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Hawai‘i Journal of Health and Social Welfare Special Issue on Health Disparities in US Affiliated Pacific Islanders: The Voyage Forward

Introduction by Guest Editors: Neal A. Palafox MD, MPH and Lee Buenconsejo-Lum MD

Auwe! We celebrate the completion of a 4-year voyage of this special issue of the Hawai‘i Journal of Health and Social Welfare titled *"Health Disparities in US Affiliated Pacific Islanders: The Voyage Forward."* In April 2016, a call for papers was made for this issue to build sufficient health and surveillance data that would provide a more precise understanding of health and health care disparities in the US Affiliated Pacific Island (USAPI) jurisdictions. A section called "Lessons Learned from the Field" was planned to provide a space for understudied community based innovative policies, practices, and programs affecting USAPI population health.

"The Voyage Forward" is the fourth special publication of the USAPI journey towards improving health and health care in the US Affiliated Pacific. Each of the publications was sponsored through a now 18-year partnership between the Cancer Council of the Pacific Islands (CCPI), Federal Partners, Hawai‘i State Advocates, and the Department of Family Medicine and Community Health (DFMCH) at the John A. Burns School of Medicine (JABSOM).

The first special publication was "Cancer in the Pacific" in the Pacific Health Dialog (PHD) in September 2004 (Vol. 11, No. 2). Led by a partnership between Papa Ola Lokahi and the DFMCH - JABSOM, the issue housed manuscripts about the evolving Cancer Council of the Pacific Islands (CCPI), described cancer disparities in Hawai‘i and in Native Hawaiians, and accumulated the available cancer data throughout the USAPI. The role of Pacific Island networks in Hawai‘i and the continental United States was discussed, and the systematic development of Native Hawaiian researchers was presented as an innovative cancer initiative.

The second in the series entitled "Developing Human Resources for Health in the Pacific" was published in March 2007 in the PHD (Vol. 14, No. 1). The PHD issue spoke to building healthcare capacity in the USAPI through human resource training, distance education, and professional development.

The third in the series was published in the Hawai‘i Medical Journal (Vol. 69, No. 6, Suppl. 3, June 2010). This edition gathered articles addressing health disparities in Native Hawaiians and Pacific Islanders in Hawai‘i and cervical cancer screening in the USAPI and in the migrants from the Compact of Free Association (COFA) nations. Several articles described the health disparities of COFA migrants in Hawai‘i in terms of social justice and politically generated structural barriers. Health policy promotion, building distance communications throughout the Pacific, and academic–community partnerships, and new centers of learning at the University of Hawai‘i John A. Burns School of Medicine were described as paths forward.

There were three major goals for *"The Voyage Forward."* First, was to bring new knowledge from the Pacific that addresses health disparities in the USAPI. Second, was to ensure that a significant proportion of the narrative describing the new knowledge was conceptualized and narrated by the indigenous peoples of the USAPI through a Pacific-centric lens. Third, that the internal and external partners of the CCPI would nurture, assist, support, and continue *"The Voyage Forward."*

Iebjeltok is the Marshallese saying for voyagers bringing gifts to the community. The basket "Ieb" is facing the community in offering "jeltok". The voyage landed new knowledge in the previously uncharted waters. The first six articles, written by indigenous and local peoples, include topics regarding collaborating with traditional leaders and chiefs in Yap and Pohnpei. While building non-communicable disease (NCD) prevention programs, these innovative programs focused on developing health systems management tools to synergize programs using a limited number of committed staff and affecting community policies, systems, and environments to reduce NCD risk behaviors. Affecting change in the culture through institutions of the culture is a turning point in the health and health care disparities dialogue as the process empowers the community by promoting community agency.

Nine manuscripts led by academic-based authors, some Indigenous Pacific Islanders, speak to specific issues. The academic authors begin with articles about the association of otitis media and dental caries in Palau, and breast cancer in Guam. Two articles explore e-health needs and development in Pohnpei and Majuro, followed by a report of a cervical cancer research project in Guam that encounters incompatible international digital connectivity that hinders research progress.

Gathering data, using a National HINTS format is made relevant through community focus groups input on the survey content and design; and we learn how refugee women's health in the Northeastern United States may inform the migrant Pacific

Islanders about advocating for reproductive health during the Pacific diaspora. Two manuscripts, caregiving in Yap and palliative care in the Marshall Islands, describe the development of these programs in a community-based cultural framework and note that these programs may be adapted and scaled throughout the Pacific.

The Centers for Disease Control and Prevention brings the voyage close to shore with the last three manuscripts about cancer mortality data, cancer registries, and an adapted canoe logic model.

The final manuscript, co-authored by the Hawai‘i based nephrologist who developed hemodialysis and renal disease monitoring programs in the USAPI, speak to the health care and health financing implications across the USAPI and brings this leg of the voyage to anchor.

Indigenous Pacific Authors

In much of the Pacific health and healthcare literature the observer, funder, creator, and disseminator of the narrative was an academic, a funder, or other interested Pacificans. Rarely did the indigenous community stakeholder take the lead. This special issue moves us deeper towards some Pacific health interventions though a community and indigenous Pacific peoples point of view. Sharing health narratives in this manner reframes common representations that emphasize structural limitations, including academia, at the expense of Pacific peoples.

This *"Voyage Forward"* issue speaks to legitimizing norms and interventions of Pacific peoples around disease control and outcomes. The world-view of the Pacific peoples, who come from island countries with small populations and small economies, as powerless within the global context can create a geographic, economic, and scientifically deterministic framework, which becomes a limiting populous belief. This special issue *"Voyage Forward"* is in and of itself a population health intervention and serves to establish the assets that the Pacific and Pacificans hold to affect their own health outcomes.

This edition challenges the myth that the dissemination of science can only be legitimized by academics and scientific institutions. Rather, the interdependence of community, academics, funders, and federal partners, working in a culturally-centric manner allows a relevant multi-view narrative to emerge. Western cultural hegemony then fades in the Pacific. The indigenous community role in the creations, presentation, and dissemination of new knowledge in a Western format illustrates versatile self-agency.

Honoring the diversity of Pacifican authors (Table 1) and partners who were part of the foundation of *"The Voyage Forward,"* we note participation by peoples with the following ancestry: 21 Filipinos, 7 Asian Indian, 5 Japanese, 4 Koreans, 4 Chinese, 1 Vietnamese, 5 Black Americans, and 33 Caucasians.

Table 1. Indigenous Pacific author metrics that define this special issue

Ethnicity	Number	Non-Academic	Academic	Belonging to Federal Agencies
Chamorro	10	6	4	0
Palauan	7	7	0	0
Marshallese	3	2	1	0
Pohnpeian	2	2	0	0
Yapese	2	2	0	0
Kosraean	1	0	1	0
Papua New Guinean	1	1	0	0
Total	26	20	6	0

Conclusion

"Health Disparities in US Affiliated Pacific Islanders: The Voyage Forward" navigated to its goal, to provide and disseminate new knowledge in the domains of surveillance data and interventions, which mitigate health disparities in the USAPI. The voyage also served a purpose greater than the content of the individual articles, as it moved disparities science towards a Pacific-centric point of view.

This issue reflects the resilience of Pacific Peoples - demonstrating Pacific peoples, their community, and their cultural frameworks are assets and are essential to address USAPI health disparities. Pacific peoples writing their own narratives about their interventions, in their communities defines their norm from their own lens, and that they are in charge of developing, describing, and interpreting their circumstance.

The special issue demonstrates that the USAPI Pacific Islanders can share their narratives in a scientific health-related peer-reviewed format, that their work can be written by Pacific peoples to meet the standards of Western scholarship. Further, the Pacific peoples authors are from the community, from the health systems, those who are students, as well as academics. This reframing in the course of sharing health intervention narratives not only allows us to challenge the structural limitations of peer-reviewed publication, which may be at the expense of Pacific peoples, but also enables us to center indigenous worldviews and agency in relation predominant Western science and global academic control.

Over the course of the series, in addition to an evolution in the types of authors, there has been an evolution in the content - there is descriptive and observational research, but also translational research that is T4 and T5 type research where interventions are tested in real life then institutionalized by the community. At the T6 global level - the information is applied throughout the USAPI.

And finally - in order to complete this edition of HJHSW, the Editorial Board, the Chief editors, the key staff journal staff along with the academics, supporting and Federal funders exercised great patience, institutional tolerance, flexibility, as they heard a repetitive - “almost-soon,” when asked when will the issue arrive to port. It supports the idea of the collective community-academic-federal partnership. The fleet of canoes landed together with more than what it originally set out to do. It was indeed a collective effort, about the collective - now in digital ink.

The voyage continues –

Si Yu‘us Ma‘ase, Mahalo, Mesulang, Kinisou Chapur, Kalahngan, Kommol Tata, Fa‘afetai Tele Lava, Kulo Malulap, Oloomway, Kammagar

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Lovedhi Aggarwal, MD
Roxanna Bautista, MPH
Kathryn L. Braun, DrPH
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Hali Robinett, MPH
Lola Sablan Santos
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Rae S. Seitz, MD
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Lilnabeth P. Somera, PhD
Sora Park Tanjasiri, DrPH, MPH
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The Traditional Monarch of Kitti in Pohnpei Addresses the High Rates of Non-Communicable Diseases through Local Policy

Johnny Hadley, Jr. BA and Evonne Sablan MPA

Abstract

Almost a quarter of Pohnpei's population is overweight or obese, a major factor influencing a 2010 non-communicable diseases (NCD) emergency declaration. The Racial and Ethnic Approaches to Community Health (REACH) project in Pohnpei is implementing a culturally tailored policy, systems, and environmental (PSE) intervention to reduce NCDs through healthy nutrition projects. Through collaboration with traditional leaders and using traditional protocols, REACH succeeded in soliciting formal approval from a Traditional Monarch to serve only healthy beverages during events at all traditional houses in the municipality. The Governor, in turn, also supported this initiative. This project cultivated relationships with traditional and government leaders to implement a culturally appropriate healthy nutrition PSE change intervention.

Keywords

Micronesia, Pacific Islander, traditional leaders, nutrition

Issue

The Federated States of Micronesia (FSM), a low-middle income country, has over 600 islands across more than a million square miles of the Western Pacific Ocean. The FSM consists of the following four states: Chuuk, Kosrae, Pohnpei, and Yap. Pohnpei Island, which has a population of approximately 36,000, is the largest island in the FSM and is home to the nation's capital.[1] There are six municipalities in Pohnpei Island, which are Kitti, Kolonia, Madolenihmw, Nett, Sokehs, and U.

After World War II, the FSM states were part of the United Nations Trust Territory under the United States (US) before entering an agreement named the Compact of Free Association. Currently, under the Compact of Free Association, the US provides grant and program assistance to the FSM and allows FSM citizens to live and work in the US without a green card or visa.

Since World War II, the FSM has been influenced by the Western diet of high-fat processed foods and sugary drinks and has adopted widespread tobacco use. In Pohnpei, 32.1% of the adult population had diabetes.[2] Data also showed that 73.1% of the adult population was overweight or obese, 25.0% of adults smoked tobacco daily, and 42.1% chewed betel nut with tobacco daily.[2,3] Whereas, 17.4% of youth were overweight and 4.5% were obese.[4] According to a youth survey, 22.3% of Pohnpeian high school students used cigarettes daily and 50.1% used smokeless tobacco.[3] These unhealthy lifestyle practices have led to high non-communicable disease (NCD) morbidity and mortality rates. In fact, the life expectancy in the FSM is ten years less than in the US.[5]

The 2010 US Affiliated Pacific Islands health emergency declaration called for regional, national, and local agencies to mobilize and respond to reduce the incidences of NCDs in the region.[6] Due to the state of emergency, the Pohnpei State Department of Health Services (DHS) has worked on health interventions that impact the Pohnpeian population. Previously, Pohnpei State DHS implemented public health and behavior change programs, such as health education campaigns and exercise programs, which targeted individual change and were non-sustaining. Whereas, the new approach focused on policy, system, and environmental strategies that affect population health and is a long-term approach.[7]

Description

To help in the efforts, in 2014, the Pohnpei State DHS became a sub-grantee of the University of Hawai'i John A. Burns School of Medicine Department of Family Medicine and Community Health's Racial and Ethnic Approaches to Community Health (REACH) project, a Centers for Disease Control and Prevention funded grant that implements culturally-tailored policy, systems, and environmental (PSE) interventions to improve health in the US Affiliated Pacific Islands. Community PSE strategies are designed to reduce exposure to adverse health risks and to promote healthy behaviors by ensuring healthy choices are practical and accessible in the community.[8-10] The REACH PSE interventions aligned with existing objectives within the Pohnpei State DHS and the 2010 Non-Communicable Diseases State of Emergency declaration. The REACH project was designed to develop a local health policy to promote healthy behaviors and improve community health knowledge. Due to the accessibility of water and coconut water in Pohnpei, the REACH nutrition objective focused on increasing access to healthy beverages at events held at the traditional houses in Pohnpei. Water is a crucial nutrient for normal body functioning along with physical and cognitive performance.[11] Also, research has demonstrated comprehensive approaches that includes both promoting an environment in support of water-only consumption and community education can decrease the risk of being overweight for children by 31%.[12]

At the end of Pohnpei's centralized government system of the Saudeleur Dynasty in the 1600s, the Pohnpeian government was decentralized into municipalities. Each of the municipalities is lead by a Traditional Monarch called the *Nahnmwarki*, who is assisted by a *Nahnken* (second in command), and supported by many village chiefs. The *Nahnmwarki* is the paramount chief of the municipality and the *Nahnken* serves as the liaison or bridge between the people and the Traditional Monarch.[13-16] The Traditional Monarchs inherit the title and are highly respected in the community as they oversee all affairs in their municipality. Traditional Monarchs can make formal resolutions or rules, which are verbal directives carried out by the village chiefs, who are appointed by the Traditional Monarch.[15,16]

Currently, in the Municipality of Kitti, the leadership council is comprised of the Traditional Monarch and other non-elected traditional leaders, the elected Chief Magistrate (mayor) and the elected officials of the Municipal Council, who represent the village and districts in Kitti Municipality. The Chief Magistrate and Municipal Councils have no role in the traditional system but must interface with the traditional leaders because government services are provided to the people of the municipality. Meetings with the Traditional Monarch of Kitti on government-related services or affairs are handled by the Chief Magistrate, who would then relay the information to the Traditional Monarch.

To reach 75% of the population in Pohnpei, traditional houses or *nahs* were strategically chosen for the PSE interventions due to their high frequency of utilization by many Pohnpeians and for their cultural and traditional value as places of gathering and community events. These events, including meetings, social gatherings, and funerals, constantly have food and beverages available for the attendees. The traditional houses are managed by the traditional chiefs who oversee the matters of the village and help preserve their cultural heritage.

Methods

During a family gathering at a traditional house, the Pohnpei REACH Local Project Assistant (LPA) learned that the Traditional Monarch of Kitti supported banning unhealthy foods and beverages during events at traditional houses. Since the initiative was administered by the Pohnpei State DHS, the communication protocol started within the government organizational structure, beginning with the Pohnpei State DHS Director, who then contacted the Governor. As a courtesy and by way of protocol, the Governor communicated with the Chief Magistrate's office, who would usually work within the traditional protocol system. In this case, the Chief Magistrate worked directly with the Traditional Monarch of Kitti Municipality. Due to the REACH LPA's working relationships within the traditional system, it was appropriate to communicate directly to the traditional leaders of Kitti to avoid the lengthy communication process and any delays. The LPA was versed in the communication and traditional protocols, as well as the organizational structure of the Traditional Monarch system, to ensure rules were being followed. Per the instructions of the Traditional Monarch of Kitti, the LPA worked closely with the Chief Magistrate and the Traditional Monarch's appointed a Council Member on the REACH project. While it is common for resolutions to only be verbalized by the Traditional Monarch, the LPA asked the Chief Magistrate and Council Member for a formal written commitment showing support of serving only healthy beverages at traditional houses.

Initially, the LPA created a healthy beverage commitment template that documented support for the REACH initiative. However, advisors to the Traditional Monarch asked if the written commitment could be changed to an official resolution. To create this resolution, the LPA worked with a Pohnpei State Cancer Coalition member who had experience with legal language and terminology for the Pohnpei government. The advisors to the Traditional Monarch and the LPA met a few times to edit and review the resolution. A draft of the resolution was shared with the Government of Kitti Municipality for review and approval before it was given to the Traditional Monarch of Kitti Municipality.

Results

The Chief Magistrate worked with the Council Member to secure a meeting between the REACH LPA and the Traditional Monarch of Kitti. When meeting with the Traditional Monarch, the guest must bring *sakau* (or kava or ava as known throughout Polynesia), which is a Pohnpeian cultural beverage that is used for all ceremonial practices. The Chief Magistrate volunteered to provide the *sakau* to the Traditional Monarch in support of the efforts of the REACH project. After the ceremonial *sakau* session, the Traditional Monarch of Kitti signed a resolution proclaiming that only healthy beverages will be served during events at all traditional houses in the municipality. The municipality includes 41 villages and this resolution impacted approximately 6,500 Kitti residents.

Healthy beverages to be served during gatherings and events held at the traditional houses included water, coconut water, and local tea (*madeu*). The Traditional Monarch also incorporated in the resolution a mandate that only healthy foods would be served and a prohibition of tobacco use and betel nut chewing. Upon signing the resolution, the Traditional Monarch called on the Chief Magistrate and the Speaker of the Municipal Council to oversee and ensure that the people were educated about this new policy and that appropriate enforcement protocols and measures were to be established. For the first time a resolution made by the Pohnpeian traditional leader in modern-day Kitti Municipality was written and documented.

The Pohnpei REACH nutrition objective demonstrated that there was support from the traditional leaders to improve the health of their people. When the Pohnpei State Governor was notified that a nutrition resolution was being discussed with the Chief Magistrate and Traditional Monarch of Kitti, the Governor wanted to provide his administration's support and commitment to this community-based initiative. As a result, the Governor stated that the resolution would be shared with relevant departments and agencies. The resolution signing by the Traditional Monarch of Kitti and the Pohnpei State Governor was publicized in the community. An article of the resolution signing was written and disseminated in the local newspaper the Kaselehlie Press, as well as posted on the Pohnpei State Government website and shared on the REACH Facebook webpage.

Conclusions

This REACH initiative established a culturally appropriate intervention to increase access to environments with healthy options. Since there are many traditional houses throughout Kitti Municipality, the intervention in this setting impacted many families. This community-based policy may decrease NCD-related health disparities in this municipality.

The REACH project cultivated relationships with traditional leaders along with government leaders to implement this intervention. The Traditional Monarch of Kitti Municipality's support of serving healthy beverages during community events at traditional houses was instrumental in establishing the necessary connections and partnerships with the village leaders. The support by the Pohnpeian leaders and the signing of the resolution may ensure sustainability of the REACH goals.

Traditional leaders have a vital role and influence modern governance in the Pacific Islands, including in the FSM and other countries. Thus, the lessons presented in this paper can likely resonate with other Pacific Islands whose traditional chiefs have significant political, positional, and cultural influence. The traditional leaders are the gatekeepers in Pohnpei. As it is in other communities, the buy-in and approval of gatekeepers or community leaders are essential for the successful implementation of an effort in the community.

Lessons Learned

This healthy beverage initiative had its challenges and lessons were learned.

Due to social and cultural events, including funerals, the resolution signing ceremony was rescheduled twice. Project flexibility was necessary in order to accommodate social and cultural practices to maintain support from the traditional leaders while upholding deadlines for grant requirements. There was a delay in the scheduling of the signing ceremony with the Traditional Monarch related to the cultural *sakau* purchase. *Sakau*, which is used for Pohnpeian ceremonial practices, is essential, so there was a need to consider other options to acquiring gifts to show respect to cultural practices. Flexibility was also needed to accommodate the schedule and priorities of those within the traditional system who had a role in the signing of the resolution.

There is still a need to educate the traditional leaders and the public about this new local health policy at the traditional houses. The LPA plans to work with the Chief Magistrate and Speaker of the Kitti Municipal Council to provide education to the community about the resolution and importance of drinking water and coconut water through educational workshops and local media, including local radio, newspaper, social media, and partner websites. Continuous awareness in the community regarding the policy at the traditional houses in Kitti is needed to ensure adherence.

An evaluation would have been helpful to monitor compliance and assess the changes of knowledge, attitudes, and behavior to demonstrate effectiveness. The LPA created evaluation assessments; however, the evaluation was not implemented due to limitation of time and resources. Metrics should include actual use of water and other beverages at the event (number of bottles before and after), the number of events adhering to the policy, and the average daily consumption of different beverages.

Conflict of Interest

None of the authors identify any conflict of interest.

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Authors' Affiliations:
-Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawai'i, Honolulu, HI (JH, ES)
-Pohnpei State Department of Health Services, Pohnpei, Federated States of Micronesia (JH)

Correspondence to:
Johnny Hadley, Jr.; Pohnpei State Department of Health Services, Pohnpei, Federated States of Micronesia; Email: pnireach@gmail.com

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Lessons from Yap - Changing Government and Cultural Practice Through Public Health Policy

Martina Reichhardt BJRN

Abstract

The heavy burden of non-communicable diseases (NCD) in Yap State, Federated States of Micronesia overwhelms the resources of this small population. Traditional cultural practices strongly influence all aspects of life, especially in the remote outer islands. The traditional Chiefs must grant permission to perform any type of health outreach or services for about one-third of the population. One key cultural practice promotes tobacco and alcohol use. The Yap Comprehensive Cancer Control Program, in collaboration with other entities in public health, systematically engaged the traditional Chiefs, resulting in a landmark policy that paved the way for other system and environmental interventions to reduce the risks of developing NCD.

Keywords

non-communicable diseases, traditional culture, Pacific islands, prevention, policy

Issue

The burden of non-communicable diseases (NCD), especially cancer, is high in Yap State having a small population of 11,376 people[1] with growing incidences of not only cancers but also diabetes, hypertension, heart disease, stroke, kidney failure, and more recently gout.[2,3] All of these affect labor productivity and quality of life, eventually leading to disability and early death. For such a small population, the very survival of the people of Yap is threatened by the presence of growing NCDs.

Thirty-five percent of this population resides on 18 outer island atolls spread across 600 miles of ocean, east from the main island of Yap.[1] These islands are still very much traditionally and culturally oriented with subsistence living, where the power and influence of the Chiefs are still intact and central to community life.

However, the health of these island populations is tenuous, with the effects of climate change affecting food security and causing more reliance on the import of unhealthy western foods into these islands. In addition, the use of tobacco and alcohol is high in these small island populations and often employed as a medium of exchange for community work within the islands and also for visitors to the islands.

An unpublished Household Survey conducted in the outer islands from 2008-2009 showed that half of the population aged 15 years and over chewed betel nut with tobacco, 43% smoked tobacco, and 28% drank alcohol.[4] Over half of adult cancers are tobacco-related (54%) with lung cancer as the leading cancer for outer island males and ranked fourth in the outer island female population.[5]

One traditional practice is called “Kaptel-Wa”. This is the offering of tobacco and often alcohol as part of a cultural tribute to the Chiefs of each island when first meeting the Chief to pay respect, and secondly, to inform them of the planned activities. This is the time-honored pathway to be assured of the Chief’s approval and assistance and to engage the community in whatever activity one visiting the island has planned. In essence, any program that has work to carry out in these islands is required to fulfill this obligation.

