesian Studies Program, a master’s program at the University of Guam.

Student Training in Cancer Research

With a focus on community outreach, opportunities for master’s students in social, behavioral, and cultural studies at UOG are made available through graduate cancer research fellowships supported by the UOG/UHCC Partnership. UOG students with undergraduate degrees in disciplines such as Biology, Chemistry, Psychology, and others, are solicited to participate in MS degree training at UOG in cancer research with an emphasis on cancer health disparities. Two students are accepted into the program each year and are provided tuition waivers and graduate research assistantships for a period of up to two years. Students accepted into the fellowship program are mentored by faculty members at UOG to work on cancer health disparities research related to their thesis project.

Students trained in the Master’s Training Program in Cancer Research at the UOG are strongly encouraged to continue with their graduate education by participating in the PhD Training Program in Cancer Research at the UH Cancer Center, or in a PhD cancer research training program at another institution on the US mainland.

With funds provided by the UOG/UHCC Partnership grant and additional support from the UH Cancer Center, two students are supported each year in PhD level training in cancer research under the mentorship of established investigators at UHCC. Students interested in the PhD cancer training opportunity must first apply and fulfill the admission requirements to the PhD graduate program to which the sponsoring UHCC faculty member belongs. Graduate programs at the University of Hawai’i considered by students pursuing careers in cancer research include Epidemiology, Nutrition, Public Health Sciences, Social Welfare, Molecular Sciences and Bioengineering, Chemistry, and Cell and Molecular Biology.

In their first year of study, PhD students accepted into the training program experience research rotations in the laboratories — basic or behavioral — of their mentors. This experience expands their knowledge of the types of cancer research conducted which is essential, for example, to the student’s decision to select a particular cancer research laboratory to perform their dissertation research.

In years two through four, students focus on their dissertation research necessary to fulfill their PhD requirements. During this period, the trainee learns the skills, knowledge, and concepts, while exercising the perseverance necessary to perform independent cancer research. While the UOG/UHCC Partnership provides a graduate research assistantship and tuition waiver in the first year of training, funding secured by the trainee’s mentor typically supports the student’s dissertation research in years two through four.

Students participating in both the master’s and PhD training programs offered through the UOG/UHCC Partnership are encouraged to attend regional and national-level cancer research meetings to present their research results. Likewise, trainees participate in the UOG/UHCC Partnership’s Cancer Health Disparities Seminar Series, launched in September 2010, and other research seminars, journal clubs, and learning opportunities sponsored by the partnering institutions.
Since the inception of the UOG/UHCC Partnership, 1 PhD and 6 master’s students have completed their training. Currently, there are 5 masters students and 3 PhD students supported by the program. In addition, 2 masters student graduates have been accepted by PhD programs at US mainland institutions.

Ultimately, students trained by the UOG/UHCC Training Program in Cancer Research will contribute to a nucleus of cancer researchers committed to addressing cancer health disparities and other health priorities in Guam and the USAPI.

**Stimulate Cancer Research Efforts at the University of Guam**

Faculty at the UOG are selected by the Partnership’s Internal Advisory Committee to participate in a 3 month summer research experience in association with the appropriate faculty partner at UHCC. This exchange provides an opportunity for UOG faculty to engage in cancer research as it is performed in leading research programs. The faculty summer research experience assists in a significant way in the development of pilot projects, and has proven to facilitate the development of long-standing research collaborations. Where appropriate, reciprocal visits of UHCC faculty to the University of Guam to develop collaborative research projects are also supported.

Since the inception of the UOG/UHCC Partnership, 9 UOG faculty have benefitted from the mentorship and training received through the summer exchange program. Leadership at the partnering institutions continue to make every effort to encourage and facilitate research collaborations between the UOG and UHCC faculty, recognizing that sustainable collaborations are critical to the long term cancer research activities at the UOG and to building the capacity and infrastructure necessary to support future cancer research in the Pacific region.

**Cancer Health Disparities Research Track for Master’s Students at UOG**

With funding from the UOG/UHCC Partnership, the Micronesian Studies Program (MSP) master’s degree now includes a specialization in Pacific Islander Cancer Health Disparities Research. The new specialization builds on the unique and strong interdisciplinary foundation currently supporting several other MSP specializations. In addition to the MSP curriculum, which provides rigorous social and behavioral science training as well as cultural sensitivity and language skills training, students who pursue the MSP cancer health disparities research option are required to conduct cancer health disparities research under the guidance of a faculty mentor and participate in required enrichment and preparatory activities. A research thesis is required, and graduating students are expected to publish their research in a refereed journal.

In addition to the new MSP curriculum and adaptations to existing MSP courses, a cancer health disparities seminar, open to faculty and students at UOG and UHCC, has been developed and made available through the partnership. Students and faculty at the partnering institutions participate in and contribute to the seminar series conducted simultaneously via video-telconferencing at both institutions. Speakers have presented on a variety of cancer topics such as tumor registries and cancer surveillance, sample size calculations and power analysis, community based participatory research, and cervical cancer and the human papillomavirus. Students and faculty from the UOG and UHCC have also presented their research during the seminar series which is offered three times each semester.

**Today’s Undergraduate Student, Tomorrow’s PhD Researcher**

The Training and Education Program of the UOG/UHCC Partnership responds to the critical need for cancer health research and community outreach capacity in Guam and neighboring USAPI to address the growing cancer burden in the region.

For more information about the UOG/UHCC Partnership, and applications for the master’s and PhD Training Program in Cancer Research, visit the partnership’s Website at www.uog.edu/cancer/

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**Reference**
A stone path in Yap

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