This chiefly practice, while historically traditional in nature, directly encourages and promotes tobacco and alcohol use by all. The customary practice of traditional and locally grown tobacco has predominantly been replaced by western imported tobacco, which is more toxic.

Description

By directing efforts towards the creation and implementation of policies that contribute to enabling systems and environments that allow for people to make or receive healthier lifestyle choices and options, there is hope to slow the NCD tidal wave over time.

The Yap Comprehensive Cancer Control (CCC) Program, along with the Yap Department of Health Services (DHS) and Public Health partners, set out to engage traditional leaders in health education and health promotion meetings over a year sharing on the NCD burden and how the traditional leaders can contribute to the well-being of their people by rethinking some of their practices.

Yap, being a predominantly cultural and traditional society following certain norms and practices, is made up of the main island of Yap and 18 inhabited outer islands only reachable by one ship that services these islands 4 times annually. Only two islands have small airstrips and can receive small planes weekly. There is a third island that has a runway which is not operational at this time.

Historically and traditionally, the chiefs yield great power in community affairs and their influence permeates all of society, so it is only natural to engage them as key stakeholders in preserving the health and well-being of their people. With only approximately 4000 people living on the 18 outer islands, the NCD impact could portend the demise of the entire population.

The government and traditional leadership were engaged to enable them to recognize the NCD crisis in Yap as well as the rest of the Federated States of Micronesia (FSM) nation and the Pacific region. Focusing on NCDs enable the Yap DHS to have the mandate to call on other agencies to ensure that a "health-in-all-policies" approach is at the forefront of all governmental efforts starting with the DHS.

Methods

The primary objective was to engage traditional and government leaders and policy makers to recognize their role and responsibility in health prevention and promotion efforts in the context of population survival and dwindling limited resources. There was a need to recognize the unsustainable current entrenched practices and the need to develop stronger policies that can effect systems and environmental changes that impact behavior towards positive and healthier choices.

This was approached by arranging face-to-face meetings with relevant traditional and government leaders and policy makers collectively and separately to educate them about the current practices of health services and programs offered in the outer islands and on the main island and future plans to have each outer island take ownership of its own community health.

The people and programs in attendance at the various face-to-face meetings were the Cancer Program staff and Division of Public Health Program coordinators working for Maternal Child Health, Family Planning, Immunization, Tobacco, Behavioral Health, and Wellness and Diabetes. These partners met with traditional and government leaders and policy makers from the outer island communities to share and provide updates on health services, programs, and projects in the outer islands with an emphasis on the growing NCD burden. In light of the limited resources that are reducing each year under the United States Compact of Free Association agreement with the FSM, the need is to shift focus from treatment of disease to prevention of disease.

Results

The outcome of the various face-to-face meetings was the passage of COT Resolution # 2015-1, which was adopted during the Council of Tamol's (COT) Second Biannual Session on July 16, 2015. This Resolution directs all government agencies to ensure that no cigarettes, alcohol, or drugs are to be used as "Kaptel-Wa" for any work carried out in the 18 outer islands. This Resolution is a landmark decision by the traditional COT as it recognizes the important role of traditional chiefs in taking the first step to ensure the health of the future generation by changing this chiefly practice and making way for a new norm.

Three months after this historical decision by the COT Chiefs, another policy milestone was achieved. This was the issuance of Executive Order #2015-03 on October 12, 2015 by the Governor of Yap State declaring a state of health emergency due to the epidemic of NCDs in the State of Yap. This Executive Order gave power to the Director of Health Services to align all policies, programs, services, and activities of the Department to curb the incidence of NCD with emphasis on prevention rather than curative measures. It also calls on all other government departments and agencies to work with Yap DHS to address the NCD crisis.

Following this collective empowerment, additional policy changes were adopted. In December 2015, the Yap DHS made the decision to change its outer island medical referral feeding program from store food to local foods only via a coupon system. Under the feeding program, patients can redeem the coupons for local food from authorized participating vendors who sell local food produce instead of canned food and rice.

In addition, the Yap DHS also imposed a partial betel nut chewing ban in all patient service areas and strictly enforces the no smoking policy in the hospital compound or within 50 feet of its open entrances, exits, windows, and doors.

Conclusions

This policy effort is significant in that slowly, traditional, governmental, and policy leaders are recognizing the growing burden of NCD on the social and economic fabric of life and realizing that the government does not have the means and resources for treatment but should focus on prevention and self-help. The policies (resolution, executive order, and department policy) are outcomes of the education, awareness, and advocacy efforts by the collaborative partners beginning in 2015.

Lessons Learned

Regular face-to-face meetings with traditional and government leaders in small island settings is the most effective means by which to educate and inform them of health issues affecting the islands' populations.

In addition, there are four languages in Yap, so it is important that the health team is comprised of staff who can communicate in the local language of the leaders for transfer of knowledge to take place with increased understanding and appreciation of the problem at hand.

It is also important to widely disseminate the Resolution to all of the community by word of mouth, radio, emails, and posting in public places so that they are aware. By doing so, everyone becomes an enforcer of the Traditional Council of Chiefs decision because no one wants to be seen as publicly breaking the Chiefs rules.

Conflict of Interest

None of the authors identify any conflict of interest.

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Author Affiliation:
Yap State Department of Health Services, Yap, Federated States of Micronesia

Correspondence to:
Martina Reichhardt BJRN; Yap State Department of Health Services, Yap, Federated States of Micronesia. Email: mreichhardt@fsmhealth.fm

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LESSONS FROM THE FIELD

Going Local—Everybody Wins

Aileen C. Tareg DrPH, CHES and Martina L.E. Reichhardt BJRN

Abstract

Pacific Islanders suffer from chronic diseases attributed largely to an overconsumption of processed foods. As a response, the CDC-funded Racial and Ethnic Approaches to Community Health (REACH) Go Local Project in Yap, Federated States of Micronesia (population: 12,000) sought to create a food intervention that would not only increase access to fresh, local foods, but benefit food vendors as well for a sustainable effect. For this program, a number of markets were chosen for selling any fresh local produce, meat, and catch. These markets agreed to allow purchasers of healthy local food of a minimum amount to be entered into a monthly raffle. Monthly winners received fresh food gift certificates while participating markets received a gift upon certificate redemption. REACH and partners distributed healthy island recipes and nutrition information at these partner markets. Formative evaluation examined customer and vendor satisfaction through interviews and surveys, and tracking of healthy food purchases and customer demographics were garnered via raffle information. Brief interviews with customers and vendors revealed favorable reactions to the Go Local Project. People enjoyed winning and vendors found satisfaction in promoting health through their businesses.

Keywords

REACH, Pacific Islander health, Federated States of Micronesia, Yap, nutrition, fresh food, local

Introduction

Non-communicable disease is rapidly taking hold of the state of health in the Pacific. The World Health Organization reports that at least 10 Pacific Island countries are over 50-90% overweight, due largely to the popularity of convenient imported foods.[1] Yap State of the Federated States of Micronesia, a nation in the Northwestern Pacific, is no different. Much like the rest of the Pacific in their prime days of health pre-World War II, the average Yapese toiled hard under the sun and was leaner than the typical Yapese today; men would catch food from the sea and women would harvest from the land. The people, both young and old, physically worked to feed their families and labored to maintain order in the social system of the times. They ate fresh food, maintained their village structures, celebrated their culture with dance and local sport, and found pleasure and leisure in nature. Chronic disease was very uncommon then.

Today, many Yapese people suffer from health issues related to a poor diet of processed foods. The last quinquennial Wa'ab Community Health Center Household Survey (2012) revealed that 20% of youth and 61% of adults were overweight or obese. Obesity is linked to cancer, pneumonia, heart disease, and stroke—some of the leading causes of death in Yap. Obesity leads to other chronic diseases such as high blood pressure and diabetes. The same survey showed that 27% of adults (21+ years) had diabetes, an increase from 23% in the previous 2007 survey, and 24% had high blood pressure. Both conditions are linked to kidney failure, blood infections, as well as most of the aforementioned causes of death in the state.[2] As the rates of chronic diseases and their related complications continue to rise, it is important to target and promote healthy behaviors more than ever.

To compete with the copious amounts of imported, preservative-filled, processed foods popularly preferred for their convenience of speedy preparation and long shelf-life, the Wa'ab Healthy Lifestyle Coalition initiated a project called "Go Local" in the fall of 2012. This was a healthy food promotion project designed to motivate people to buy fresh, locally grown fruits and vegetables, as well as local meat and seafood. Feedback from this two-year long project was positive from the markets and vendors that participated and among people who would buy local food or those who would hear about it.

The goal of the Centers for Disease Control and Prevention's Racial and Ethnic Approach to Community Health (REACH) from 2015-2017 was to implement a high impact, population-wide strategy to reduce health disparities. Accordingly, the Yap State REACH branch revived Go Local to increase access to environments with healthy nutrition options, reaching at least 75% of the general population. To accomplish this, Yap REACH would not only reinitiate Go Local to increase healthy food options, but more than double the original number of markets in the past from four to nine by September 2017 to boost the community's accessibility. These markets were defined as stores or vendors that sold fresh food items, either exclusively or inclusively. The purpose of this paper is to share the results of the revival project and how it continued to encourage healthy food consumption while considering Yap's economy.

Methods

The following concept drove the Go Local Project: buying local food would benefit both people and businesses. In order to reestablish former vendor partnerships and build new ones, the Local Project Assistant for Yap REACH first visited and spoke to targeted vendor owners and managers to explain the conditions of Go Local and gain commitment. In order to be chosen as a vendor in the project, which could happen at anytime during the project period, a market had to carry any locally grown fruits, vegetables, or fresh local meats and seafood. Once a partnership was formed, each market was provided with a stack of customer surveys and a red box for drop-in of completed surveys. Market cashiers were then instructed to encourage customers to fill out the brief survey and then drop it in the marked box kept at the counter. Only customers who purchased at least $5.00 worth of only local foods were eligible for a monthly drawing. Customers could enter as many times as desired, so long as they met the purchase criteria for each transaction; 3 winners were drawn monthly. In the previous Go Local project, there was no minimum purchase amount, and not only were the collection and entry of data overwhelming, but sale entries for the raffle ranged in the cents and validity of entries was questioned.

When markets joined, they agreed to give free food to winners ($25 worth) in exchange for free promotion to help support healthy behaviors. Project progress was tracked through the survey used for the monthly raffles. The following information was collected on the short survey: customer name, customer phone number (to inform winners via phone call or text message), amount sold, vendor, cashier initials (for verification and accountability), customer age, customer municipal residence, and type of food purchased (Appendix A). Surveys were collected from all vendors by the Local Project Assistant the first week of each month. All data were entered into a Microsoft Excel database to calculate frequency, means, and percentages. Entries without sale amounts, cashier initials, vendor, age, village, or food type were excluded from analyses and drawings. Monthly reports of this information were shared with the public via newsletter and e-bulletin, and distributed as one-page printout summaries to market owners and managers.

Many more Yap REACH partnerships went into the mechanics of Go Local. V6AI, the only radio station in the state, played a role in the project by providing free vendor advertisement, airplay of winner-announcements, as well as health education messages about the benefits of eating fresh, local food. Similarly, the Yap Cancer Program offered free space for ads, nutrition and other health information, and announcements on their printed newsletter, which was dropped off at markets, health sites, schools, and other heavy-traffic spots. The Wa'ab Community Health Center assisted in printing and distributing these newsletters, supporting Yap REACH as needed in its efforts to strengthen partnerships. The Yap News Brief, the state government's online and electronic news bulletin, offered to transmit the same information on the newsletter at no cost. Members of the Yap Cancer Program, the Non-Communicable Disease (NCD) Program, the Wa'ab Community Health Center, and the project-conceiver, Wa'ab Healthy Lifestyle Coalition, all played a role in printing the surveys, distributing them to all Go Local markets, collecting the surveys at the end of each month, entering data, and promoting Yap REACH's efforts in the community through reports and outreach presentations.

Brief, intermittent surveys were conducted for qualitative feedback on the community's response to Go Local. The first was a brief interview conducted mid-way through the project with market cashiers, managers, and owners to obtain their perspective on, if and why, they thought people participated in the program and if there was support for it among customers (Appendix B). An intercept survey was conducted in the final year to ask customers about their eating habits and if they had heard or seen any of the REACH market promotion (Appendix C).

There were nine total participating markets, each of which joined at various points throughout the project period.

Results

The results described in this manuscript summarize data collected from June 2015 to September 2017. Table 1 contains information on the breakdown of purchasers by age group. The total number of purchasers was 3,052, with most project participants age 51 and over (n = 1,053), followed by those 41-50 years old (n = 819), 31-40 years old (n = 650), 18-30 years old (n = 365), and finally those age 17 and under (n = 165).

Figure 1 shows totals for how much the markets made individually and collectively. Both Island Farm and YCA joined at the beginning in June of 2015. People's Market, Keng Store, and Island Fashion all joined in July of 2015; People's Market was a farmer's market event held only 2 days per month. Quality Catch joined in September 2015. Savannah Store joined in January of 2016, Aces Mart in October of the same year, and New Market in November, the following month. The market with the most sales was Quality Catch, the seafood market, which joined the project four months into the start.

Figure 2 shows number of purchases for each type of food: fruit (eg, apple, coconut, tangerine, grapefruit, guava, banana, mango, etc.), green vegetables (eg, beans, cabbage, kangkung,

Table 1. Demographic Characteristics of All Go Local Participants/Purchasers (N=3,052)

Respondents' Demographics	n	%
Age (in years)		
≤17	165	5%
18-30	365	12%
31-40	650	21%
41-50	819	27%
≥51	1,053	35%

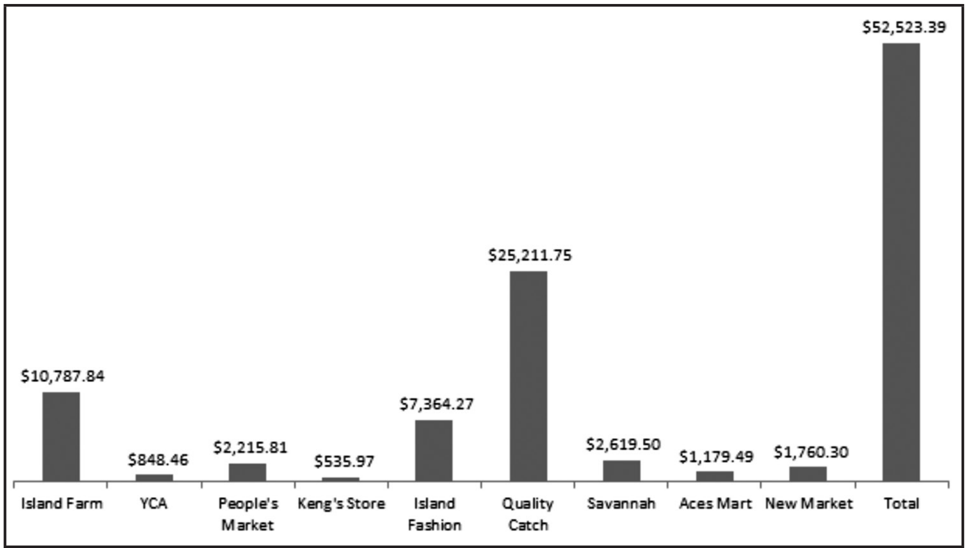

Figure 1. Chart of Go Local Sales: Overall and by Market, June 2015-September 2017

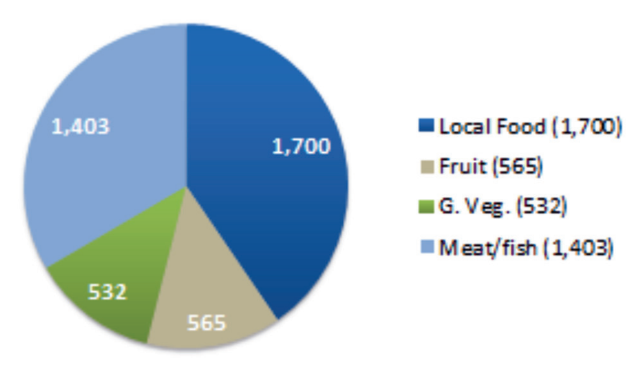

Figure 2. Chart of Go Local Food Type Purchases

okra, etc), local food (eg, breadfruit, taro, sweet potato, tapioca, yam, or other staple foods that are usually starch roots), and local meat and seafood (eg, crab, fish, pork, etc.). Of the 4,200 total purchases made, respondents bought local food (1,700 purchases, 40%), meat or seafood (1,403 purchases, 33%), fruits (565 purchases, 14%), and green vegetables (532 purchases, 13%).

The brief interviews with several market cashiers, managers, and owners included the following comments to the questions:

Question: Why do people participate in the project at this site?

> "For good health, [to] help [the] economy, [because the] food is fresh."
> "For the raffle."
> "For the prize."
> "Because the cashier encourages filling out the survey."

Question: Do people generally like or support the program? Why or why not?

> 9/9 answered 'yes.'
> "To eat local food."
> "People like to buy food, but sometimes we have no market because our market board is not stable at the moment."
> "People are fine with the cashier's suggestion to participate."
> "Local food is good for health."
> "Healthy food promo is good."

The intercept survey initiated at the start of the final year asked customers about their food-purchasing behavior. When asked how often they bought healthy local food whenever they went shopping, 43% said they **sometimes** did, followed by 28% who said **a lot**, and 26% who said **every time** they went shopping (0% said **never** and 3% did not answer). Another question asked if they had bought more, less, or the same amount of the healthy food types this year compared to the previous year (2016). Of the 1,304 survey participants, 45% indicated buying more of these foods, followed by 39% who said they bought the same amount as the previous year, 13% who said they purchased less, and 3% who left blank responses. The highest positive change was the purchase for more local food.

When asked if they had heard or seen messages about the Go Local Project, 82% of respondents had heard or seen messages, 14% said they had not, and the last 4% either left their responses blank or provided unclear or unreliable responses.

Discussion

According to the results of the project, most of the survey respondents were in the 51 and above age range. Many adults said they grew up eating fresh, locally grown food, are accustomed to, and tend to prefer it. It is the trend now for younger generations to grow up on and prefer store-bought food, and the data reflects this. Also, it was revealed that some of the names written on the surveys belonged to infants or young children; parents substituted their own names with their children's—a popular practice with raffle participation in Yap. Fewer young people (15-19 years of age) tended to shop for fresh market food because fewer were employed (lowest percentage of members of any age group in the workforce).[3]

Sales information was included in report summaries shared with vendor managers and owners primarily to foster 'friendly competition' between stores, thereby motivating their staff and stakeholders to encourage the filling out of more surveys and higher-value purchases. Figure 1 shows total sales for fresh food, overall and by each market. Vendors were recruited and began their participation at different times of the project period, which explains the large differences between total sales figures. Some of the markets also have special conditions that affected how much money they made compared to the others. For instance, People's Market is held only two consecutive half-days each month (during the last government pay-week of the month), whereas the rest are open at least five days a week and for at least eight hours at a time. Also, not all purchases were counted in the data analyses because qualifying entries into the raffle had to be of $5 value or above. This would also explain why Quality Catch, the only seafood vendor, had the most sales (the majority of their fish sales ranged well over $5 each, which would qualify almost all of their transactions for the raffle), as opposed to other markets with much lower value sales. Regardless, it is still evident that people are buying fresh, local food and both customers and vendors are supportive of the project.

As for food type purchased, the most popular were local foods, which are staples that many consumers eat with meat or fish. They are the foods that take the place of white rice or bread in health-conscious meals and are common in older folks' meals. Many have stated that eating these dense foods can sustain oneself throughout the day better than other foods (store-bought or in fresh fruit or vegetable form). Local food won out as most bought despite the $5 minimum purchase that might have put local meat and seafood at the top of the list. Local meat and seafood came in second. An increase in gasoline prices over the years (currently at over $4/gallon) has affected people's ability to catch fish themselves. A fruitful fishing trip can use around 12 gallons of gas, and this does not include the price of oil for the fuel mixture. With modern-day jobs, people find it more worthwhile to buy food than to plant, harvest, or catch their daily sustenance. Fruits and vegetables were last in the purchasing breakdown, in that order. Fruits and vegetables are less hardy and more prone to spoilage in the markets; only one vendor (YCA) kept imported fruits and veggies in a refrigerator as opposed to leaving all fresh local food, fruits, and veggies in the open. Maintaining electrical appliances and availability of electricity in general are important factors in food storage and finances.

As for other similar efforts, US federal nutrition assistance programs served to be environmental interventions in the community to increase access to healthy foods.[4] An article reviewing studies on the effectiveness of these programs showed that with WIC Farmers Market Nutrition Program and Senior Farmers Market Program, consumption of fresh fruits and vegetables generally increased among recipients of food vouchers.[5] Like Go Local, they provided food vouchers and tracked their redemption to observe program success. Another article on a related program called "Fresh To You" also found increased consumption for fresh foods when discounts were offered at participating markets.[6]

In the future, should Go Local be continued, all short purchase surveys could be counted for more complete information on actual sales (ie, remove the minimum purchase cut-off) and collaboration could be done with a local marketing expert and artists to create colorful, eye-catching signage in the markets with nutritional information specific to foods for better education and promotion. The project would be manageable under different programs and organizations, as it used to be operated by the Wa'ab Healthy Lifestyle Coalition with the help of the Yap Cancer Program. Both the Division of Agriculture and the NCD Programs are using the data from the Go Local Project and several other entities are expressing interest in the data for the promotion of local farming and fishing. It will not be difficult to find groups that can sustain the efforts of Go Local, as it showed promising results and change in the community.

Conflict of Interest

None of the authors identify a conflict of interest.

Acknowledgments

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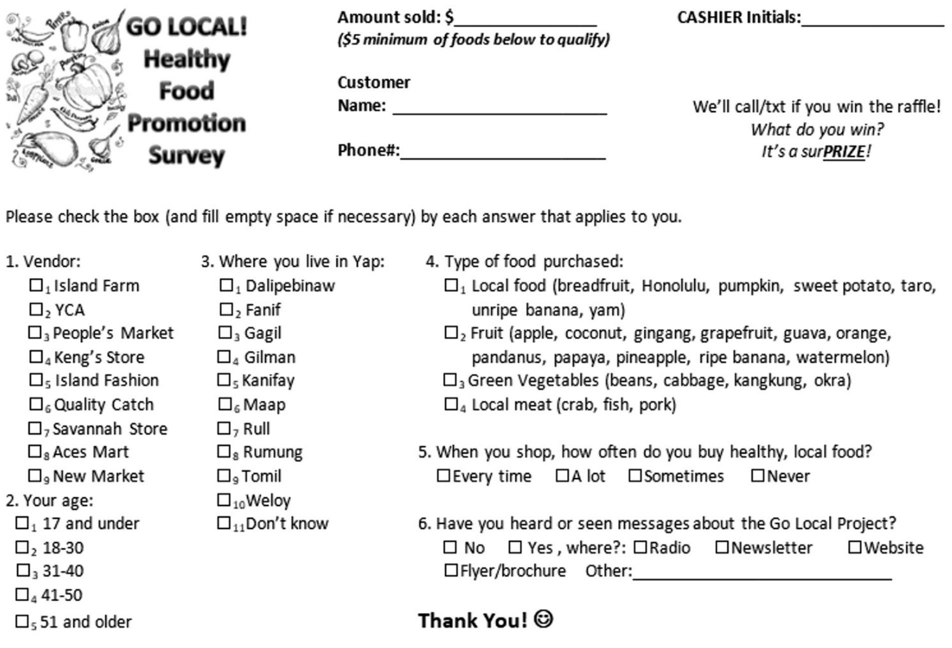
Appendix A. Go Local Short Survey (final version)



GO LOCAL!
Healthy
Food
Promotion
Survey

Amount sold: $________________
($5 minimum of foods below to qualify)

CASHIER Initials:________________

Customer
Name: ________________________

Phone#:_______________________

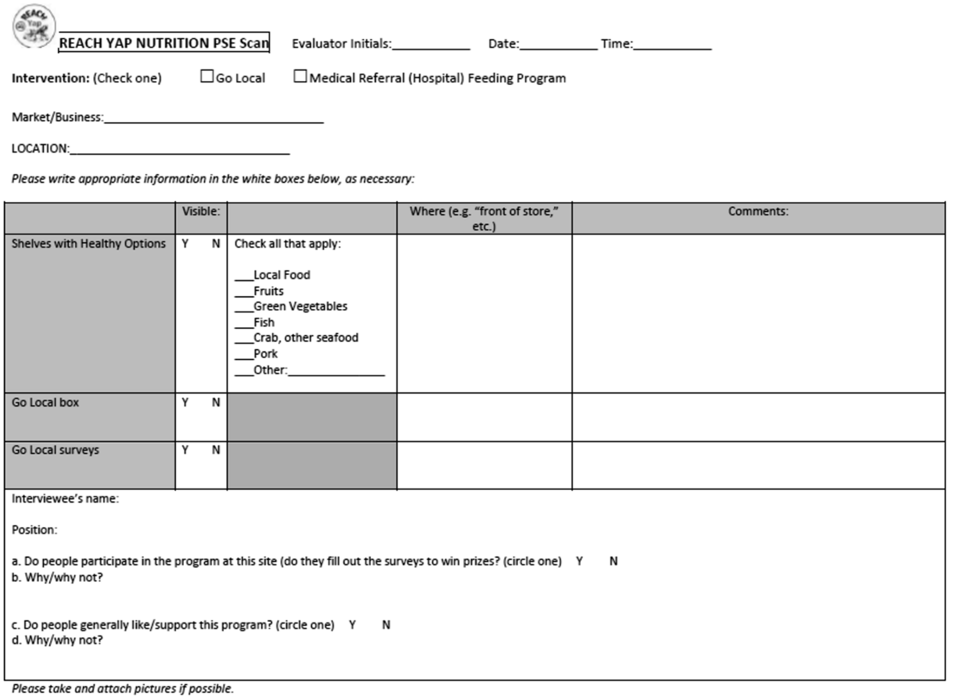
We'll call/txt if you win the raffle!
What do you win?
*It's a sur**PRIZE**!*

Please check the box (and fill empty space if necessary) by each answer that applies to you.

1. Vendor:
   - ☐$_1$ Island Farm
   - ☐$_2$ YCA
   - ☐$_3$ People's Market
   - ☐$_4$ Keng's Store
   - ☐$_5$ Island Fashion
   - ☐$_6$ Quality Catch
   - ☐$_7$ Savannah Store
   - ☐$_8$ Aces Mart
   - ☐$_9$ New Market
2. Your age:
   - ☐$_1$ 17 and under
   - ☐$_2$ 18-30
   - ☐$_3$ 31-40
   - ☐$_4$ 41-50
   - ☐$_5$ 51 and older
3. Where you live in Yap:
   - ☐$_1$ Dalipebinaw
   - ☐$_2$ Fanif
   - ☐$_3$ Gagil
   - ☐$_4$ Gilman
   - ☐$_5$ Kanifay
   - ☐$_6$ Maap
   - ☐$_7$ Rull
   - ☐$_8$ Rumung
   - ☐$_9$ Tomil
   - ☐$_{10}$ Weloy
   - ☐$_{11}$ Don't know
4. Type of food purchased:
   - ☐$_1$ Local food (breadfruit, Honolulu, pumpkin, sweet potato, taro, unripe banana, yam)
   - ☐$_2$ Fruit (apple, coconut, gingang, grapefruit, guava, orange, pandanus, papaya, pineapple, ripe banana, watermelon)
   - ☐$_3$ Green Vegetables (beans, cabbage, kangkung, okra)
   - ☐$_4$ Local meat (crab, fish, pork)
5. When you shop, how often do you buy healthy, local food?
   ☐Every time ☐A lot ☐Sometimes ☐Never
6. Have you heard or seen messages about the Go Local Project?
   ☐ No ☐ Yes , where?: ☐Radio ☐Newsletter ☐Website
   ☐Flyer/brochure Other:_____________________________

Thank You! ☺

Appendix B. Brief Interview (last two questions are for the interview with cashiers, managers, and owners)



REACH YAP NUTRITION PSE Scan Evaluator Initials:___________ Date:___________ Time:___________

Intervention: (Check one) ☐Go Local ☐Medical Referral (Hospital) Feeding Program

Market/Business:________________________________

LOCATION:_______________________________

Please write appropriate information in the white boxes below, as necessary:

	Visible:		Where (e.g. "front of store," etc.)	Comments:
Shelves with Healthy Options	Y N	Check all that apply: ___Local Food ___Fruits ___Green Vegetables ___Fish ___Crab, other seafood ___Pork ___Other:_______________		
Go Local box	Y N			
Go Local surveys	Y N			

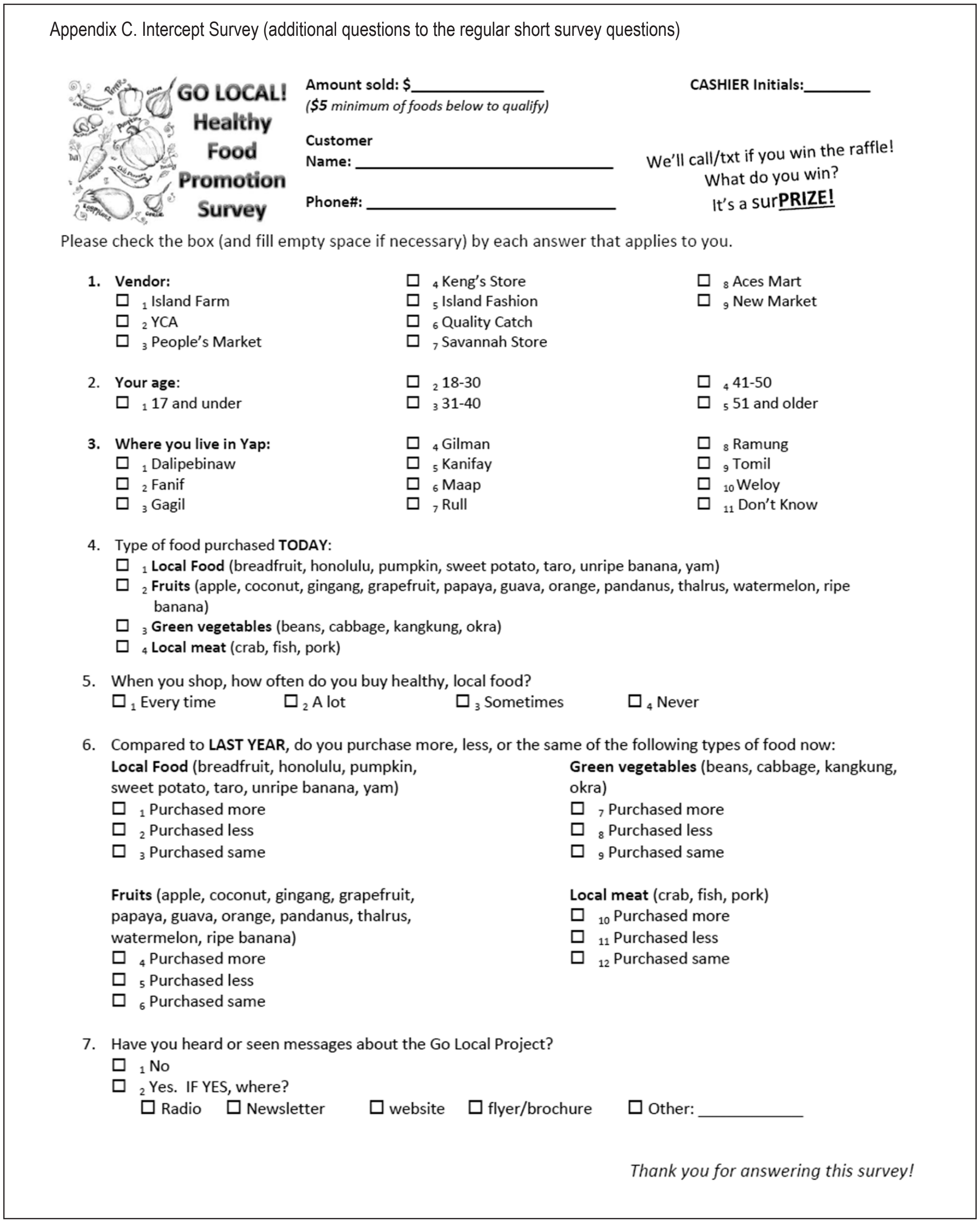
Interviewee's name:

Position:

a. Do people participate in the program at this site (do they fill out the surveys to win prizes? (circle one) Y N
b. Why/why not?

c. Do people generally like/support this program? (circle one) Y N
d. Why/why not?

Please take and attach pictures if possible.



Appendix C. Intercept Survey (additional questions to the regular short survey questions)

GO LOCAL! Healthy Food Promotion Survey

Amount sold: $______________
*(**$5** minimum of foods below to qualify)*

CASHIER Initials:________

Customer Name: ____________________________

Phone#: ____________________________

We'll call/txt if you win the raffle!
What do you win?
It's a sur**PRIZE!**

Please check the box (and fill empty space if necessary) by each answer that applies to you.

1. **Vendor:**
   - ☐ 1 Island Farm
   - ☐ 2 YCA
   - ☐ 3 People's Market
   - ☐ 4 Keng's Store
   - ☐ 5 Island Fashion
   - ☐ 6 Quality Catch
   - ☐ 7 Savannah Store
   - ☐ 8 Aces Mart
   - ☐ 9 New Market
2. **Your age**:
   - ☐ 1 17 and under
   - ☐ 2 18-30
   - ☐ 3 31-40
   - ☐ 4 41-50
   - ☐ 5 51 and older
3. **Where you live in Yap:**
   - ☐ 1 Dalipebinaw
   - ☐ 2 Fanif
   - ☐ 3 Gagil
   - ☐ 4 Gilman
   - ☐ 5 Kanifay
   - ☐ 6 Maap
   - ☐ 7 Rull
   - ☐ 8 Ramung
   - ☐ 9 Tomil
   - ☐ 10 Weloy
   - ☐ 11 Don't Know
4. Type of food purchased **TODAY**:
   - ☐ 1 **Local Food** (breadfruit, honolulu, pumpkin, sweet potato, taro, unripe banana, yam)
   - ☐ 2 **Fruits** (apple, coconut, gingang, grapefruit, papaya, guava, orange, pandanus, thalrus, watermelon, ripe banana)
   - ☐ 3 **Green vegetables** (beans, cabbage, kangkung, okra)
   - ☐ 4 **Local meat** (crab, fish, pork)
5. When you shop, how often do you buy healthy, local food?
   ☐ 1 Every time ☐ 2 A lot ☐ 3 Sometimes ☐ 4 Never
6. Compared to **LAST YEAR**, do you purchase more, less, or the same of the following types of food now:

   Local Food (breadfruit, honolulu, pumpkin, sweet potato, taro, unripe banana, yam)
   - ☐ 1 Purchased more
   - ☐ 2 Purchased less
   - ☐ 3 Purchased same

   Fruits (apple, coconut, gingang, grapefruit, papaya, guava, orange, pandanus, thalrus, watermelon, ripe banana)
   - ☐ 4 Purchased more
   - ☐ 5 Purchased less
   - ☐ 6 Purchased same

   Green vegetables (beans, cabbage, kangkung, okra)
   - ☐ 7 Purchased more
   - ☐ 8 Purchased less
   - ☐ 9 Purchased same

   Local meat (crab, fish, pork)
   - ☐ 10 Purchased more
   - ☐ 11 Purchased less
   - ☐ 12 Purchased same
7. Have you heard or seen messages about the Go Local Project?
   - ☐ 1 No
   - ☐ 2 Yes. IF YES, where?
     ☐ Radio ☐ Newsletter ☐ website ☐ flyer/brochure ☐ Other: ____________

Thank you for answering this survey!

Authors' Affiliation:
- Yap State Department of Health Services, Yap, Federated States of Micronesia

Correspondence to:
Aileen C. Tareg DrPH, CHES; Yap State Department of Health Services,
P.O. Box 1010, Colonia, Yap 96943 FSM; Email: atareg@fsmhealth.fm

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Interventions to Improve Health and Quality of Life to Address the NCD Crisis in Palau - Fostering Collaboration Across Sectors within the Government and Civil Society

Edolem Ikerdeu MA; Annabel Lyman MPH; Candace Koshiba BA; Irish Tutii;
Valerie Whipps BA; Komtil Ngirmang BA; and Sylvia Osarch DCHMS

Abstract

The Republic of Palau is a small island nation in the North Pacific with a population of 17,501. The islands of Palau are geographically isolated, considered rural, and medically underserved. The prevalence of non-communicable diseases (NCDs) and risk factors are very high and account for more than 75% of all deaths and disabilities. Recognizing that the high rates of NCDs are undermining health and sustainable development of the nation, Palau declared a state of health emergency due to the epidemic of NCDs. It was recognized during the development of the NCD Prevention and Control Strategic Plan of Action 2015-2020 (Palau NCD Plan) that improved collaboration between government agencies, civil society, and the private sector was needed to address this epidemic. A multi-sectoral solution was needed to address a multi-sectoral problem. Through Presidential Executive Order, the National Coordinating Mechanism for Non-Communicable Diseases (CM) was established to mobilize sufficient resources and coordinate actions to prevent and control NCDs, ensure successful implementation of the Palau NCD Plan, the World Health Organization Framework Convention on Tobacco Control, and other related plans and commitments, align such plans to national policies, ensure a health-in–all-policy approach to address health inequities, and bridge the gap between health and quality of life. Though the CM is young, improved coordination between agencies and accelerated action has taken place. Legislation was enacted that mandates 10% of alcohol and tobacco taxes be directed to NCD prevention through the Coordinating Mechanism, thus ensuring sustainability.

Keywords

non-communicable diseases, collaboration, Pacific Islands, health-in-all-policy

Background

The Republic of Palau (Palau) is located in the North Pacific Ocean, 722 miles southwest of Guam and 528 miles southeast of Manila, Philippines. The capital was relocated from the State of Koror to Ngerulmud, Melekeok in 2006; however, Koror remains the economic center where two-thirds of Palau's 17,501 population reside.[1] About 73.5% of the nation's residents are of Palauan ethnicity, followed by Filipinos making up 16% of the population.[1] Approximately 15% of the population has a college bachelor degree or higher.[1] Palau is considered a low-income country with 60% of households making less than \$20,000 annually.[2]

The prevalence of non-communicable diseases (NCDs), including injuries, and risk factors in Palau are very high and account for more than 75% of all deaths and disabilities on this small island nation.[3] There are alarming rates of smoking and alcohol use among youth, betel nut chewing with tobacco, binge drinking, low consumption of fruits and vegetables, physical inactivity, obesity, hypertension, and diabetes in adults (Table 1).[4-6]

Recognizing that the high rates of NCDs are undermining health and sustainable development in the nation, Palau, along with the global community, declared a "state of health emergency due to the epidemic of NCDs".[7] Progressing from political commitment to action, the government and community stakeholders set national targets, specific goals and objectives, and identified evidence-based and cost-effective strategies in the revised NCD Prevention and Control Strategic Plan of Action 2015-2020 (Palau NCD Plan) during a strategic planning workshop in 2014. Stakeholders understood that collaboration was key to the effective implementation of the Palau NCD Plan and that it was critical to establish a governance framework that could facilitate and allow partners to work together to develop and implement strategies that promote and protect public health. For many years, the Palau Ministry of Health has taken the lead in responding to the NCD crisis, and most health promotion strategies took the form of education and awareness campaigns. Stakeholders at the strategic planning workshop further recognized the complex nature of NCDs and health as determined by social, economic, and cultural factors, that a call for a health-in-all-policy approach was needed, and that collaboration among the "whole of government and society" was necessary. This collaboration was necessary to ensure mobilization of sufficient resources and implementation of sustainable strategies to create environments that support and protect healthy behaviors and lifestyles, which in turn would help to address the health inequities that have led to the high rates of these debilitating conditions.[8] Parties to the World Health Organization Framework Convention on Tobacco Control (WHO FCTC) also recognized this need for multi-sectoral coordination to address tobacco control issues as articulated in the Treaty's Article 5.2(a) — Palau is a Party to this Convention.

Table 1. NCDs and Risk Factors Profile for Palau[4-6]

Indicator	Overall prevalence	Males	Females
NCD mortality	Over 70% of all deaths in 2003-2012		
Smoking, current, adults	17%	24%	8%
Smoking, current, youth	41%	58%	42%
Betel nut + tobacco, adults	63%	60%	66%
Smokeless tobacco use, youth	29%	31%	27%
Current alcohol consumption, adults	37%	50%	23%
Current alcohol consumption, youth	43%	51%	38%
Binge drinking, adults	Male 43.5% Females 16.6%	44%	17%
Binge drinking, youth	33%	40%	26%
< 5 servings fruits and vegetables, adults	92%	94%	90%
No recreation-related physical activity, adults	52%	42%	62%
Raised blood pressure (measured)	49%	53%	44%
Raised blood glucose (measured)	20%	21%	20%
Overweight/obesity, adults	77%	78%	76%
Raised cholesterol, adults	23%	29%	26%

Adults = 25-64 years old; Youth = 13-25 years old

The call to action, resulting from the 2014 strategic planning workshop, was to establish a system or mechanism to focus a multi-sectoral response to the NCD crisis that faces Palau. The prevention and control of NCDs go beyond the health sector and successful intervention requires collaboration across sectors within governments and the community. Health promotion goes beyond the individual and interventions must also be directed at social and physical environments that can either support or deter health; these include interpersonal, organizational, community, and public policy change strategies.[9] Therefore, in addition to strengthening the health sector to respond effectively to the healthcare needs of people with chronic conditions, sectors outside health such as finance, education, justice, and infrastructure can influence or adopt public policies that address risk factors. Examples of such policies include those that reduce access to and affordability of alcohol and tobacco, such as advertising bans of these products, raised alcohol and tobacco excise taxes, the enforcement of existing regulations such as ones on tobacco sales to minors, and the augmenting of the environment to promote physical activity.[10] Despite historical partnership between government agencies and various civil society groups to address common goals like the prevention and control of NCDs, without consistent or more formalized coordination among the partners, there were duplication of efforts, wasted or untapped resources, and a lack of policy coherence.

Methods

During the NCD strategic planning workshop in March 2014, the planning committee ensured that several presentations relayed information on the critical need for a comprehensive and multi-sectoral response framework. With resource materials (eg, Centers for Disease Control and Prevention [CDC] Four Domains on Chronic Disease Prevention and Health Promotion, WHO FCTC, and Pacific Island Health Officers Association's NCD Policy Toolkit) from technical advisors and the University of Hawai'i and Coalition for a Tobacco Free Palau, workshop presenters gave in-depth information on the different roles that each government agency, community-based organization, or non-governmental organization could play within the entire scheme of the response. Information was presented on how, for example, the Ministry of Public Infrastructure, Industries and Commerce could influence the design and development of roads to promote walkability and physical activity in Palau. In addition, other presenters explained how the Ministry of Finance was responsible for promulgating tobacco tax regulations as well as having the power and information to influence further increases in both tobacco and alcohol taxes. Each of Palau's eight Ministries and several civil society groups were provided examples of what they already do with respect to NCD prevention and what more they could do. This served to illustrate that there was a need for responses to the NCD crisis from other non-health sectors. A small work group (WG) comprised of Ministry of Health chronic disease program staff and partners from community health coalitions was tasked to consult with more stakeholders to finalize the Palau NCD Plan by the end of 2014 and to facilitate the development of an implementation framework. Stakeholders had suggested such an approach during the workshop out of concern for the successful implementation and evaluation of the Palau NCD Plan and after the realization that an effective NCD crisis response called for multi-sectoral, multi-level actions.

Initial discussions and brainstorming sessions resulted in the idea of a mechanism that would not limit membership but would include relevant government agencies, civil society, and private sector organizations to come to the table and take responsibility for actions that would contribute to the prevention and control of chronic diseases and the promotion of health. The WG organized another workshop to explore ideas and models of such a mechanism and invited a few organizations (largely from the environmental arena) to present their experiences. The WG found limited literature and documented experiences from other countries who have tried to establish similar structures. Formal and informal committees, coalitions, and similar mechanisms were examined and discussed. Participants to this second workshop agreed that a formalized mechanism (eg, formal policy, Executive Order, or legislation), as opposed to a voluntary and informal coalition, would result in stronger support and commitment, at least from the government. Discussions during these two workshops explored why Palau needed stronger commitment and action through this formal mechanism. The increased rates of NCDs globally, regionally, and locally secured Palau's political commitment; yet, work was needed to accelerate action. Initially, many partners were unsure of their roles in the NCD response. Second, the community coalitions did not have strong administrative support, and volunteers, most of whom worked full-time, were stretched to their limits. With a formal mechanism in place, an administrative arm could be mandated and assigned to coordinate and move the activities forward.

Through a year-long series of workshops, meetings, and stakeholder engagement, this mechanism of coordination was developed. Toward the end of 2014, the workgroup drafted terms of reference (ToR) including background information that supported the mechanism, its purpose, membership of the government sectors and civil society that played key roles in disease prevention and health promotion, membership terms, member roles and responsibilities, establishment of a secretariat and working groups, and reporting requirements. With help from the Office of the President and a legal advisor from the Ministry of Health, the ToR were finalized. From January to May 2015, the ToR were presented to Palau's leadership and more partners for review.

Results

As a result of the extensive preparatory work by all stakeholders, the President of Palau signed Executive Order No. 379 in May 2015 "to create a National Coordinating Mechanism to facilitate and coordinate the Government of the Republic of Palau's efforts to combat the occurrences and impacts of non-communicable diseases in the Republic of Palau", and to engage appropriate civil society and private sector organizations to ensure a "whole of society" approach to the NCD response. The Coordinating Mechanism for Non-Communicable Diseases (CM) was established to mobilize sufficient resources, coordinate actions to prevent and control NCDs, ensure successful implementation of the Palau NCD Plan, the WHO FCTC, and other related plans and commitments, align such plans to national policies, ensure a health-in–all-policy approach to address health inequities, and bridge the gap between health and quality of life.

Membership includes representation from the Office of the President and the entire Executive Branch (education, health, justice, tourism, environment, commerce and trade, public infrastructure, culture, community and state, and finance), as well as from academia, public health insurance, traditional leadership, early childhood education, youth, conservation, farmers' association, parents' and families' associations, students' association, principals' association, employers' alliance, Red Cross, the various health coalitions (tobacco, behavioral health, early childhood, HIV/Sexually Transmitted Infections, community health centers, and cancer), and technical advisors. There are currently 32 active members serving this committee.

A five-member secretariat provides administrative support to the CM. Two of the members are from the Ministry of Health's Non-Communicable Disease Unit and the Prevention Unit within the Bureau of Public Health. The other three secretariat members are chosen by the CM members and serve for two years. During the first year, Ministry of Education, Ministry of Finance, and Ministry of Public Infrastructure, Industries and Commerce also served on the secretariat. A chairperson is elected and serves a year-long term. Members serve on a two-year rotational basis but may be elected to remain by the head of their respective organizations.

The CM subsequently established Working Groups (WGs) for each of the four major NCD risk factors (tobacco, alcohol use, physical inactivity, and unhealthy diets), a fifth on metabolic risk factors (high glucose and lipids and hypertension), and a sixth on monitoring and evaluation. Members of these WGs are assigned by CM members and there can be more than one WG member from each organization, depending on their roles in the response. For example, the CM recommended that the Ministry of Justice assign two of their staff, one for the alcohol WG and another for the tobacco WG. Palau Community College recognized a need to assign its staff to each of the four major WGs. During one of the CM's early meetings, a substantial amount of time was spent discussing membership and purpose of these working groups.

For the first year of the Palau NCD Plan (October 2015 – September 2016), the CM members determined annual activities from the Plan; however, when the working groups were established, their members were tasked to set their own annual action plans; each working group had set annual activities for year 2 (October 2016 – September 2017) and submitted a proposed budget narrative to the CM for review and approval before submission to the Palau Congress in July 2016. WG members meet between the quarterly CM meetings, once a month or more depending on the activity being implemented.

However, at times, a working group might work more through email or other means, depending on the type of activity. It was decided by the CM that the secretariat provide administrative support to the WGs, coordinate their meetings, provide relevant information to the members, and document and report on their progress to the CM every three months. However, the intent was to build the capacity of working group members to lead the implementation of activities on their own within 12-18 months.

Results of a mid-year evaluation of the CM's first year and the implementation of the Palau NCD Plan reveal over 70% participation rate from CM members, timely implementation of annual activities, and documentation and dissemination of meeting minutes, progress reports, and other pertinent information. Finally, because of the strong NCD Plan and the existence of an organized NCD coordinating mechanism, CM members were successful in allocating 10% of alcohol and tobacco tax revenues towards NCD prevention and health promotion activities through Palau Public Law (RPPL) 9-57. To distribute the funds, the CM will review proposed programs from government and community organizations according to agreed upon selection criteria and submit a budget request to the Palau Congress for approval. Funds are non-lapsing and projected to be up to $1,000,000 every year.

Conclusions

Although the CM is still early in its life, it has far reaching potential. Having a formalized mechanism in existence is significant and the allocation of ten percent (10%) of tobacco and alcohol tax revenues to NCD prevention activities through the CM is landmark legislation. More government organizations are taking action within their respective areas to promote health (eg, the Cabinet has requested that all the Ministers, Directors, and Chiefs be screened for NCDs). The Ministry of Education has revised its physical education curriculum and implemented innovative ways to increase physical activities in schools. More CM member organizations and individuals in the community are taking steps to ensure that meals provided during meetings or in public gatherings are healthier. For example, the public schools' food service program has revised its menu to ensure healthier meals for students. Recently, a school cook was recognized as an employee of the year for her work and her efforts to ensure that lunches served in the cafeteria are "NCD free". There is increased networking, sharing, and coordinating of activities.

The established mechanism has underscored the fact that NCDs are not the concern of only the health sector but very much entrenched in daily lives, work, customs, policies, and environments. Changes have already been noted, especially in how people feel about the shared responsibility in working towards a healthier Palau. There is also an overall increase in networking and coordination of activities addressing the NCD epidemic. Coordination of multiple partners is accomplished through the existing multi-sector NCD and Comprehensive Cancer Control Coalitions which have shared goals. Sustainability is ensured, in part, by involvement of the grass roots sector, cultural alignment with all interventions, support by traditional leaders, and support from Palau's Government.

Lessons Learned and Next Steps

Support from the Republic's leadership has been key as well as the engagement of stakeholders every step of the way. Other lessons learned indicate that a strong administrative arm is necessary to sustain coordination and communication among partners. The two Ministry of Health chronic disease programs were designated by the Minister of Health to be permanent secretariat members to this mechanism, tasked to provide administrative and technical support to the members and working groups. Capacity building from the start has been another important lesson. During the first meeting, members were provided a detailed presentation of each of their roles, what they were already doing, and how they fit into the response. This helped to make the case for multi-sectoral action.

However, there remains work to be done to form a firmer understanding of health and the broader social determinants of health and disease. Not yet completed is a code of conduct for members that will ensure no interference from tobacco, alcohol, or junk food industries or their representatives to influence public policy. Continuing technical assistance and capacity building for members is also warranted so that the burden is not placed on the few who are well-informed, resulting in burn out. It is necessary that these select few share their responsibilities for effectiveness and sustainability. The high level of political support and early engagement from stakeholders, in combination with a secure funding stream, should contribute greatly to the sustainability of the mechanism.

Conflict of Interest

None of the authors identify a conflict of interest.

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Authors' Affiliations:
- Republic of Palau Ministry of Health, Koror, Palau (EI, CK, IT, KN, SO)
- Coalition for a Tobacco Free Palau, Koror, Palau (AL, VW)

Correspondence to:
Edolem Ikerdeu; Ministry of Health, Republic of Palau;
Email: edolem.ikerdeu@palauhealth.org

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Smoking, Nutrition, Alcohol, Physical Activity, and Obesity (SNAPO) Health Indicators Among College Students in Guam

Nicole Nazareno; Audrey Benavente; Michael Alicto; Joane Arceo; Ayn Charfauros;
Courtney Dizon; Ethan Flores; Jesse Fontanilla; Brandon Holm; Calvin Johanes;
Joed Mercado; Karina Perez; Kendrick Perez; Jordan Tingson;
and Yvette C. Paulino PhD, CPH

Abstract

Background/Purpose: *The Guam Non-Communicable Disease (NCD) Consortium developed action teams as part of their strategic plan to reduce the risk of NCDs. Smoking, Nutrition, Alcohol, Physical Activity, and Obesity (SNAPO) health indicators were targeted. The primary objective of this study was to describe SNAPO among students at the University of Guam.*
Methods*: A cross-sectional study was conducted from September to December 2015 on a non-random sample of students (n=378; 185 males, 193 females) ≥18 years old attending the University of Guam. Information on SNAPO indicators (smoking/tobacco-related uses, poor nutritional behaviors, alcohol use, physical inactivity, and obesity) were collected using questions from the Guam Behavioral Risk Factor Surveillance System and other local studies. Statistical tests were used to determine sex-specific differences.*
Results: *The overall prevalence of SNAPO health indicators included cigarette smoking (9.1%), smokeless tobacco use (6.7%), areca nut chewing (7.5%), alcohol consumption (44.3%) and binge drinking (24.6%), physical inactivity (54.5%), infrequent fruit (77.5%) and vegetable (68.0%) consumption, frequent fast food consumption (31.5%), inadequate water intake (89.1%) and obesity (22.6%). Sex-specific statistical differences were marginal for cigarette smoking and smokeless tobacco use and significant for physical inactivity and obesity.*
Conclusion: *The SNAPO health indicators provide an updated status of substance use and obesity-related risk factors of college students in Guam. Continued collection of the data is encouraged to inform campus-wide policies or programs that promote student health, monitor student health trends, and evaluate the Guam NCD Strategic Plan over time.*

Keywords

Areca (Betel) nut, Alcohol, College students, Health indicators, Non-communicable disease, Nutrition, Physical Activity, Obesity, Smoking, SNAPO, Tobacco

Abbreviations

BMI = Body Mass Index
BRFSS = Behavioral Risk Factor Surveillance Systems
CVD = Cardiovascular disease
NCD = Non-Communicable Disease
PAR-Q = Physical Activity Rating Questionnaire
SD = Standard Deviation
SNAPO = Smoking, Nutrition, Alcohol, Physical Activity, Obesity
SPSS = Statistical Package for the Social Science
UOG = University of Guam
YRBSS = Youth Risk Behavior Surveillance System

Introduction

Approximately 41 million people worldwide die each year from non-communicable diseases (NCD), with 15 million deaths occurring between the ages of 30 and 69 as of 2018.[1] Cardiovascular disease (CVD) was the leading cause of NCD deaths as of 2018 (17.9 of 41 million deaths), followed by cancer (9.0 million), respiratory disease (3.9 million), and diabetes (1.6 million).[1] Guam, an island in the Western Pacific, has been experiencing a similar burden and recently responded by developing the Guam NCD Strategic Plan.[2,3] Cardiovascular disease was the leading cause of NCD deaths on Guam in 2014 (297), followed by cancer (175), cerebrovascular disease (71) and diabetes mellitus (40).[4] The Guam NCD strategic plan describes the Consortium's strategies to improve the health indicators of smoking and smokeless tobacco use (S), nutrition (N), alcohol (A), physical activity (P), and obesity (O), collectively known as SNAPO, to reduce the risk of NCDs in Guam.[2,3]

SNAPO Health Indicators

Smoking increases the risk of developing NCDs such as lung cancer, heart disease, and chronic obstructive pulmonary disease.[5,6] Smokeless tobacco and areca nut use can increase the risk of developing oral cancer and CVD.[5,7,8] The percentage of adults who smoke in Guam decreased from 29.3% in 2014 to 26.4% in 2017, while the percentage of adults who use smokeless tobacco increased from 6.6% in 2014 to 7.9% in 2017.[9] The percentage of adults who chew areca nut also decreased from 12.5% in 2007 to 10.6% in 2010.[10,11] The harmful consumption of alcohol is associated with developing NCDs such as liver cirrhosis, cancer, and CVD.[12] Alcohol use among adults in Guam decreased from 46.5% in 2014 to 43.7% in 2018.[9]

A healthy diet and nutrition protects against NCDs such as diabetes, heart disease, stroke, and cancer.[13] Fruits and vegetables are an important component of a healthy diet.[13] A diet low in fruits and vegetables or high in trans fats could increase one's risks of developing NCDs.[14] In 2017, 44.1% and 26.7% of Guam adults consumed fruits and vegetables, respectively, less often than once a day.[9] Regular physical activity is essential to overall health and can reduce the risk of CVD, cancer, and diabetes.[15] The percentage of adults on Guam who reported that they did not participate in any physical activity for the past month was 33.4% in 2017, up from 27.7% in 2014.[9] Compared to those with a healthy weight, adults who are obese have a higher risk of developing NCDs such as diabetes, CVD, and cancer.[16,17] The obesity rate reported on Guam increased from 28.0% in 2014 to 34.3% in 2017.[9]

Through the research curriculum in the Health Sciences Program at the University of Guam, students enrolled in the research course began monitoring the health and wellness status of a sample of students. The objective of this paper is to describe the SNAPO indicators of college students, who will be in the future workforce of Guam and the Pacific Islands.

Methods

Ethics approval was obtained from the Committee on Human Research Subjects at the University of Guam (CHRS #15-63). The study was conducted by the students enrolled in the course HS 416 Research in Health Sciences. All members of the research team successfully completed the Protecting Human Subject Research Participants Training offered online by the National Institutes of Health. Additionally, each member underwent training on the consenting of research subjects, the administration of the survey questionnaires, and the collection of anthropometric measurements.

A cross-sectional study was conducted on a non-random sample of students at the University of Guam between September and December 2015. Recruitment flyers were posted throughout the campus, and the student researchers actively sought participants through word-of-mouth. Study participation was limited to students who were at least 18 years old and able to consent to the study in English. The target sample size was 396 students, or 10% of the 3,958 students enrolled during the 2014 – 2015 Academic Year.[18] Of the 392 participants interviewed, 14 (3%) were excluded from the analysis because they were later found to be younger than 18 years old or had failed to provide proper consent. The remaining 378 participants consisted of 185 males and 193 females.

SNAPO Tools

Measurement of Smoking (Cigarette, Smokeless Tobacco, and Areca Nut), Nutrition, and Alcohol

Questions on cigarette smoking and smokeless tobacco, nutrition, and alcohol were adopted from the Behavioral Risk Factor Surveillance System (BRFSS).[19] To assess tobacco use, participants were asked if they currently smoke cigarettes or use chewing tobacco, snuff, or snus. Areca (betel) nut chewing, a behavior sometimes practiced with cigarette smoking and smokeless tobacco use, was assessed using questions developed by Paulino and colleagues.[20] Nutrition characteristics included fruit, vegetable, fast food, and water consumption. The fruit and vegetable intake questions were from the 2015 BRFSS Survey and assessed the frequency in times per day, week, or month. Questions were added to measure fast food frequency (times per day) and water intake, including plain water and other liquids. Reported use reflected intake during the past 30 days.

Measurement of Physical Activity

Physical activity was estimated using the Physical Activity Rating-Questionnaire (PAR-Q) adapted from the Baecke questionnaire and had been used in a previous study of a broader Guam population of adults ages 25-65.[21,22] The PAR-Q was broken down into eight classifications that ranged from 0 to 7, with 0 being defined as least active and 7 being most active. More specifically, the classifications were defined as follows: 0 = avoid walking or exertion (eg, always use elevator, drive instead of walk), 1 = walk for pleasure, routinely use stairs, occasionally exercise sufficiently to cause heavy breathing or perspiration, 2 = 10 to 60 minutes per week, 3 = over one hour per week, 4 = run less than one mile per week or spend 30 minutes per week in a comparable activity as running, 5 = run one to five miles per week or spend 30 to 60 minutes per week participating in a comparable physical activity, 6 = run 5 to 10 miles per week or spend one to three hours per week participating in a comparable physical activity, 7 = run over ten miles per week or spend over three hours per week participating in a comparable physical activity. Participants selected only one classification.

Obesity

The research team was calibrated in the collection of anthropometric measurements, which had to be within 0.2 units. Each student was calibrated against the instructor and a percent agreement was calculated for each student-instructor pair. A percent agreement of 70% or more was required to pass. The median percent agreement was 86% for height and 83% for weight. A stadiometer (Enterprises Stadiometer, Portage, MI) was used to measure height and a weight scale (Perspective and Health O Meter Professionals, Countryside, IL) was used to measure weight. Body mass index (BMI) was calculated as: [(weight in pounds) / (height in inches)^2] x 703. The BMI was used to categorize participants into categories of underweight (BMI < 18.5), normal weight (18.5 to 24.9), overweight (25.0 to 29.9), or obese ($\geq$30).[15] Body fat was measured using the Omron Fat Loss Monitor, Model HBF-306C/Black (Omron Healthcare Inc., Lake Forest, IL). All measuring equipment were calibrated weekly.

Statistical Analysis

The data were entered the following semester, Spring 2016, by students enrolled in the course HS 451 Research and Report Writing. The research students cleaned and analyzed the data using the Statistical Package for Social Sciences (SPSS™), version 22 (International Business Machines Corporation, Armank, NY). The chi-square test for independence was used to test the relationship of selected categorical variables with sex. The independent t-test was used to compare the means of selected continuous variables between males and females. Values of $P < .05$ were considered statistically significant. Some variables were recoded. Smoking, alcohol, and areca nut use frequency responses were recoded into yes (every day and some days) and no (never) responses. Vegetable and fruit consumption variables were recoded into yes (less than one time per day) and no (one or more times per day) to reflect the units reported in the BRFSS. Fast food consumption was recoded to yes (three or more times per week) and no (less than three times per week). Water consumption, which included plain water and other liquids, was recoded to yes (adequate intake of 3.7 or more liters for males or 2.7 or more liters for females) and no (less than 3.7 liters for males or less than 2.7 liters for females).[23] Physical activity was recoded into sedentary (PAR-Q score of 0-4) and active (PAR-Q score of 5-7), while the four BMI categories were collapsed into obese (BMI ≥ 30) and not obese (BMI < 30).

Results

Characteristics of Sample

The mean age of participants was 22.7 ± 3.5 years as shown in Table 1. Of the 378 students, 185 (48.9%) were males and 193 (51.1%) were females. All class levels were represented: 51 (13.5%) freshmen, 82 (21.7%) sophomores, 127 (33.6%) juniors, 109 (28.8%) seniors, and eight (2.1%) post-baccalaureate or graduate students. Ethnicity was classified into single (67.5%) or mixed (31.7%) categories, with the largest groups being Filipino (31.8%), CHamoru (20.9%), or both (10.8%). For employment and marital status, the majority of students reported being employed (59.3%) and single (93.1%). The students in this study represented 9.5% (378 of 3,958) of the university's enrolled population, and the sex and major ethnic distributions were quite similar to the University's enrollment distributions.[18]

SNAPO Health Indicators

As shown in Table 2, the SNAPO-related indicators of the college students were compared between sexes and reported alongside the values extracted from the 2015 Guam BRFSS, which served as the adult reference population. The smoking indicators included cigarettes, smokeless tobacco, and areca nut. The percentages among the college students were 9.1% for cigarette smoking, 6.7% for smokeless tobacco, and 7.5% for areca nut. The sex-specific difference was not significant for areca nut and only marginally significant ($P = .05$) for cigarette smoking and smokeless tobacco use, with higher usage in males versus females (12.0% versus 6.3% for cigarette smoking and 9.2% versus 4.3% for smokeless tobacco use). Cigarette smoking and areca nut use appeared lower in college students than in the BRFSS.

The nutrition indicators included low frequency consumption of fruits and vegetables, high frequency consumption of fast foods, and low consumption of water (from plain water and other liquids). The sex-specific distributions were similar for all nutrition indicators. The percentage of college students with low frequency consumption was 77.5% for fruits and 68.0% for vegetables. The low frequency of fruit and vegetable consumption in college students was higher than in the BRFSS. Additionally, the percentage of college students with frequent fast food consumption was 31.5%. The percentage with inadequate water intake, including plain water and other beverages, was 89.1%. Unfortunately, data on fast food and water consumption were not available in the 2015 BRFSS.

Alcohol use was measured at 44.3% among the college students, with 24.6% engaging in binge drinking. Compared to the BRFSS, binge drinking was slightly higher in the college students, though college males and females reported similar alcohol consumption patterns.

Table 1. Characteristics of the 378 College Students, Guam, 2015

	Mean ± SD or Frequency (%)
Age, years	22.7 ± 3.5
Grade Level	
Freshman	51 (13.5)
Sophomore	82 (21.7)
Junior	127 (33.6)
Senior	109 (28.8)
Post-baccalaureate / Graduate	8 (2.1)
Gender	
Males	185 (48.9)
Females	193 (51.1)
Ethnicity	
Single	255 (67.5)
Predominant: Filipino	120 (31.8)
CHamoru	79 (20.9)
Mixed	120 (31.7)
Predominant: CHamoru / Filipino	41 (10.8)
CHamoru / Japanese	13 (3.4)
Employed for Wages	
Yes	224 (59.3)
No	153 (40.5)
Marital Status	
Single	352 (93.1)
Married	17 (4.5)
Divorced	4 (1.1)
Common-law	4 (1.1)

Results may not add up to total sample size due to some participants refusing to answer
SD = Standard deviation

Table 2. Smoking, Nutrition, Alcohol, Physical Activity, and Obesity (SNAPO) Health Indicators of the Adult Reference Population and the College Students Stratified by Sex, Guam, 2015

	Adult Reference Population[a] Frequency (%) or Mean ± SD	College Student Population[b] All Frequency (%) or Mean ± SD	College Students Males Frequency (%) or Mean ± SD	College Students Females Frequency (%) or Mean ± SD	*P*-value[c]
Smoking					
Cigarette					
Yes	358 (25.9)	34 (9.1)	22 (12.0)	12 (6.3)	.052
No	1247 (74.1)	340 (90.9)	161 (88.0)	179 (93.7)	
Smokeless Tobacco					
Yes	98 (7.1)	24 (6.7)	16 (9.2)	8 (4.3)	.057
No	1506 (92.9)	336 (93.3)	157 (90.8)	179 (95.7)	
Areca Nut					
Yes	13,404 (12.5)[d]	28 (7.5)	16 (8.7)	12 (6.3)	.382
No	93,641 (87.5)[d]	345 (92.5)	168 (91.3)	177 (93.7)	
Nutrition					
Fruits, <1 time per day					
Yes	659 (42.3)	293 (77.5)	141 (76.2)	152 (78.7)	.622
No	872 (57.7)	85 (22.5)	44 (23.7)	41 (21.2)	
Vegetables, <1 Time Per Day					
Yes	394 (27.1)	257 (68.0)	121 (65.4)	136 (70.4)	.322
No	1108 (72.9)	121 (32.0)	64 (34.5)	57 (29.5)	
Fast Foods, ≥ 3 Times Per Week					
Yes	NA	100 (31.5)	50 (31.8)	50 (31.2)	.909
No	NA	217 (68.5)	107 (68.1)	110 (68.7)	
Water (Plain Water and Other Liquids), Met Daily AI[e]					
Yes	NA	40 (10.9)	20 (11.2)	20 (10.6)	.841
No	NA	327 (89.1)	158 (88.8)	169 (89.4)	
Alcohol					
Yes	698 (41.8)	153 (44.3)	72 (43.6)	81 (45.0)	.475
Binge drink[f]	298 (19.8)	93 (24.6)	46 (24.8)	47 (24.3)	.908
No	896 (58.2)	192 (55.7)	93 (56.4)	99 (55.0)	
Physical Activity					
Sedentary (PAR-Q = 0-4)	1148 (79.2)[g]	205 (54.5)	79 (42.9)[c]	126 (65.6)	0
Active (PAR-Q = 5-7)	321 (20.8)[g]	171 (45.5)	105 (57.1)	66 (34.4)	
Obesity					
Obese (BMI ≥ 30)	459 (30.8)	77 (22.6)	46 (28.0)[c]	31 (17.5)	.020
Not Obese (BMI < 30)	1129 (71.0)	264 (77.4)	118 (72.0)	146 (82.5)	
Percentage of Body Fat	NA	24.0 ± 8.6	20.1 ± 8.0[c]	27.7 ± 7.4	0

Results may not add up to total sample size due to participants refusing to answer

[a] Reference population source is the 2015 Behavioral Risk Factor Surveillance System (BRFSS) Survey for Guam, n = 1669

[b] College students of n = 378

[c] Reflects sex-specific comparisons among the college students; statistically different from college females at $P \leq .05$

[d] Reflects weighted data from state-added questions

[e] Reflects the Adequate Intake: 3.7 liters for males and 2.7 liters for females, ages 19 to 30 years old

[f] Reflects ≥5 drinks in males and ≥4 drinks in females in any one occasion

[g] Reflects BRFSS calculation on the "number of adults that participated in enough aerobic and muscle strengthening exercise to meet guidelines"

SD = Standard deviation
NA = Not available in 2015
PARQ = Physical Activity Readiness Questionnaire
BMI = Body mass index

The overall percentage of sedentary students was 54.5% while active students was 45.5%. Physical inactivity was statistically significantly higher in females (65.6%) than in males (42.9%). In Table 2, the activity levels appeared higher in college students than in the BRFSS.

The percentage of obesity among the college students was 22.6% and was statistically significantly higher in males (28.0%) than in females (17.5%). The mean percent body fat of the college students was 24.0% ± 8.6% and was statistically significantly lower in males (20.1%) than in females (27.7%). This type of obesity measurement was not available in the BRFSS.

Discussion

The percentages of cigarette smoking (9.1%), smokeless tobacco use (6.7%), areca nut use (7.5%), and binge drinking (24.6%) provide a current overview of substance use among college students in Guam. Similarly, the percentages of frequent fast food consumption (31.5%), inadequate water intake (89.1%), physical inactivity (54.5%), and very high BMI weight status (22.6%) provide a current, comprehensive overview of obesity-related risk factors among college students. Compared to the adult population of Guam in 2015, the lower percentages of cigarette smoking, areca nut use, physical inactivity and obesity, and higher percentages of binge drinking and infrequent fruit and vegetable consumption among college students suggest behavioral differences in substance use and obesity-related risk factors between the two populations.[9] Therefore, the results of this study may not be generalizable to the adult population of Guam but may be used to monitor the health indicators of the college students and supplement the Guam BRFSS data.

The sex-specific differences were marginal for cigarette smoking and smokeless tobacco, with higher use in males. These differences were consistent with findings from Spangler and colleagues (2014) which found cigarette smoking and being male, among other variables, to be correlated with smokeless tobacco use among first year college students.[24] Among the substances reported, the percentages of smokeless tobacco (9.2% in males and 4.3% in females) and binge drinking (24.8% in males and 24.3% in females) were each reported at a higher percentage than in the United States (3.9% smokeless tobacco, 16.3% alcohol).[9] Furthermore, there are no reports on the prevalence of areca nut use in the United States; however, compared to the global estimate of 10%, Guam had a slightly higher percentage at 12.5% among the adult population and a lower percentage of 6.7% among college students found in this study.[25] Other sex-specific differences were statistically significant for physical inactivity, obesity, and percentage of body fat.

Males were significantly more active than females; however, obesity, calculated via BMI, was also significantly higher in males than in females. In contrast, the mean percent body fat in males (20.1% body fat), calculated using the Omron body fat measuring device, was significantly lower than in females (27.7% body fat). The sex differences within and between types of obesity measurements may be due to biological differences, such as hormone levels and body fat percentage, and obesity categorization based on BMI, which may not be a reliable indicator for athletes as it does not reflect regional body fat distribution.[26-28]

The limitations of this study include non-random sampling and the absence of trending substance use indicators such as e-cigarette and marijuana use.[29] Inclusion of the e-cigarette and marijuana use will be considered in upcoming academic years. Despite the non-random approach to recruitment, the study sample reflected the university's sex distribution and dominant ethnic groups, and thus the health SNAPO health indicators in this study are presumably representative of the university's student population. The study findings were immediately disseminated to the student body via the first Health Awareness to Reach Tritons (HART) Fair on campus. The data stimulated discussion on the need for campus-wide policies or programs that promote student health. The population surveyed in this study will enter the future workforce of Guam and the neighboring Pacific. This is a critical time for primary prevention since students are young enough to implement lifestyle changes to prevent the onset of NCDs. Working to build a healthy workforce now may translate to a healthy economy in the future.

Conclusion/Recommendations

The SNAPO health indicators in this study provided the current status of substance use and obesity-related risk factors of college students in Guam. The profile of the student health indicators is quite different from the adult population in Guam. The use of the student SNAPO indicators to: (1) supplement the BRFSS and other data sources to evaluate the Guam NCD Strategic Plan, (2) monitor health trends among college students, and (3) inform campus-wide policies or programs that promote student health is strongly encouraged.

Conflict of Interest

None of the authors identify any conflict of interest.

Authors' Affiliation:
- Health Sciences Program, School of Nursing and Health Sciences, University of Guam, Mangilao, Guam

Correspondence to:
Nicole Nazareno; Health Sciences Program, School of Nursing and Health Sciences, University of Guam, Mangilao, Guam 96923; Email: njcnazareno@hotmail.com

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Guam Salt Reduction Campaign

Ruby Gonzales; Lawrence Alam; Al Silverio; and Dioreme Navasca MPH

Abstract

To lessen the salt-intake of people in Guam for the prevention of non-communicable diseases (NCD) associated with a high sodium diet, the Racial and Ethnic Approach to Community Health (REACH) program and NCD Consortium of the Guam Bureau of Community Health Services (BCHS) formed strategies that encourage healthier eating behavior. Project stakeholders, like restaurants, food services establishments, and vendors, removed salt products from dine-in tables, including saltshakers, soy sauce, and finadene. Combined programmatic efforts resulted in support by 47 restaurants out of 140 restaurants that were approached for the salt reduction initiative: the removal of saltshakers and other high sodium-containing condiments from tables, made available only upon a customer's request.

Issue

Guam is an unincorporated and organized territory of the United States (US). Located in the northwestern Pacific Ocean, Guam has a population of about 160,000 people.[1] Guam is the largest and southernmost of the Mariana Islands and the largest island in Micronesia. According to the World Health Organization (WHO) 2017 report, rates of non-communicable diseases (NCDs) have increased with about a third of deaths in Guam attributed to heart disease (31%).[2] Guam declared a state of health emergency in 2010 due to the NCD epidemic, along with five other United States Affiliated Pacific Islands (USAPI).[3] Reliance on imported and processed foods has been a trend in the Pacific, including Guam, and has mirrored the increasing rates of NCDs such as obesity and cardiovascular diseases.[4] These diseases are the result of unhealthy lifestyles, the consumption of inexpensive, energy-dense foods high in fat, sugar and salt, as well as the relative inaccessibility of healthier food options in food establishments in Guam.[5] The Guam morbidity and mortality data laid the groundwork for this nutrition intervention.[5]

Guam Bureau of Community Health Services

Within the Guam Department of Public Health and Social Services (DPHSS), the Bureau of Community Health Services (BCHS) mission is to improve the health and quality of life of the people in Guam. The department's goal is to eliminate health disparities by increasing access to health care, early disease detection, disease prevention, and healthy lifestyle promotion through policy development, implementation, surveillance and social services.[6]

Services provided by the BCHS programs include:

- Trainings and seminars that educate the community on better nutrition and healthier lifestyles through local events and media campaigns
- Support for health screening events
- Health campaigns that raise public awareness

The BCHS also collaborates with local and international partners that promote community health, NCD prevention and sustainability of programs and other initiatives that complement the mission of the BCHS.

Racial and Ethnic Approach to Community Health

In 2014, the Guam DPHSS received funding from the Centers for Disease Control and Prevention (CDC) to implement the Racial and Ethnic Approaches to Community Health (REACH) grant, a 4-year initiative that used tailored community-based participatory approaches (CBPA) to identify and develop effective and culturally grounded strategies to address health disparities. This CBPA strengthened the existing collaboration between local coalitions, health departments and associated stakeholders from various sectors in the community and promoted action in addressing NCD-related risk factors. The overall goal of the Guam REACH program was to increase access to healthier environments and encourage healthy behavior as the default behavior of choice.

Description

Due to the lifestyle and convenience, many Guamanians purchase meals from restaurants, stores and other fast food services where the types of food available generally contain high levels of salt. The salt reduction initiative specifically aimed to improve eating habits and food options by encouraging restaurants to offer healthier food alternatives and reduce opportunities for people to add more salt to their meals. The NCD Consortium, the REACH program, and partners collaborated and recruited food establishments, such as restaurants, caterers and businesses that supply food, to remove salt products (saltshakers, soy sauce, and finadene—an all-purpose sauce primarily made of soy sauce, onion, chile peppers, and vinegar used as a marinade or poured over rice or cooked meat) from dine-in tables, to be made available only upon request.

Methods

Four activities were developed and implemented under the salt reduction initiative:

Activity #1: Baseline data was collected through policy, systems, and environmental (PSE) scans. Visual scans for salt products assessed a restaurant's feasibility for the REACH project. Convenience sampling identified the busiest and most popular restaurants, based on project partners' anecdotal accounts and observations. Target settings for the salt reduction initiative were restaurants that mostly cater to the local population of Guam and serve condiments with high salt content. Pre and post intervention scans monitored the restaurants' compliance with the salt reduction initiative and ensured the removal of saltshakers from dine-in tables. The REACH staff conducted 50 pre-intervention scans of the 140 target restaurants in Guam to gather baseline information and gauge restaurant interest in participating in the REACH project's salt reduction initiative. When possible, the project staff conducted interviews and brief impromptu educational sessions with restaurant owners and staff during pre-scan visits.

Activity #2: Organizational policies were developed and adapted by participating food establishments in Guam. The project staff presented to restaurants and chefs' associations on objectives of the REACH project. The NCD Consortium also provided educational sessions about the project with the 33rd Legislature's Senator and Chairman of the Committee on Health to the Mayor's Council of Guam as part of an awareness campaign. Additionally, the Salt Reduction Action Team (SRAT) wrote a letter to the Guam Hotel and Restaurant Association on behalf of the REACH project as an appeal for support for the salt reduction initiative.

Activity #3: Education and materials were created and disseminated for the population in Guam. Flyers, handouts, brochures, television campaigns, commercials, posters, and banners on salt-reduction were created, reproduced, and distributed to the community and the project partners (food establishments, restaurants, and supporting organizations). Media communications promoting the salt reduction initiative, such as the Guam Memorial Hospital Health Talk Radio Show, newspaper articles and a television appearance on KUAM, were utilized for the dissemination of health messages reinforcing the goals and objectives of the salt reduction campaign.

Activity #4: Monitoring and evaluation of the salt reduction initiative were completed by random visual scans of the 47 restaurants that pledged to support the salt reduction initiative. At the conclusion of the project period, the REACH project partners took an active role in project sustainability by conducting quarterly visits of the restaurants to ensure salt products were kept off of dining tables.

Results

In 2015, Guam's REACH project conducted two salt reduction pledge signing ceremonies with the participating restaurants. The salt reduction pledge signing events were public ceremonies proclaiming the restaurants' commitment to the salt reduction initiative by removing the saltshakers, soy sauce and other high sodium condiments from dine-in tables and making them available only upon customer request.[7] Restaurants that were unable to attend the pledge signing events were approached and recruited separately. By the final year of the REACH project, 47 local food establishments in Guam completed the salt reduction intervention.

The REACH project leveraged project activities with other partner programs that share the same objectives and aims of reducing the NCD burden in Guam and making the healthier PSE approach the default option for the community. The Guam Lifestyle Disease Prevention and Control Program sponsored printing costs for the salt reduction trifolds. The trifolds were printed materials displayed at tables and checkout counters of participating restaurants, educating the patrons and restaurant staff about the harmful health effects of a high sodium diet. At least 500 salt reduction trifolds were provided to participating restaurants as well as 2,000 more for replenishing purposes during project monitoring and sustainability.

By the end of the project period, the project published 100 nutrition messages to the public via social media and distributed 27 messages including project success stories to project partners. At the September 2018 NCD Consortium meeting, the Local Project Assistant provided updates on the progress along with the sustainability plan of the REACH salt reduction initiative. The NCD SRAT agreed to monitor restaurants every quarter, provide additional or replacement trifolds when requested by management, as well as report progress and lessons learned to the consortium at the monthly meetings.

Conclusions

Continued health campaigns are important to increase public awareness and sustain the positive momentum of healthy eating behaviors among target populations.[8] The NCD Consortium has a strong collaboration with the organizations, leaders, and stakeholders in the community that helped develop and advocate a restaurant policy to remove saltshakers (and other salt products) from dine-in tables, making them available upon request only.[6,9]

In January 2016, the BCHS conducted the NCD Consortium's meeting with project partners as well as local and national public health agencies, such as the WHO, CDC, Pacific Island Health Officers Association, the Pacific Community and the Guam BCHS team. With the recommendation of partners and endorsement from the Guam BCHS, the state added the following questions to the Guam Behavioral Risk Factor Surveillance System survey: (1) Are you currently watching or reducing your sodium intake? (2) How many days, weeks, months, or years have you been watching or reducing your sodium or salt intake? (3) Has a doctor or other health professional ever advised you to reduce sodium or salt intake?[6]

The salt reduction initiative was a useful introduction to health messages and leveraged other nutrition initiatives, such as the Healthy Menu Labeling and Healthy Menu Option projects. The project activities facilitated the recruitment of partners and the development of other related initiatives that encourage healthy lifestyles in Guam such as the Menu Labeling and Healthy Food Options projects.[10]

Lessons Learned

Occasional monitoring of restaurants is necessary to keep staff and owners reminded and motivated about complying with the salt reduction initiative. In addition, restaurants need occasional replenishment of the dwindling supplies of trifold displays due to weathering and customers taking or disposing of the trifolds.

The REACH project was one of Guam's salt reduction PSE change interventions to improve nutrition and there were many lessons learned in its implementation. The SRAT is instrumental in sustaining the success of the intervention and exploring other funding sources to continue project activities now that the REACH funding cycle has ended.

From anecdotal accounts of the participating restaurants, food establishments and other businesses in the food industry that were approached expressed values towards the health of the consumers and patrons. Despite limitations of the project being a novel initiative and never implemented in the USAPI before, competing priorities for the project staff between responsibilities and project deadlines, as well as language barriers between the project staff and some of the restaurant owners or points of contact, most restaurant owners were generally cooperative and very willing to promote health and wellness if they were properly informed and guided in their role for a healthier Guam.[5,10]

Conflict of Interest

None of the authors identify a conflict of interest.

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Authors' Affiliations:
- Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawai'i at Manoa, Honolulu, HI (RG, DN)
- Guam Comprehensive Cancer Control Program, Guam Department of Public Health and Social Services, Mangilao, GU (RG, LA)
- Guam Office of Minority Health, Guam Department of Public Health and Social Services, Mangilao, GU (AS)

Correspondence to:
Ruby Gonzales and Lawrence Alam; Guam Department of Public Health and Social Services, 123 Chalan Kareta, Mangilao, Guam 96913;
Email: Ruby.Gonzales@dphss.guam.gov and lawrence.alam@dphss.guam.gov

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Dental Caries and Otitis Media Among Schoolchildren in Palau

Inger B. Appanaitis MPH; William E. Lambert PhD; Eli Schwarz DDS, PhD, MPH;
Michael R. Lasarev MS; and Berry Moon Watson MPH

Abstract

Both oral disease and middle ear infections are highly prevalent in Pacific Island children. These diseases are multifactorial and likely attributable in part to both social and environmental factors. It has been two decades since these diseases were defined in Palau, and at the time were noted to be among the most common conditions and presented a substantial burden among Palau's children. In 2006, the Ministry of Health in Palau began conducting comprehensive school health screenings in grades 1-11. While primarily used as a referral tool, this survey can also be used in epidemiologic studies to describe health trends. The current study utilized this screening data from the 2011-12 school year to characterize the prevalence of dental caries and otitis media and explore a previously suggested relationship between the two conditions, including common risk factors. It was found that over one-quarter (28.9%) of Palauan students had abnormal tympanometry results, with up to 17% indicating active otitis media. In addition, 85% of students had at least one decayed or filled tooth, with an average of 3.9 decayed or filled teeth in 12-year-olds. Both conditions were found to be more prevalent in public than in private schools; however, the two disorders were not significantly associated with each other. These findings place the prevalence of decayed, missing, and filled teeth, and otitis media in Palauan schoolchildren among the highest reported in the world. The widely recognized consequences of poor oral health and hearing impairment on learning, nutrition, and chronic disease make urgent the need for early intervention.

Keywords

Oral Health, Dental Caries, Epidemiology, Global Health, School Health, Children, Pacific Islander, Micronesia, Pediatric Audiology, Health Disparities

Abbreviations

AIC = Akaike information criterion
AOM = acute otitis media
BIC = Bayesian information criterion
BMI = body mass index
CDC = Centers for Disease Control and Prevention
DFT = decayed, filled teeth index (primary dentition)
DMFT = decayed, missing, filled teeth index (permanent dentition)
MOH = Ministry of Health
OM = otitis media
OR = odds ratio
SD = standard deviation
ZINB = zero-inflated negative binomial

Introduction

A decade prior to this study, Greer and colleagues (2003) warned of a "silent epidemic" of oral disease among children in Pacific Island nations, characterizing the age-weighted mean for decayed and filled primary teeth (DFT) among children ages 5 to 9 years in Hawai'i, Guam, and the Republic of Palau to be three times that of the mainland United States.[1] Otitis media (OM), or middle ear infections, has also been documented as highly prevalent in Pacific Island children. For instance, an earlier survey in Palau found 16% of Head Start children and 10% of elementary school children having "active disease" and concluded that OM was one of the most common handicapping conditions among Palau's children.[2]

The etiologies of tooth decay and OM are complex and perhaps interrelated, as both diseases have shown evidence of genetic, lifestyle, and environmental risk factors.[3] In the mid-1990s, several studies in Finland proposed a connection between the two childhood diseases.[4-6] The hypothesized association was suggested after it was found that xylitol chewing gum, which has historically been used for the prevention of dental caries, reduced the incidence of acute otitis media (AOM) in preschool-aged children.[4,5,7,8]

Since then, two additional studies tested the association between OM and dental caries but produced mixed results. The first, a case-control study, found no difference in ear infection history between children experiencing or with history of dental caries and those that were caries-free.[6] However, despite failing to reach statistical significance at $P<.05$, the mean number of ear infections was higher in the dental caries group than in the caries-free group. The second study, an analysis of 30,000 Medicaid records, did demonstrate a significant association between OM and dental caries.[9] In this study, children with claims (ie, clinical visits) for AOM or respiratory infections were at a 29% higher risk of developing caries after their first year of life as compared to children with no claims. However, when OM and respiratory infections were evaluated individually, data showed that children with claims for OM only were at an 11% higher risk of developing caries, while children with claims for respiratory tract infections only were at a 34% higher risk.

Although the epidemiological evidence for a relationship between these two childhood disorders is limited, at least two biological hypotheses have been proposed to explain this relationship. The first claims that OM may directly contribute to the development of dental caries when high levels of bacteria (eg, *Streptococcus pneumonia)* disrupt enamel formation, causing enamel hypoplasia and leaving teeth more susceptible to lesions or cavities.[9,10] The second biological hypothesis posits that OM and tooth decay are indirectly related but are comorbid conditions due to shared risk factors such as inappropriate bottle use, inadequate personal hygiene, and poor living conditions.[11-16]

This report presents a secondary analysis of data from a comprehensive school health survey of children in Palau. The school health survey is conducted annually by trained teams from the Ministry of Health. Through standardized methodology, the survey allows for estimation of the prevalence of dental caries and AOM and further analysis of the co-occurrence of these two conditions.

Methods

Setting

The Republic of Palau has been an independent sovereign nation since 1994 when it signed The Compact of Free Association with the United States. Located in Western Micronesia, the nation is made up of approximately 340 volcanic and limestone islands spread across 700 square miles of ocean. The population of Palau, estimated at 17,501 in 2012, inhabits twelve of these islands, which are divided into 16 political states. The residents of Koror, the commercial capital of Palau, and Airai, its neighboring state, make up approximately three-quarters of the total population.

Data Source

This study was a secondary analysis of data with protocol approval from the Institutional Review Boards of the Ministry of Health (MOH) in Palau and Oregon Health & Science University in Portland, Oregon. The MOH School Health Program Physical Examination Screenings began in the 2006-07 school year. Both physical and behavioral health are examined with data collected on demographics, vital signs, body mass, vision, dental health, hearing, substance use, and depression. The annual screenings are conducted on students of the odd-numbered grades 1-11 to ensure screening of all students every other year. This analysis was restricted to data collected in 2011 of students between the ages of 5 and 12 for a final sample of 831 students, which was equivalent to 31% of the country's total school enrollment for the 2011-12 school year.

Measurement and Data Collection

All data were collected between August 16, 2011 and November 18, 2011 by a team of clinical and public health professionals from the MOH. Dental nurses conducted regular dental exams, recording the number of decayed teeth, treated and untreated, in each child, and identifying if the decay was in the primary or permanent dentition. Each tooth was classified as healthy, decayed (ie, carious), or previously treated decay (ie, filled), and recorded as healthy or decayed.

Specialists from the Ministry's Ear, Nose, and Throat Clinic conducted tympanometry tests of each ear to measure the mobility of the eardrum and conduction bones.[17] The mobility results are classified according to three types of curves (Type A, B, and C) and have high sensitivity and specificity in diagnosing middle ear effusions in children.[17-18] Both Type B and Type C were categorized as abnormal results. An overall result was created based on the weakest compliance of the two ears, with Type A representing the best compliance, Type C representing moderate compliance, and Type B representing poor compliance. An additional dichotomous variable was created to classify 'normal' (Type A) and 'abnormal' (Type B and Type C) results.

Statistical Analysis

Zero-inflated negative binomial (ZINB) regression was used to model dental caries. Multivariate regression models were constructed using the backwards elimination method. Along with age, sex, and school type, the confounders considered included: ethnicity (self-identified Palauan or 'Other'); BMI, continuous (kg/m2) and categorical (in adherence to CDC classification according to age: underweight, healthy weight, overweight, and obese); self-reported physical activity levels (light, moderate, or vigorous); school location (urban or rural); self-reported nicotine use (yes or no); and self-reported alcohol use (yes or no). Lastly, tympanometry variables were added to the models to test if the inclusion of these variables significantly improved fit and explained variance. Significant predictors were based on Wald χ^2 statistics at $P < .01$. Candidate models were compared using Nagelkerke (adjusted) R^2 statistics, Akaike Information Criterion (AIC), and Bayesian Information Criterion (BIC).

Results

831 students between the ages of 5 and 12 had complete data from the 2011-12 school physical examinations. The mean age of students was 8.8 (SD 2.2) years and the sample was evenly distributed between male (51%) and female (49%) students (Table 1). Nearly 60% of the students came from urban schools and three-quarters attended schools that were public. While substance use was reported as early as 7 years of age, the overall proportion of students reporting substance use was low (nicotine users, n = 23; alcohol users, n = 6). Nicotine use was significantly associated with age (OR = 1.73, P=< .001), but alcohol use was not (OR = 1.33, P= .171).

Description of Tympanometry Findings

Approximately 71% of the students had a normal tympanometry finding (Type A), while 29% had abnormal results (17% Type B and 12% Type C). Abnormal results ranged from 19% in the 12-year-olds to 37% in the 7-year-olds, with a significant inverse association between age and proportion of abnormal tympanometry results (OR = 0.92, $P = .02$). There were no significant differences in tympanometry results by gender (two-sample test of proportions: $z = 0.52$, $P = .60$), but differences were observed by school type. Among children who attend public schools, only 68% had normal tympanometry results, while 81% of children attending private schools had normal results (Figure 1; two-sample test of proportions: $z = -3.01$, $P = .003$).

Table 1. Population Characteristics of Children Surveyed in 2011-2012 School Health Screening (n=831)

		Primary Dentition		Permanent Dentition	
	Total Sample	Decay-Free	Mean Decay[a] (SD)	Decay-Free	Mean Decay[a] (SD)
Sex					
Boys	51.3%	37.6%	4.79 (3.45)	37.1%	3.30 (2.49)
Girls	48.7%	42.2%	4.85 (3.14)	33.3%	3.39 (2.43)
School Type					
Private	21.8%	47.5%	3.86 (2.65)	48.6%	2.70 (1.77)
Public	78.2%	37.7%	5.05 (3.41)	31.5%	3.48 (2.56)
Ethnicity					
Palauan	91.0%	39.3%	4.89 (3.29)	33.6%	3.37 (2.48)
Other	9.0%	45.3%	4.10 (3.43)	52.0%	2.94 (2.18)
BMI (cat)					
Underweight	5.1%	26.2%	5.42 (3.35)	26.2%	3.42 (1.95)
Healthy weight	65.7%	37.0%	4.99 (3.42)	35.5%	3.32 (2.37)
Overweight	12.0%	48.0%	4.46 (3.32)	38.0%	3.26 (2.71)
Obese	17.2%	49.0%	4.04 (2.60)	35.0%	3.45 (2.76)
Physical Activity (PA)					
Light PA	12.0%	42.0%	4.71 (3.07)	40.0%	3.02 (2.31)
Moderate PA	73.9%	41.0%	4.77 (3.28)	34.0%	3.38 (2.49)
Vigorous PA	14.1%	31.6%	5.11 (3.60)	37.6%	3.40 (2.39)
School Location					
Urban	57.2%	40.0%	4.64 (3.03)	35.8%	3.57 (2.54)
Rural	42.8%	39.6%	5.07 (3.64)	34.6%	3.04 (2.32)
Nicotine					
No	97.2%	39.2%	4.81 (3.27)	35.6%	3.30 (2.41)
Yes	2.8%	60.9%	5.44 (5.20)	21.7%	4.67 (3.41)
Alcohol					
No	99.3%	40.0%	4.83 (3.31)	35.5%	3.33 (2.46)
Yes	0.8%	16.7%	4.20 (3.03)	16.7%	4.83 (1.47)
Tympanometry					
Type A (normal)	71.1%	41.6%	4.75 (3.24)	35.9%	3.35 (2.55)
Type B (abnormal)	17.0%	32.6%	5.05 (3.41)	34.8%	3.15 (1.92)
Type C (abnormal)	11.9%	39.4%	4.87 (3.56)	32.3%	3.60 (2.58)

[a] Mean decay in students experiencing decay in one or more teeth.

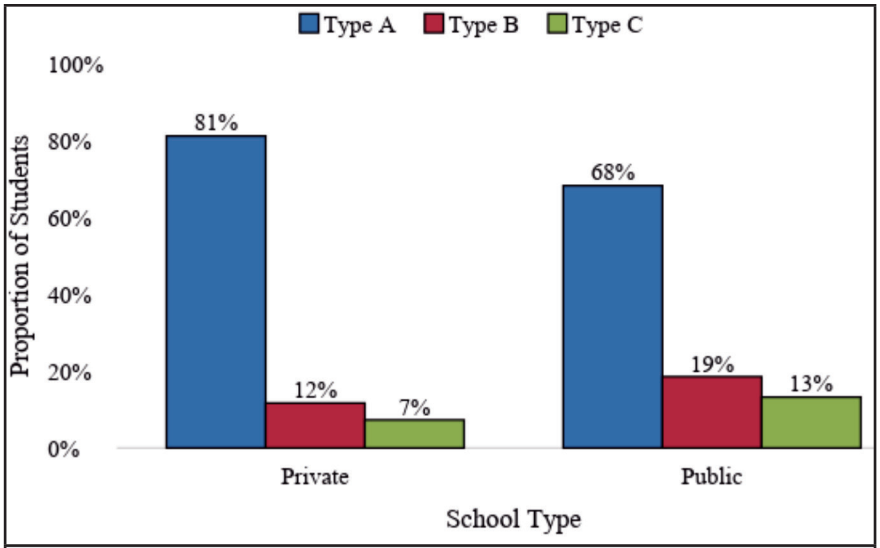

Figure 1. Tympanometry Results of Palauan Children by School Type

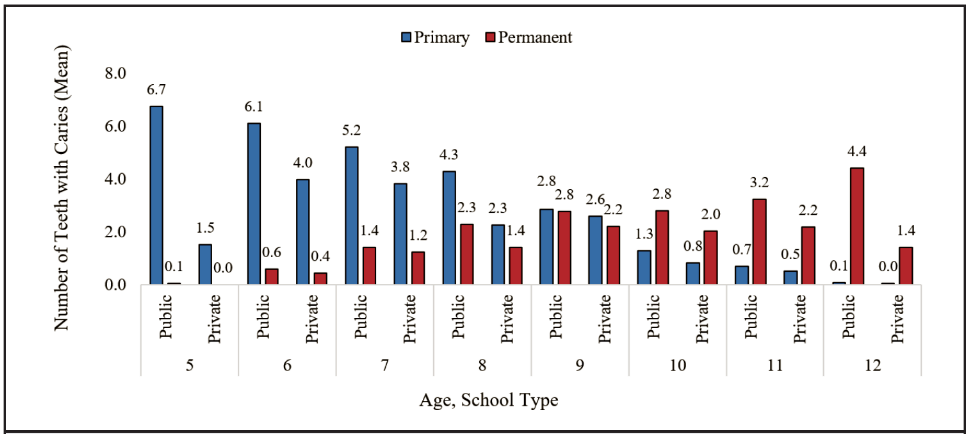

Figure 2. Mean Number of Teeth with Caries in Primary and Permanent Dentition by Age and School Type

Description of Dental Caries Findings

Caries experience (both treated and untreated decay) was identified in 85% of students. The mean number of primary and permanent teeth with caries experience is summarized in Figure 2. A significant inverse correlation was observed between total number of teeth with caries and student age (ρ=-0.24, $P<.001$). There was no significant difference in total number of teeth with caries between male and female students in public schools (5.66 vs 5.39; rank-sum test, $P=.52$) nor in private schools (3.07 vs 3.81; rank-sum test, $P=.12$). However, there was a significant difference between students of the same sex attending different school types; the mean number of teeth with caries in public schools was 1.5 times that of in private schools. For example, the mean number of total teeth with caries for boys in public schools was 5.66 (SD 4.13), but only 3.07 (SD 3.25) in private schools (rank-sum test, $P<.001$). Also, the mean number of total teeth with caries for girls in public schools was 5.39 (SD 3.89) compared to 3.81 (SD 3.22) in private schools (rank-sum test, $P<.001$).

Analysis of Caries in Primary Dentition

ZINB models were inflated by age under the assumption that age explains the excess of zero counts in the data. Univariate analyses were conducted to assess the individual influence of each predictor on primary caries. To minimize type II error, significant predictors were identified at $\alpha<0.2$ level. Following this criteria, *age* ($P<.001$), *school type* ($P<.001$), *ethnicity* ($P=.071$), *BMI* ($P<.001$), and *school location* ($P=.047$) were identified as significant predictors of primary caries in univariate analyses. *Primary caries* was regressed on these five variables. From this model, variables that did not achieve a stricter $P<.10$ level of significance were eliminated and Wald test statistic was

Table 2. Final Zero-Inflated Negative Binomial (ZINB) Multivariate Model(s) Relating Mean Number of Teeth with Caries by Primary and Permanent Dentition

	Primary dentition[a]		Permanent dentition[b]	
Variable	**Multiplicative effect[c]**	**95% CI**	**Multiplicative effect[c]**	**95% CI**
Age	0.77	0.74, 0.82	1.16	1.11, 1.20
School Type				
Private	Referent		Referent	
Public	1.44	1.20, 1.73	1.84	1.54, 2.20
Ethnicity				
Palauan	Referent		Referent	
Other	0.78	0.60, 1.01	0.74	0.57, 0.96
BMI (1 kg/m2)	0.96	0.95, 0.98		
State			P<.001	
1			Referent	
2			1.89	1.08, 3.30
3			0.10	0.01, 0.83
4			0.70	0.20, 2.37
5			2.91	1.72, 4.94
6			0.80	0.33, 1.94
7			2.14	1.13, 4.08
8			2.35	1.26, 4.39
9			2.42	1.14, 5.11
10			1.45	0.75, 2.80
11			1.23	0.55, 2.76
12			0.97	0.49, 2.01
13			1.22	0.58, 2.55
14			2.22	1.20, 4.09
Nicotine				
No	Referent			
Yes	1.65	0.96, 2.83		

[a] Estimates of Pr(caries=0) inflated by age; Estimated dispersion parameter =0.46 (95%CI:0.33, 0.60).
[b] Estimates of Pr(caries=0) inflated by age; Estimated dispersion parameter =0.29 (95%CI:0.21, 0.39).
[c] Multiplicative effect for a Poisson-like regression is the ratio of two means.

used to test improvements. After eliminating *school location*, various models were tested with additional variables. *Nicotine* significantly improved the final model (based on AIC and Nagelkerke R^2; Table 2), and therefore was included. A final model including *age, school type, ethnicity, BMI* and *nicotine* tested the hypothesis that tympanometry was a significant predictor of caries in primary teeth. However, neither Type B nor Type C tympanometry findings were significant predictors of caries in primary teeth (P= .970 and P=.994, respectively).

Analysis of Caries in Permanent Dentition

Univariate analysis of each independent variable found *age* (P<.001), *school type* (P<.001), *ethnicity* (P=.005), *school location* (P=.006), and *state* (P<.001), as well as *nicotine* (P=.083) and *alcohol* (P=.077), to be significant predictors of permanent caries at an α level <0.2. These variables were used to begin building the final model for permanent teeth. After eliminating *school location* at the P<.10 level, the addition of other variables of interest were explored. Several of these models with different variable combinations had relatively similar goodness-of-fit measures. A final model for permanent teeth was selected based on goodness-of-fit as well as concordance with the model for caries in primary teeth and known risk factors. This final model included *age, school type, ethnicity,* and *state*, but again, neither of the tympanometry variables met the P<.1 level of significance (Type A/Type B/Type C, P=.598; and normal/abnormal, P=.312).

Discussion

Findings from the 2011-12 student health surveys indicate that dental caries and OM remain prevalent conditions, with 85% of surveyed students having had at least one tooth with signs of decay and over one-quarter of students with abnormal (Type B and Type C) tympanograms. Moreover, 17% of Palauan students had a Type B tympanogram, a sign of poor or no mobility in the tympanic membrane and indicative of an active middle ear infection.[15]

The burden of oral disease observed in this study is consistent with the earlier findings of Greer, et al, (2003) indicating 87.7% of 6-year-olds in Palau experiencing decay in primary teeth. The prevalence of both studies falls within the estimated range reported by Petersen, et al, (2005) for industrialized countries (ie, 60%-90%). Of great concern, however, is the severity and distribution of oral disease within the population. Of surveyed students, the number of teeth with caries ranged from 1 to 16 in primary dentition and 1 to 15 in permanent dentition. Of students with at least one cavity in a primary tooth, the mean number of total cavities was 4.8 (n = 500, SD 3.31). Likewise, of students with at least one cavity in a permanent tooth, the mean number of total cavities was 3.3 (n=538, SD 2.46). School type was a significant predictor of dental caries, with children in public schools having a greater burden of disease. These findings also suggest the total caries burden to be higher among younger children (age-total caries, $\rho=-0.24$, $P<.001$).

The level of oral disease among Palauan schoolchildren remains much higher than the global goal established by the World Health Organization (WHO). The mean Decayed, Missing, or Filled Teeth (DMFT) measure for 12-year-olds is used as an indicator of oral health status within a given population. The mean number of decayed and filled permanent teeth for 12-year-old Palauans from the school health survey is 3.88 (n=138, SD 3.79). Interpretation of this prevalence estimate is somewhat limited since this survey recorded only decayed and filled teeth without considering permanent teeth lost to decay. Including missing teeth in the survey would have allowed a direct comparison to the WHO statistics in DMFT units. Even so, this estimated prevalence—though an underestimation—remains above the WHO goal of 3.0 DMFT.

In this analysis, the strongest predictor of caries in permanent dentition was the type of school a child attended. This variable, as well as the variable, *age*, was found to be highly significant across several alternative models for both primary and permanent dentition. For caries in primary teeth, this final model included the following predictors: age, the type of school a child attended, ethnicity, BMI, and nicotine use. Although nicotine was not significant at the $\alpha=0.05$ level, it did significantly improve the model fit for primary caries, explained total variance, and is a known risk factor for oral disease. Groups at higher risk of dental caries in primary teeth were children who attended public schools, identified as Palauan ethnicity, or used nicotine. Additionally, both age and BMI were inversely related with mean number of caries in primary teeth. Significant predictors for dental caries in permanent dentition included: age, school type, ethnicity, and state of residence.

The prevalence of OM in this population is higher than previously reported by Dever, et al, (1990), who focused on a younger population, specifically preschool-aged children attending Head Start schools. The present study found Type B tympanograms to be even more prevalent among students ages 5 and 6 (19.1% and 22.0%, respectively) than previously reported by Dever, et al, however, not significantly higher than the prevalence among all age groups in this study. The differences between this study and the Dever, et al, study may be due to the small sample sizes. The World Health Organization has identified several other indigenous Pacific Rim populations with high prevalence of chronic OM, including Inuits at 12%-46% and Australian Aboriginals at 12%-25%.[19] The prevalence of active OM within Palau's student population falls in these ranges. Including the students with Type C tympanograms, the prevalence of abnormal tympanograms is 29%. In addition, children attending public schools had a higher proportion of abnormal tympanometry results than their counterparts attending private schools. An estimated 18.5% of students in public schools showed signs of active middle ear infections. A second WHO report indicated that populations with greater than 4% prevalence of OM (specifically, chronic suppurative otitis media) represent a "massive public health problem" that requires urgent attention.[20,21]

Although both dental caries and OM are highly prevalent in school children in Palau, this analysis failed to establish an association between the two conditions. In the multivariate models for caries in primary and permanent teeth, tympanometry variables as predictive measures, whether classified as normal/abnormal or type of tympanogram (Type A/B/C), were not statistically significant. In light of this, several strengths and limitations should be considered in the interpretation of these findings. First, the sample population was large and provides a good representation of the general population of Palauan children. Second, trained survey teams used clinically accepted methods, producing accurate measurements of decayed and filled teeth, and objectively ascertaining the presence of OM using tympanometry. Because the numbers of missing teeth were not recorded, the DFT is expected to slightly underestimate DMFT, the preferred metric used in many reports. It was not feasible to use otoscopy in this survey to visualize the tympanic membrane and diagnose OM, however tympanometry as a diagnostic tool has reasonably high positive and negative predictive value.[18]

In conclusion, the school health surveys conducted by the MOH serve as an important tool for revealing the health profile of Palau's children and the current study demonstrates the potential of these data to support translational research. Both OM and dental caries are highly prevalent in the school-aged population of

Palau. The identification of school type as a significant predictor suggests that these diseases may share common social causal factors. There is insufficient information to conclude that the observed disparity by school type is related to socioeconomics; however, it will be important for future surveys to obtain more detailed information on demographics and health care behavior that may illuminate demographic differences between children attending public and private schools in Palau. In the meantime, school-based interventions may be an effective strategy for addressing these conditions, especially interventions which incorporate daily toothbrushing and hand washing. Improving hygiene standards and community knowledge of preventive health strategies may be effective in combatting OM and dental caries in children.

Conflict of Interest

None of the authors identify any conflict of interest.

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Authors' Affiliations:
- Department of Public Health & Preventive Medicine, Oregon Health & Science University, Portland, OR (IBA, WEL, MRL)
- Office of Health Policy, Research, & Development, Ministry of Health, Republic of Palau (IBA, BMW)
- Department of Community Dentistry, Oregon Health & Science University, Portland, OR (ES)

Correspondence to:
Inger B. Appanaitis MPH; Email: inger.appanaitis@gmail.com

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Cumulative Incidence Rates of Breast Cancer by Age for Filipinos and Chamorros in Guam

Grazyna Badowski PhD; Brayan Simsiman BS; Renata Bordallo MSW, CTR;
Michael Green CTR; Yurii B. Shvetsov PhD; Lynne R. Wilkens DrPH;
Rachel Novotny PhD, RDN; and Rachael T. Leon Guerrero PhD, RDN

Abstract

Breast cancer is the second leading cause of cancer-related death among women on Guam and Hawai'i. Breast cancer incidence rates are described here for the multiethnic population in Guam, a United States (US) Pacific island territory, and compared to Hawai'i and other US populations, to understand the risk by age and race/ethnic group in this understudied group. The study included all breast cancer cases (n=576) reported to the Guam Cancer Registry, all breast cancer cases (n=8345) reported to the Hawai'i Tumor Registry and all breast cancer cases (n=678,637) reported to the Surveillance, Epidemiology, and End Results program from 2000 to 2009. Cumulative incidence rates by age were calculated for two time periods: 2000-2004 and 2005-2009. Differences were seen in cumulative incidence rates by age, ethnicity, and place of residence. Cumulative incidence rates by age 40 were the highest (0.7%) among Filipinos in Guam but, after age 40, the rates for Chamorros (indigenous Pacific Islanders of Guam) increased rapidly. The lifetime cumulative incidence rates were the highest for Chamorros in Guam (15.3%), close to the US rate (15.5%). Results were similar for 2005-2009. Women in Guam are at high risk for breast cancer, with the indigenous Chamorros having the highest risk, and the most prevalent Asian group of Filipinos, having a younger age at diagnosis. These patterns are similar to the comparable Pacific Islander and Filipino populations in Hawai'i and the US generally.

Keywords

breast cancer, Pacific Islanders, Chamorros, Filipinos, Hawai'i, Guam, US

Introduction

Breast cancer is thought to be a disease of Western industrialized nations,[1] and is the most common malignancy among women worldwide. In the United States (US), including Hawai‘i and the territory of Guam, breast cancer is also the most commonly diagnosed cancer and is the second most common cause of cancer death among women.[1-4] Women on Guam appear to exhibit slightly lower breast cancer incidence rates than US women in general, and in Guam, the incidence of this cancer varies among the ethnic groups of Guam and may be diagnosed at a younger age. However, women of Guam also have a higher mortality rate for breast cancer compared to women in Hawai‘i and the US.[4-5] The reasons for high breast cancer incidence and mortality rates among women in Guam are poorly understood.

Guam is located in the northwestern Pacific Ocean, approximately 3,700 miles west of Hawai‘i and 1,300 miles southeast of Japan. Chamorros are the original inhabitants of Guam and the other Northern Mariana Islands, though the current population of Guam is characterized by substantial ethnic variation:[6] 37% Chamorro, 26% Filipino, 7% White, 7% other Asian, 12% other Pacific Islander, and 11% other ethnicity. This ethnic diversity evolved through centuries of migration that continues today.[7] In addition, Spanish colonization of Guam, between 1521-1898, and the subsequent US possession since then, has led to ethnic and cultural mixing. Hawai‘i also has substantial ethnic diversity as Hawaii's population is comprised of indigenous Native Hawaiians (21%), Whites (23%), Filipinos (17%), Japanese (16%), Chinese (7%), and other ethnicities (16%).[8]

Cancer incidence rates for specific Asian[9] and Pacific Islander[10] populations living in the US have been reported elsewhere; and overall cancer rates in Guam and Hawai‘i have been reported by Hernandez and colleagues.[4] The purpose of this paper is to describe breast cancer rates by age and ethnicity of the Asian and Pacific Islander populations in Guam, and to compare them with the rates of comparable ethnic groups in Hawai‘i, as another multiethnic Pacific population, and with the overall US population. Cumulative incidence rates (CIRs) by age are reported, as they are more stable compared to age-specific rates and thus are suitable for smaller populations such as Guam.

Methods

We obtained data from the Guam Cancer Registry (GCR) for all reportable cancer diagnoses for Guam. For comparison, we obtained the Hawai‘i Tumor Registry (HTR) data and US national data on all female breast cancers from eighteen registries in the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program, including HTR, from January 1, 2000 through December 31, 2009. These eighteen registries cover approximately 28% of the US population and >28% of the Asian and Pacific Islander populations in the US. Therefore, this study included all breast cancer cases (n=576) reported to the GCR, all breast cancer cases (n = 8345) reported to the HTR and all breast cancer cases (n=678,637) reported to the NCI SEER from 2000-2009. The GCR provides demographic, tumor and survival information on cancer cases diagnosed since 1998.[11] GCR's membership in the North American Association of Central Cancer Registries (NAACCR) and the US Pacific Regional Central Cancer Registry (PRCCR) assures that cancer data collected by GCR is completed in a manner which meets the exacting standards set by NAACCR and NCI SEER research programs.[11]

Cumulative incidence rates are weighted sums of age-specific incidence rates R_A, $CIR = \sum_{A=1}^{m} \omega_A R_A$, in which the weights ω_A are the lengths of the age intervals, and m varies from 0-24 up to 0-85. We stratified the rates by Chamorro and Filipino ethnicity, with the time period based on the year of diagnosis (2000-2004, 2005-2009), and location. Average annual age-specific rates were computed as input per strata and 5-year age group, where the numerators were the sum of counts of breast cancer cases per year and denominators were the sum of the female population sizes per year, within the appropriate strata; that is $R_A = \frac{d_A}{S_A}$, where $d_A = \sum_{y=1}^{p} d_{Ay}$ is the sum of events for age group A across the years of interest and $S_A = \sum_{y=1}^{p} S_{Ay}$ is the sum of the populations for age group A across the years of interest. We used the US 2000 and 2010 census data to compute the denominators. For each strata, yearly counts of the size of the population by age group from 2000 to 2010 were estimated by interpolation between the census years; the counts were then aggregated into the two time periods to serve as denominators. The standard error for the cumulative incidence rate is

$$SE\left(CIR\right) = \sum_{A=1}^{m} \omega_A^2 \left(\frac{d_A}{S_A^2}\right)$$

. The CIR's were compared between ethnicities, location, and year period using negative binomial regression using log(S_A) as an offset variable.

Results

Remarkable differences were seen in cumulative incidence rates by age and ethnicity. During the 2000-2004 time period, the cumulative incidence rates up to age 40 were the highest (0.68%) among Filipinos in Guam, which was almost three-fold higher than the rate among Chamorros (0.24%) (*P*-value =.32) (Table 1). Filipinos in Hawai'i and the US had similar cumulative rates for the same age group (0.65% and 0.47%, respectively). These data support earlier evidence that Filipino women are being diagnosed at younger ages than their Asian and Caucasian counterparts.[12] After age 40, the rates for Chamorros increased rapidly. The lifetime cumulative incidence rate (age 0-85) for Chamorros (15.3%) was close to the overall US rate (15.5%). Interestingly, there was a marked difference in lifetime cumulative incidence rates between Filipino women by location. Filipinos in Guam had the lowest rate (9.3%), followed by Filipinos in Hawai'i (10.5%)(β=1.98, *P*-value<.001) and in the US (11.7%) (β=4.06, *P*-value<.001). Differences were observed between rates of Chamorros and Native Hawaiians, both Pacific Islanders. Native Hawaiians had higher cumulative incidence rates than Chamorros, both up to age 40 (0.65% and 0.24%, respectively, β=1.77, *P*-value=.036) and for lifetime risk (22.3% and 15.3%, β=1.33, *P*-value=.001). The risk among Native Hawaiians particularly differed from that of Chamorros at ages 60-64. Similar results were found for the 2005-2009 time period (Figure 1, Table 1).

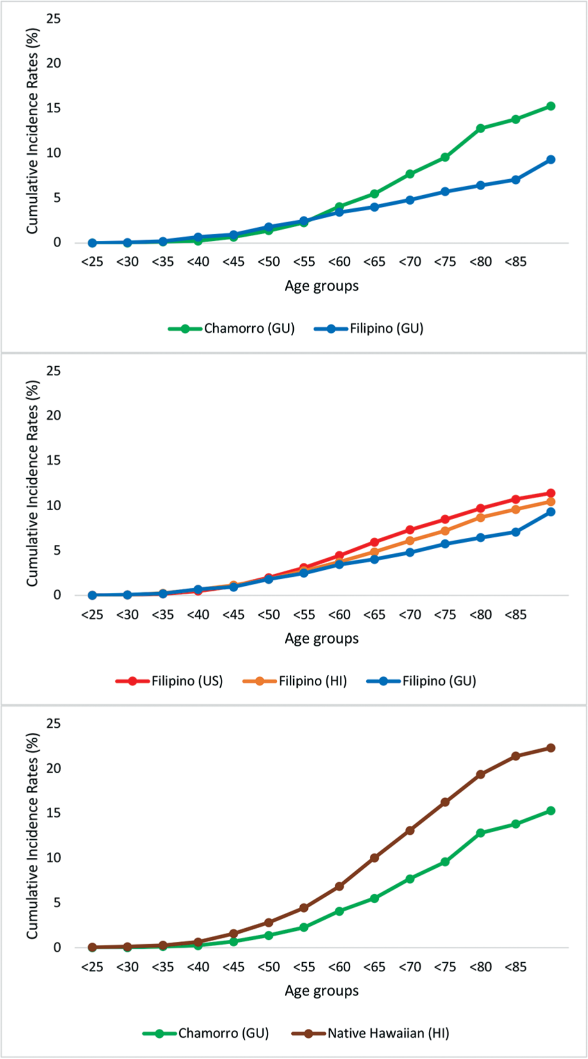

Figure 1. Lifetime (0-85) Cumulative Incidence Rates 2000-2004 by Different Ethnic Groups and Geographic Location

Table 1. Invasive Breast Cancer Cumulative Incidence Rates (%) with 95% CI

Between 2000-2004

Age groups	US	Guam	Filipino (US)	Filipino (HI)	Filipino (GU)	Chamorro (GU)	Native Hawaiian (HI)
	Rate (95% CI)	Rate (95% CI)	Rate (95% CI)	Rate (95% CI)	Rate (95% CI)	Rate (95% CI)	Rate (95% CI)
20-24	0.0 (0.006, 0.007)	0.0	0.0 (0.00, 0.009)	0.0	0.0	0.0	0.0 (0.00, 0.09)
25-29	0.0 (0.039, 0.044)	0.0 (0.00, 0.05)	0.0 (0.02, 0.06)	0.0 (0.00, 0.09)	0.1 (0.00, 0.20)	0.0	0.1 (0.04, 0.18)
30-34	0.2 (0.16, 0.17)	0.1 (0.05, 0.25)	0.2 (0.15, 0.22)	0.2 (0.13, 0.34)	0.2 (0.00, 0.41)	0.1 (0.00, 0.32)	0.3 (0.17, 0.39)
35-39	0.4 (0.43, 0.44)	0.4 (0.21, 0.52)	0.5 (0.42, 0.53)	0.6 (0.47, 0.83)	0.7 (0.28, 1.08)	0.2 (0.03, 0.46)	0.6 (0.47, 0.82)
40-44	1.0 (0.98, 1.00)	0.7 (0.51, 0.96)	1.0 (0.94, 1.09)	1.1 (0.90, 1.37)	0.9 (0.46, 1.42)	0.7 (0.31, 1.05)	1.6 (1.29, 1.84)
45-49	1.9 (1.85, 1.88)	1.5 (1.14, 1.81)	2.0 (1.87, 2.09)	1.8 (1.51, 2.12)	1.8 (1.12, 2.48)	1.4 (0.84, 1.93)	2.8 (2.45, 3.20)
50-54	3.0 (2.94, 2.98)	2.2 (1.77, 2.64)	3.1 (2.95, 3.23)	2.7 (2.26, 3.12)	2.5 (1.67, 3.29)	2.3 (1.55, 3.01)	4.5 (3.97, 4.94)
55-59	4.4 (4.37, 4.42)	3.4 (2.82, 4.01)	4.4 (4.26, 4.62)	3.7 (3.28, 4.19)	3.4 (2.43, 4.44)	4.1 (2.95, 5.20)	6.8 (6.19, 7.48)
60-64	6.0 (5.98, 6.02)	4.4 (4.02, 4.80)	5.9 (5.81, 6.07)	4.9 (4.32, 5.41)	4.0 (3.55, 4.50)	5.5 (4.73, 6.30)	10.0 (9.17, 10.91)
65-69	7.8 (7.74, 7.81)	5.8 (4.94, 6.75)	7.3 (7.05, 7.57)	6.1 (5.46, 6.75)	4.8 (3.53, 6.08)	7.7 (5.92, 9.49)	13.1 (12.01, 14.20)
70-74	9.7 (9.63, 9.71)	7.4 (6.22, 8.48)	8.5 (8.21, 8.80)	7.2 (6.47, 7.95)	5.7 (4.23, 7.26)	9.6 (7.42, 11.75)	16.3 (14.93, 17.57)
75-79	11.8 (11.73, 11.83)	9.5 (7.98, 11.02)	9.7 (9.38, 10.06)	8.7 (7.81, 9.57)	6.5 (4.64, 8.26)	12.8 (9.92, 15.70)	19.4 (17.80, 20.91)
80-84	13.9 (13.79, 13.91)	10.7 (8.83, 12.49)	10.7 (10.34, 11.12)	9.6 (8.59, 10.62)	7.1 (4.89, 9.26)	13.8 (10.62, 17.04)	21.4 (19.64, 23.15)
>85	15.5 (15.45, 15.57)	12.6 (10.08, 15.03)	11.6 (11.15, 12.05)	10.5 (9.33, 11.63)	9.3 (5.52, 13.13)	15.3 (11.50, 19.11)	22.3 (20.46, 24.47)

Between 2005-2009

Age groups	US	Guam	Filipino (US)	Filipino (HI)	Filipino (GU)	Chamorro (GU)	Native Hawaiian (HI)
	Rate (95% CI)	Rate (95% CI)	Rate (95% CI)	Rate (95% CI)	Rate (95% CI)	Rate (95% CI)	Rate (95% CI)
20-24	0.0 (0.006, 0.008)	0.0	0.0 (0.003, 0.022)	0.0	0.0	0.0	0.01 (0.00, 0.03)
25-29	0.0 (0.04, 0.05)	0.0 (0.00, 0.08)	0.1 (0.032, 0.068)	0.1 (0.01, 0.11)	0.0	0.0	0.07 (0.01, 0.12)
30-34	0.2 (0.17, 0.18)	0.1 (0.04, 0.25)	0.2 (0.13, 0.19)	0.2 (0.10, 0.30)	0.1 (0.00, 0.22)	0.1 (0.00, 0.25)	0.2 (0.12, 0.33)
35-39	0.4 (0.43, 0.44)	0.4 (0.25, 0.59)	0.4 (0.37, 0.47)	0.6 (0.46, 0.80)	0.5 (0.12, 0.81)	0.3 (0.03, 0.47)	0.5 (0.38, 0.69)
40-44	1.0 (0.99, 1.01)	0.9 (0.64, 1.14)	1.0 (0.92, 1.07)	1.3 (1.08, 1.58)	1.0 (0.48, 1.45)	0.7 (0.34, 1.09)	1.4 (1.11, 1.61)
45-49	1.9 (1.86, 1.89)	1.3 (1.04, 1.66)	1.9 (1.83, 2.04)	2.1 (1.82, 2.47)	1.5 (0.87, 2.08)	1.2 (0.72, 1.71)	2.6 (2.23, 2.93)
50-54	2.9 (2.88, 2.92)	2.2 (1.74, 2.57)	3.0 (2.87, 3.13)	3.2 (2.77, 3.56)	1.9 (1.21, 2.60)	2.3 (1.62, 3.06)	4.2 (3.73, 4.65)
55-59	4.2 (4.14, 4.19)	3.2 (2.69, 3.76)	4.3 (4.16, 4.48)	4.3 (3.86, 4.78)	2.8 (1.94, 3.70)	3.6 (2.69, 4.59)	6.2 (5.64, 6.79)
60-64	5.7 (5.66, 5.69)	3.9 (3.58, 4.16)	5.7 (5.60, 5.80)	5.3 (4.78, 5.81)	3.1 (2.79, 3.38)	4.6 (3.99, 5.12)	8.8 (8.06, 9.50)
65-69	7.4 (7.38, 7.45)	4.9 (4.12, 5.72)	7.3 (7.09, 7.55)	6.8 (6.20, 7.44)	3.7 (2.63, 4.78)	5.7 (4.36, 7.11)	12.1 (11.13, 13.06)
70-74	9.2 (9.19, 9.27)	5.9 (4.98, 6.88)	8.7 (8.39, 8.92)	8.3 (7.52, 9.00)	5.0 (3.62, 6.45)	6.6 (5.01, 8.13)	15.4 (14.21, 16.66)
75-79	11.2 (11.14, 11.24)	7.1 (5.95, 8.28)	9.9 (9.55, 10.17)	9.8 (8.97, 10.71)	5.6 (3.96, 7.15)	8.0 (6.06, 9.92)	18.3 (16.89, 19.76)
80-84	13.2 (13.11, 13.22)	8.6 (7.03, 10.10)	11.0 (10.60, 11.31)	11.0 (10.03, 12.02)	6.0 (4.19, 7.84)	10.9 (8.00, 13.76)	20.2 (18.62, 21.80)
>85	14.8 (14.70, 14.83)	11.5 (9.11, 13.85)	11.7 (11.34, 12.13)	11.4 (10.38, 12.45)	6.8 (4.40, 9.28)	15.0 (10.82, 19.27)	21.2 (19.56, 22.92)

Discussion

Other reports during the past three decades have found the incidence and mortality rates for breast cancer to be lower in Guam than in the US overall, although availability of mammography has been limited in Guam so under-diagnosis is a possibility. However, breast cancer risk is increasing among women on Guam as reflected in a rise increase in both incidence and mortality rates,[13] possibly fueled by a more Westernized lifestyle as well as by increased mammography screening. A similar transition occurred between 1975-2005 in Hawai'i in Filipino and Native Hawaiian women.[14,15]

We found that Filipinos in Guam have a relatively younger age at diagnosis, but a lower lifetime risk of breast cancer than Chamorros, and a somewhat lower highest lifetime risk of breast cancer compared to Filipinos in Hawai'i and the US generally. Chamorros, while having the highest risk of breast cancer among ethnic groups in Guam, had consistently lower risk across age groups compared to Native Hawaiians in Hawai'i.

The incidence and mortality rates for breast cancer have consistently been found to be high in Guam among Chamorros and low in Filipinos.[5,13,16,17] The reasons for these higher breast cancer rates among Chamorro Pacific Islanders on Guam are poorly understood, as historically no studies have been completed in Guam to examine breast cancer risk factors. A recent breast cancer case-control study in the Northern Marianas found no risk factors specific to this ethnic group.[11]

The differences between the rates of Filipinos by location could represent a difference in founder populations with differing breast cancer rates from those in the Philippines, or a varying level of acculturation between populations. A founder population is a group of migrants who become isolated from their parent population and that found a new population that more closely resembles the migrant than parent group. However, the Filipinos living in Guam and Hawai'i are predominantly from rural areas of the Philippines, so founder population location is unlikely to be the reason for differences between these groups. The Filipinos in Guam include a somewhat higher proportion of first generation migrants: 69% compared to 53% for Hawai'i and 66% for the US overall, in the 2010 census data.[18] Giving support to this hypothesis, the percentage of Filipinos over the age of five that speak a Filipino language at home is 80% in Guam, 58% in Hawai'i, and 65% in the US overall, according to 2010 census data. Therefore, the lower breast cancer rates in Guam could be due to less acculturation to western lifestyle and closer proximity to the Philippines (1551 miles apart), allowing for more cross-cultural exchange. This mirrors the trends found in a recent migrant study.[12]

The younger age at diagnosis was found in a literature review of breast cancer studies of Filipinos living in the US[8] and might be due to a longer immigration history, as seen among Japanese and Filipinos, and is thought to be related to the adoption of western behaviors that increase breast cancer risk, such as a later age at childbirth, lower parity, and higher body weight.[15] In addition, Filipino women are at increased risk, compared to their Asian-American cohort, of developing more aggressive breast cancer,[12] such as human epidermal growth factor receptor 2 (HER2) subtype.[19] The recent breast cancer case-control study in the Northern Marianas found that larger waist circumference was a strong risk factor among Filipinas.[11]

The two Pacific Island ethnic groups included in this report have different origins, as Native Hawaiians are Polynesians and Chamorros are Micronesians. Another Polynesian ethnic group, Samoans, have also been found to have high rates of breast cancer.[10] There is little information available on the cancer rates of other Micronesian groups.

A strength of this report is that the incidence rates are based on complete cancer registration in Guam and Hawai'i, as well as extensive coverage of cancer cases in the US generally. A limitation is that Pacific Islander and Filipino populations are internally diverse and the populations described here may not represent all subgroups.

The observed disparities in breast cancer incidence among ethnic groups suggests ethnic differences in exposure or response to risk factors. Description of these populations has not been possible previously due to low mammography rates, lack of comprehensive cancer registry information, and the difficulty of calculating rates in small populations. These factors are still limitations that continue to be strengthened. Further study is needed to examine differences in risk behaviors between Filipinos and Chamorros in Guam, and between Filipinos in Guam and in other US locations.

Conflict of Interest

The authors declare no potential conflicts of interest.

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Authors' Affiliations:
- College of Natural & Applied Sciences, University of Guam, Mangilao, Guam (GB)
- Cancer Research Center, University of Guam, Mangilao, Guam (BS, RB, RTLG)
- University of Hawai'i Cancer Center, Honolulu, HI (MG, YBS, LRW)
- College of Tropical Agriculture and Human Resources, University of Hawai'i at Mānoa, Honolulu, HI (RN)

Correspondence to:
Rachael T. Leon Guerrero PhD, RDN; University of Guam Cancer Research Center, Dean Circle #7, Mangilao, Guam 96923; Email: rachaeltlg@triton.uog.edu

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Using a Short Message System to Increase Cervical Cancer Screening Uptake among Chuukese Women in Guam: Lessons Learned from Linking Distance Technology Between Carriers and Using Telehealth Communication in a Cross-Cultural Context

Lilnabeth P. Somera PhD; Ana Joy P. Mendez RN, PhD; and Angelina Mummert

Abstract

This paper reports on a project aimed at using a short message system (SMS) to increase cervical cancer screening uptake among Chuukese women in Guam. It documents the process and identifies the unexpected challenges which led to the early termination of the study. Although the original aims of the project were not met, there were some lessons learned about technology incompatibility in the context of Guam's and the United States' cell phone technology interface, the cultural nuances of cell phone use in the study population, and the necessity to follow a protocol for the termination of a project.

Keywords

SMS, cervical cancer screening, technology challenges

Abbreviations

BCCEDP = Breast and Cervical Cancer Early Detection Programs
COFA = Compact of Free Association
FGD = focus group discussion
FSM = Federated States of Micronesia
HC = HealthCrowd
PSC = Program Steering Committee
RDS = respondent-driven sampling
SMS = short message system
US = United States

Introduction

The use of mobile phones to promote cancer screening, smoking cessation, healthy diets, and to reduce harmful behavioral risk factors has been spurred by the rapid development of technology. The growing body of research within the last two decades through the use of the short message system (SMS) technology to influence health behaviors in various populations has resulted in different levels of efficacy. The differential results have encouraged further investigation into the factors that influence responses to SMS, including those focused on increasing cancer screening rates.

While studies have reported small to moderate increases in screening rates for cancer, the benefit of using SMS to increase the uptake of screening was observed in countries that were resource-poor and had non-English speaking populations.[1] A systematic review of the impact of text message (SMS) interventions on cancer screening rates revealed that individuals who received SMS interventions had up to 15% higher screening rates than those who did not receive SMS messages.[1]

Based on the results of previous research,[2] a study to test the efficacy of SMS to increase cervical cancer screening among Pacific Islander women in Guam and Hawai‘i was developed. The study in Guam focused on Chuukese women, the biggest group of migrants from the Federated States of Micronesia (FSM) in Guam. The FSM 2013-2018 Comprehensive Cancer Control Plan noted that only 6% of eligible women received Pap tests in Chuuk.[3] Chuukese women bear a disproportionate burden of cervical cancer morbidity and mortality.[4,5] The data presented in the Cancer in the US Affiliated Pacific Islands 2007-2015 indicate that 73% of cervical cancer cases in Guam were diagnosed at advanced stages[5] and that Chuukese women comprised a higher proportion of the advanced stage cases based on an unpublished analysis from the Centers for Disease Control and Prevention National Program of Cancer Registries.

Target Population

The FSM is one of the three sovereign Pacific island nations which are in free association with the United States (US) via their respective treaties called Compacts of Free Association (COFA). The COFA allows the US military oversight, called strategic denial, over the three freely associated COFA nations. In exchange, COFA citizens are allowed free entry and the right to work in the US and any US Territory in perpetuity. Chuuk is the most populous state of the FSM with about 50,000 inhabitants,[6] many of whom rely on subsistence agriculture and fishing, and the funds from the compact with the US.[7]

The overall population of Freely Associated States citizens living on Guam – which remains to be the primary destination for FSM migrants – has increased by 9 percent between 2013 and 2018.[8] Guam was home to 18,874 Freely Associated State migrants, accounting for 11% percent of the island's total population.[8,9] Chuukese migrants comprise the largest number of FSM migrants to Guam, primarily because Chuuk State is only 1 hour and 45 minutes by air to Guam. According to the Guam Statistical Yearbook 2016, there are an estimated 11,500 Chuukese citizens in Guam, which accounts for about 60% of all migrants from the Freely Associated States.[10]

Cervical cancer disparities in migrant Chuukese women (ie, those who have recently migrated to the US) likely reflect a lack of health behaviors related to the utilization of cervical cancer screening.[4,5] Focus groups with Chuukese women held in 2016 revealed cultural characteristics that would affect their response

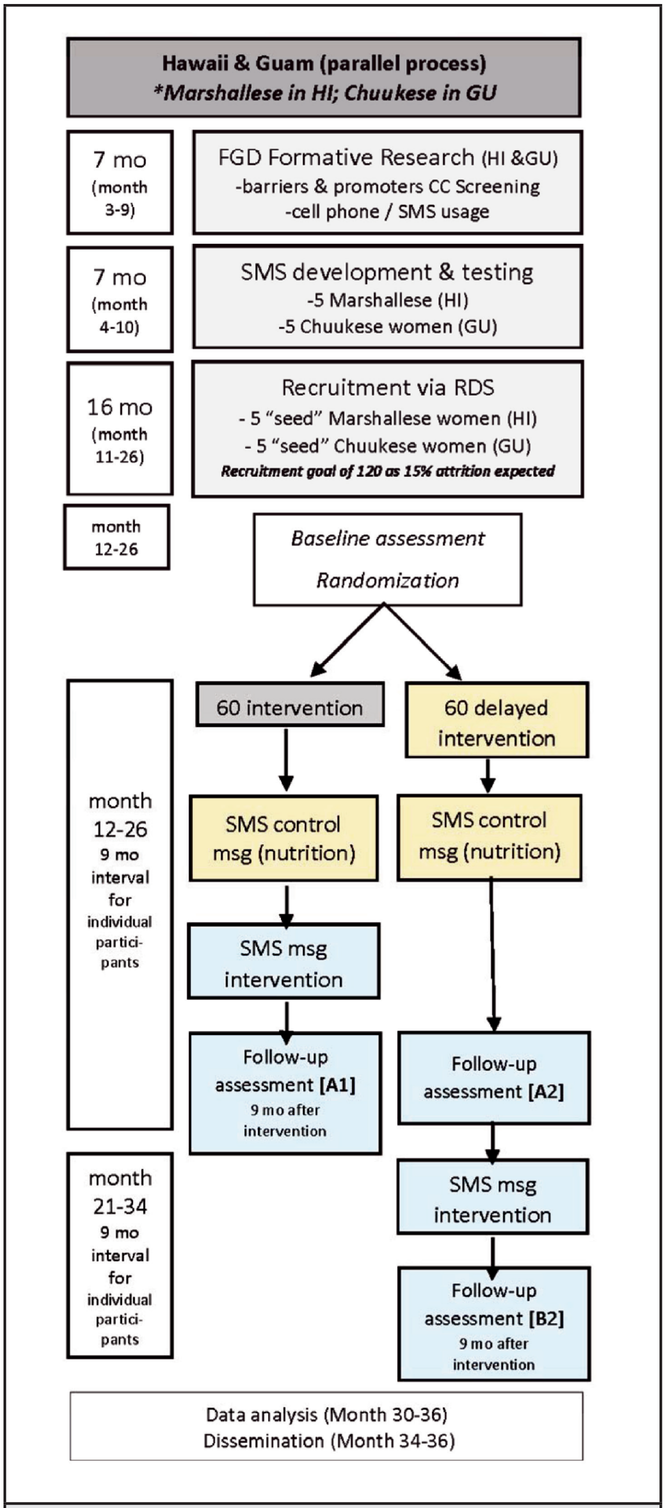


Figure 1. Research Design and Timeline

to messages about cervical cancer screening. Information about the customary use of mobile phones among Chuukese women was obtained through the 2016 focus group discussions (FGD). For instance, there were generational differences with younger women more adept at using mobile phones and more likely to use them in a variety of contexts. The majority tended to rely on prepaid cellular services with no or limited data plans, which provided inconsistent services. Consequently, FGD participants noted that members of the Chuukese community would often rely on free Wi-Fi access obtained at gas stations, laundromats, etc., and suggested that Facebook Messenger or WhatsApp may also be viable channels for conveying health behaviors messages.[2]

In addition, the degrees of acculturation differs among Chuukese women, which was associated with their willingness to discuss sensitive health topics outside the family, especially with someone who was not of the same gender. The FGD participants pointed out that a few women come from households where electrical power was not reliable and would pose a challenge to the study because mobile devices require charging. While limited in generalizability, these insights were valuable in the design of this study and the development of SMS messages.

To address the high rates of cervical cancer morbidity and mortality among Chuukese women in Guam, this study was aimed at using culturally-appropriate SMS as an intervention to increase cervical cancer screening.

Methods

The research design was based on the Fogg Behavior Model[11] and utilized concepts from the conceptual framework of Community-Based Prevention Marketing as described by Bryant and colleagues.[12] The behavior change models were founded in a community-based research approach to guide the development, planning, and implementation of evidence-based strategies.

This study was conducted in two phases (Figure 1).

In Phase 1, the team developed SMS messaging materials encouraging cervical cancer screening in English and Chuukese languages. Formative research was conducted to determine knowledge, attitudes, and beliefs about barriers and effective strategies to promote cervical cancer screening. The research was conducted among recently migrated Chuukese women age 21-65 who qualified for the Centers for Disease Control and Prevention's Breast and Cervical Cancer Early Detection Programs (BCCEDP) and other insurance programs designed for lower-income women (ie, Medically Indigent Program).

This study also sought to understand how the target populations used SMS on their cell phones. SMS messages for Chuukese women were developed, pretested, and were culturally and linguistically adapted for initiation and completion of cervical cancer screening. The weekly SMS messages about cervical cancer screening were interspersed with other messages the participants may have received which were competing for their attention. Some messages required a brief one-word response, such as “yes” or “no” and “true” or “false,” with the option to text back and ask for additional information.

In Phase 2, the team implemented the SMS intervention and assessed the impact on intent to screen, as well as to increase cervical cancer screening rates among Chuukese women. A total of 60 Chuukese women were enrolled in the Guam study, with a parallel study of Marshallese women in Hawai‘i. A delayed cervical cancer SMS intervention for the women randomized to nutrition SMS, to be carried out over the subsequent nine months, was incorporated into the intervention design.

Message Development

The SMS intervention was to be delivered to the intervention group immediately and after nine months to the delayed control group. Both groups were also to receive a ‘control’ SMS message encouraging healthful nutrition choices. The enrollees would be surveyed at baseline and again at nine months to assess post-intervention intention to screen and the completion of screening, as well as questions on other covariates.

HealthCrowd (HC), a consulting company in California, was contracted to develop the initial SMS. Two sets of SMS were developed, one for the intervention group (initiate and complete cervical cancer screening) and another for the control group (adopt / increase healthy nutrition behaviors). During the November 2016 U54 workshop, project team members met to review the messages, develop additional messages, and categorize the SMS based on components of the Health Belief Model.[13] The sequence of the messages was matched with the components of the model (perceived severity, susceptibility, benefits, and barriers, modifying variables, cues to actions, and self-efficacy). Both sets of messages for the intervention and control groups were translated into Chuukese by certified translators hired for that purpose. Translations were validated by the members of the Community Advisory Group composed of Chuukese women who represented different sectors of the Chuukese community.

HC was responsible for delivering the SMS texts on a weekly basis, tracking the responses, and conducting the analytics. The HC platform was able to send both pre-scheduled and “on the fly” text messages, and could receive replies from patients. Back-end analytics were utilized to parse incoming messages from patients, display self-reported measures such as intent to screen, confirm that they made an appointment for screening / received their screening on password-protected population and individual patient dashboards. At meetings with the HC team prior to the actual intervention, there were trial runs which were reassuring about connectivity and message transmission. The Guam BCCEDP screening program was tasked to provide a formal report regarding the research participants who agreed to release their medical information and who completed cervical cancer screening during the duration of the project. The SMS research team was responsible for following up with other non-BCCEDP health providers to determine receipt of cervical cancer screening.

Participant Recruitment

As these populations were hard to reach, respondent-driven sampling (RDS) was utilized to recruit study participants. The RDS method is a cost-efficient, non-probability sampling strategy that can generate reasonable population estimates for minority and hard-to-reach populations in a timely fashion.[14] In this chain-referral sampling method, respondent “seeds” recruit others who are eligible within their social networks; those recruited by the initial “seeds” then recruit others, with a limit of recruits per “seed” to prevent over-recruiting by some individuals. As a result, the composition of the final RDS sample is independent of the arbitrary selection of the initial “seeds.”

While the previous study demonstrated the efficacy of RDS in the recruitment of study participants, it was not as effective in this particular study. The “seeds” were not prolific and other recruitment strategies were employed, including face-to-face recruitment at health fairs and traditional snowball sampling (participants were asked to recruit their friends to participate in the study outside of the RDS process). The team also sought the assistance of other research staff, as well as non-profit organizations in the community, who worked closely with Micronesian migrants.

Enrolled participants were randomly assigned to the intervention and control groups. Blocked randomization, with random block sizes, was used to avoid a significant imbalance in size between the two study groups at any time during recruitment.

Project Implementation

While the SMS messages for the intervention and control groups were being developed, the research team recruited participants for the study. By the second week of May 2017, a full sample of 60 participants were recruited (Intervention=30, Control=30) and the team was ready to launch the project.

The initial sign-in SMS was received as expected. In essence, the welcome message was received, and the team anticipated monitoring responses on HC’s dashboard, and on the project phones which the research team used to monitor the SMS weekly messages. Within the first month, several glitches with the SMS transmissions were noted. The next section discusses the challenges that transpired during the project implementation and the factors that eventually led to the project’s early termination.

Results and Discussion

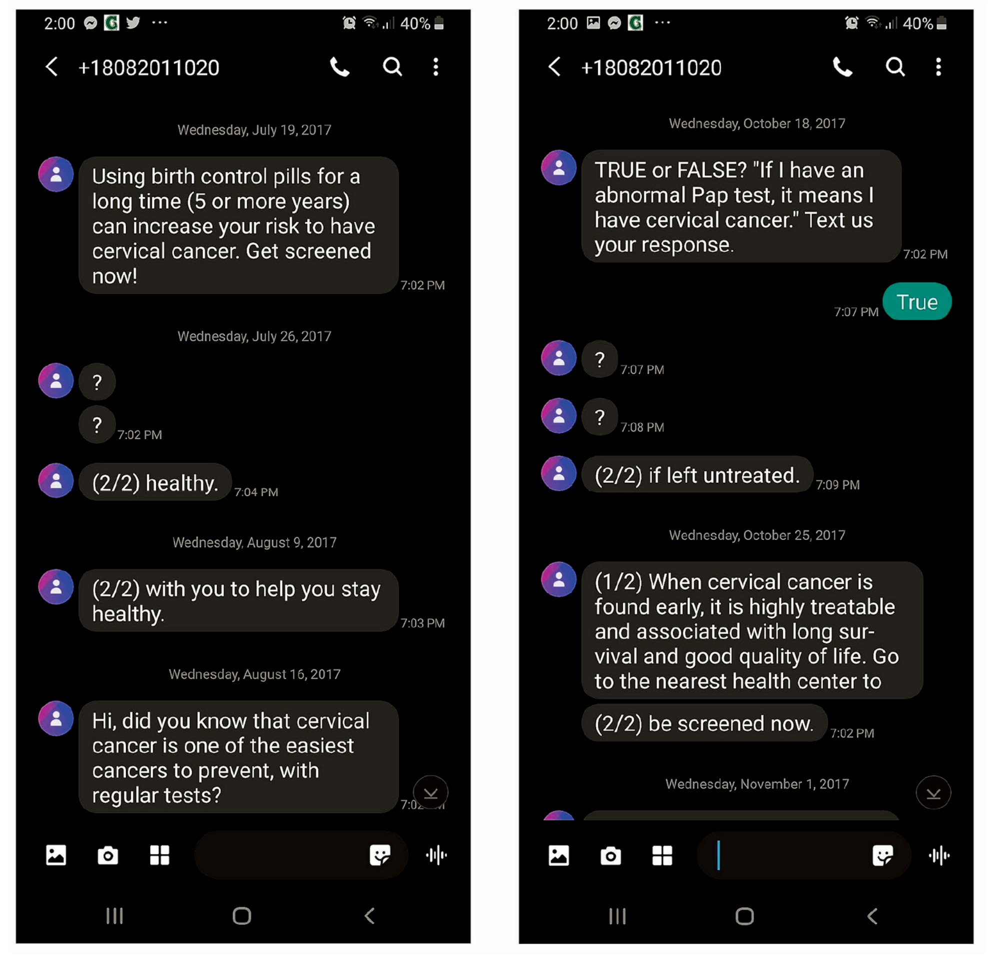
Analysis of the Project Implementation and Subsequent Challenges

As described in the research design, the SMS intervention involved the transmission of weekly messages aimed at raising awareness about cervical cancer screening and persuading research participants to get screened. In contrast, participants in the control group received messages about nutrition. HC sent the weekly messages. A local telephone service provider in Guam, IT&E, was used to deliver the messages. IT&E was the only local provider willing to work with this project, given the limited resources. In Guam, Blu Zoey flip phones with unlimited SMS text service were purchased; however, these flip phones did not have the capacity to make phone calls or to access the Internet.

In the parallel project in Hawai‘i, participants in Hawai‘i signed up for the Lifeline Program and used low cost smartphones for the project. Lifeline provided a discount on monthly service of $9.25 per month for eligible low-income subscribers. SMS texts were transmitted from HC in California. To avoid long-distance rates, messages were relayed from the area code from California (415) through Hawai‘i (808) and finally on to Guam (671). As the project progressed, the connection from HC and the local Guam IT&E company using the Blu Zoey phones did not function well.

SMS text messages were set up with HC and were scheduled to be sent weekly to the participants at 7:00 PM Guam time (when most participants were expected to be home and would be more likely to check and respond to messages). The SMS messages did not arrive consistently at the scheduled time. There was a time lag with several messages, some messages were truncated, or messages were not received at all. The project leader’s smartphone, set to receive the SMS messages, noted truncated SMS, as shown in the screen shots in Figure 2.

The examples in Figure 2 are just two of many instances where “?” appeared on the screen instead of complete messages. Inquiries with both HC and IT&E did not resolve the situation. The team was unable to determine the cause of the problem. The length of the message may have been part of the issue as



2:00 40%

+18082011020

Wednesday, July 19, 2017

Using birth control pills for a long time (5 or more years) can increase your risk to have cervical cancer. Get screened now! 7:02 PM

Wednesday, July 26, 2017

?

? 7:02 PM

(2/2) healthy. 7:04 PM

Wednesday, August 9, 2017

(2/2) with you to help you stay healthy. 7:03 PM

Wednesday, August 16, 2017

Hi, did you know that cervical cancer is one of the easiest cancers to prevent, with regular tests? 7:0

2:00 40%

+18082011020

Wednesday, October 18, 2017

TRUE or FALSE? "If I have an abnormal Pap test, it means I have cervical cancer." Text us your response. 7:02 PM

7:07 PM True

? 7:07 PM

? 7:08 PM

(2/2) if left untreated. 7:09 PM

Wednesday, October 25, 2017

(1/2) When cervical cancer is found early, it is highly treatable and associated with long survival and good quality of life. Go to the nearest health center to

(2/2) be screened now. 7:02 PM

Wednesday, November 1, 2017

Figure 2. Examples of Truncated Messages on a Smartphone

dropped messages were more frequent when a long message was transmitted as a single text. Translation of SMS into the Chuuk language resulted in longer text messages.

The local provider IT&E informed the researchers that if the individual phone was not turned on at the time when the SMS message came in on the Blu Zoey phones, their system would automatically attempt to resend the message multiple times within 48 hours. Unlike smartphones (eg, Androids or iPhones), the project phones did not automatically store messages for later review if the phones were turned off at the time the SMS was delivered. According to the provider, the messages were dumped/dropped from the system if they were not retrieved within 48 hours. They were only saved on the phones if they had been opened within that critical period. The Guam research team did not know this before the intervention started.

Regarding HC, the data and tracking information on their dashboard was unable to accommodate the necessary tracking information under a more nuanced interface. Response rates were presented in graphs such as the one shown in Figure 3. The rates were shown for 30-day periods, and expanded graphs were not available. The research staff had to take screen shots of the four-week graphs, as data on more extended time frames could not be viewed.

Figure 3 illustrates that between the October 2017 to November 2017 time frame, which was six months after the project was implemented, the total incoming text messages, ie, the SMS received by the participants ranged from 34 to 37 out of 60 SMS which should have been received for the respective intervention and control groups. For the SMS that required a response (yes/no, true/false), the responses ranged from 2 to 4. The green line, which indicates the number of phones which were turned on at a given time was erratic, ranging from 3 to 36 out of 60.

The information on the HC dashboard was not consistent with the records of Guam IT&E phone service and thereby reliable information was not robust throughout the six months of the intervention. These results and findings were presented at the annual U54 Program Steering Committee (PSC) in November 2017. Terminating the project was discussed with the PSC and the study's Internal Advisory Board in January 2018. The conclusion by the project leads, PSC, Internal Advisory Board, and Principal Investigators was that the technological problems were insurmountable and that the possibility of rectifying them, although attempted on several occasions, was not possible. While the pretesting of the technology worked, it failed when the SMS frequency was scaled up over time.

Although the incompatibility of the technology was the main factor that led to the project's termination, there are some cultural nuances of cell phone use in this population that are worth noting, as they could inform future studies.

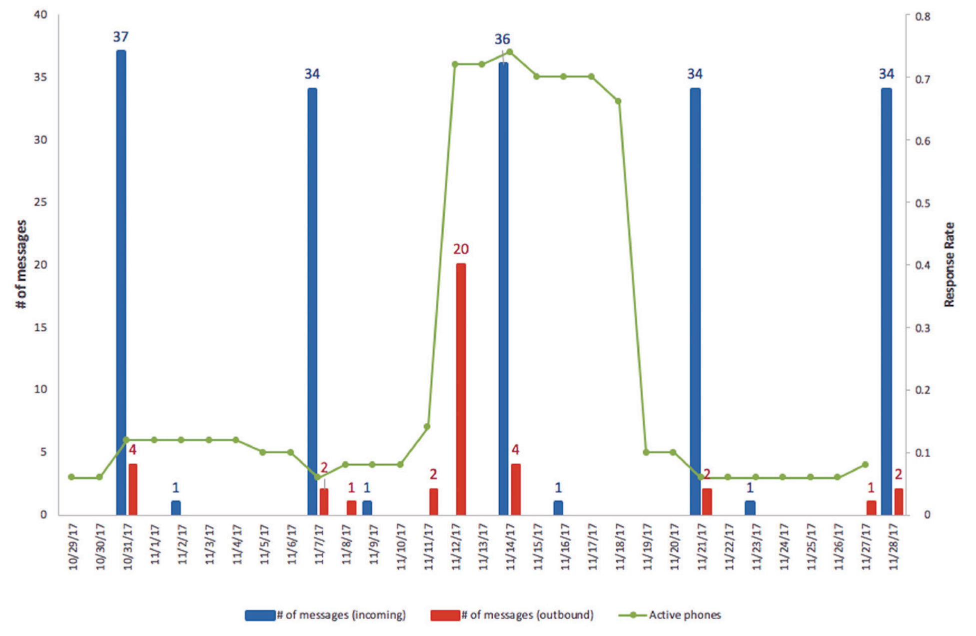


Figure 3. Response Rates of Weekly Text Messages

Cultural Nuances of Cell Phone Use Among Chuukese Women

There were cultural nuances in the use of cell phones, which were determined through the FGDs.

Familial Sharing of Phones. The women who participated in the study frequently shared phones with other family members. If the project phone was in the possession of another family member when the SMS message came from HC, the SMS may have been simply ignored. This observation was supported from the HC dashboard - interactive messages that required a brief response like "yes" or "no" remained unanswered.

In several instances when project team members attempted to follow-up with the participant on the alternate contact phone number, someone else other than the participant answered the phone. In one case, the person answering the phone questioned the motives for the research staff call and refused to give the phone to the study participant.

Transient Nature and Constant Change of Phone Numbers. While the participants were asked to give an alternate contact number and/or a Facebook account, some noted that their alternate phone numbers changed whenever they purchased new prepaid cards. It was therefore very difficult to reach the participants in several instances. Of the ones who were reachable, some indicated that they did not receive the SMS message, while others said that they received the message, but did not reply.

Limited Experience with Cell Phones. In two instances, participants indicated on their alternate phone that the Blu Zoey phone did not work. It is possible that they could have inserted the SIM card incorrectly, despite the demonstration that the research staff gave when they consented to participate in the study.

Some participants were not familiar with the technology and did not respond correctly to the interactive SMS messages. One response was gibberish; it was suspected that a child had gotten hold of the phone, and was playing with the keypad.

Following the termination of the study, the participants were contacted through all means possible (Facebook, viable alternate phone numbers, announcements in the two main local newspapers) and through a scheduled a town hall meeting to inform the participants regarding the termination of the study. The purpose of the town hall meeting was to encourage participants to see their health care providers and get screened for cervical cancer. Nine participants confirmed their attendance. Unfortunately, due to a storm on the meeting day only one participant attended. The process of locating and informing participants about the project's termination resulted in the development and strict adherence of a protocol for terminating a research project.

Implications and Recommendations (If we knew then what we know now)

The non-rectifiable issues regarding the technology incompatibility in the context of Guam's and the US cell technology interface made the early termination of the project the most prudent course of action. If there had been a local provider with the capabilities of HC for managing the SMS and tracking the response data, the issues could have been avoided or resolved. An on-site SMS provider would have made timely accessibility to technical support easier, as the time difference between Guam and anywhere in the continental US is between plus 14 to 17 hours.

Use of cell phones and SMS as an intervention was informed by prior studies and by testing the technology interface. Errors in the incompatible technology and the SMS messaging system were magnified as the frequency of SMS messages increased, and when scheduled / timely messaging was essential. Although the local Guam phone / cell service and the HC SMS company as independent entities were experienced and each company had a long positive track record with respect to their expertise and product, a longer test period (several months) and a higher volume of pre-project SMS would have been useful to test the technology interface.

The study did not work out as planned; however, the participants who were able to respond to the messages were engaged and open to this type of intervention. If the technological issues are addressed, we are confident that SMS could be a viable means of encouraging women from this particular population to get screened. Any future intervention should also take into account the cultural practices related to SMS, and ongoing shifts in the use of other communication technology. The challenges we encountered will provide some insights for other researchers who are considering future projects, which aim to increase cancer screening uptake using SMS.

Conflict of Interest

None of the authors identify a conflict of interest.

Sources of Funding or Disclosure Statement

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Authors' Affiliations:
- Division of Communication and Fine Arts, University of Guam, Mangilao, Guam (LPS)
- School of Health, University of Guam, Mangilao, Guam (AJPM)
- University of Guam Cancer Research Center, University of Guam, Mangilao, Guam (AM)

Correspondence to:
Lilnabeth P. Somera PhD; Division of Communication and Fine Arts,
University of Guam, UOG Station, Mangilao, GU; Email: lpsomera@triton.uog.edu

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An Assessment of E-health Resources and Readiness in the Republic of the Marshall Islands: Implications for Non-communicable Disease Intervention Development

Angela Sy DrPH; Candace Tannis MD, MPH; Scott McIntosh PhD; Margaret Demment PhD; Tolina Tomeing AA; Jahron Marriott MS; Tracee Fukunaga BS; Lee Buenconsejo-Lum MD; and Timothy Dye PhD

Abstract

The prevalence of non-communicable diseases (NCDs) is rapidly increasing in low and middle income countries (LMIC). The Republic of the Marshall Islands is an island country in the Pacific located near the equator and has the third highest prevalence of diabetes in the world, high rates of complications, and early mortality with limited or no resources for tertiary care of these complications. Given the limited resources of the country, there is a need for strategies which emphasize NCD prevention. E-health interventions are becoming more popular in LMICs. A rapid qualitative assessment, involving focus groups, site visits, and key informant interviews, was performed to ascertain community perceptions about the causes of NCDs including diabetes and potential solutions. An assessment of the technology infrastructure was conducted to assess capacity for potential e-health interventions. Thirty local participants were interviewed. Participants identified diabetes as the highest priority NCD with dietary shifts toward imported, processed foods and decrease in physical activity as the major causes. Text messaging and Facebook were found to be widely utilized for personal and public communication. Given the low-tech, low-cost communication mechanisms and widespread use of Facebook, a social media intervention could help support local NCD prevention communications initiatives.

Keywords

Diabetes, Marshall Islands, E-health

Background

Geographic, Economic, and Health of the Marshall Islands

The Republic of the Marshall Islands (RMI) is an island country located near the equator in the Pacific Ocean, slightly west of the International Date Line. The country's population of 53,158 people is spread out over 29 atolls covering 181 square miles. About 74% of Marshallese live on Majuro, the capital, and Ebeye. Majuro atoll has a land area of only 3.7 square miles and has a port, a shopping district, hotels, and an international airport.[1]

The RMI attained independence in 1986 under a Compact of Free Association (COFA) after almost four decades under United States (US) administration as the easternmost part of the United Nations Trust Territory of the Pacific Islands. Compensation claims continue as a result of US nuclear testing on some of the atolls between 1947 and 1962. Under the terms of the Amended COFA enacted in 2004, the US will provide millions of dollars to the RMI until 2023, at which time a Trust Fund made up of US and RMI contributions will begin perpetual annual payouts.[2]

The small island economy is largely supported by US government assistance. Imports far exceed exports because the islands have few natural resources. In 2006, about 40% of employed persons worked in the public sector and the median household income was $12,603 across the country and $14,737 in Majuro.[3]

Non-communicable diseases (NCD), such as cancer, diabetes, and hypertension, are emerging as some of the leading causes of death in the RMI. Over 62% of the population is overweight or obese. The US COFA reparation includes the provision of health care services, but funding is limited, resulting in a lack of mechanisms for health services linkages, care fragmentation, and loss of continuity in the care for patients with chronic disease.[3] Therefore, the public health approach of choice is primary prevention. Training of outreach and prevention staff with the skills and knowledge necessary to deliver health promotion and disease prevention messages is still needed. Such training should include sessions on communication skills, public relations, the nutritional value of foods and self-managing diabetes and its complications.[3]

At the same time, promising tailored health education and primary prevention approaches are present. Since 2006, a Diabetes Wellness Center provides a behavioral change program addressing healthy lifestyle, diet, and physical activity. Culturally relevant and in-language diabetes and other NCD educational materials have also been developed in Majuro.[3]

Type 2 Diabetes in the Marshall Islands

The prevalence of type 2 diabetes in low and middle income countries (LMIC) has been consistently increasing over the most recent decades. The RMI has the third highest prevalence of diabetes in the world, and about 35% of adults ages 20 to 79 have diabetes in the RMI.[4] Furthermore, there are high rates of complications and early mortality,[3] and diabetes-related amputation is the most common surgical procedure performed on the island.[5] There are no dialysis units for patients with kidney failure, a common complication of poorly controlled diabetes; and the nearest dialysis facilities are accessible only by the few who can afford costs of travel and care in Hawaiʻi or the Philippines.

E-health Readiness

E-health uses information and communications technologies to more efficiently and effectively deliver health communication and information to reach targeted audiences.[6] Like the use of traditional mass media, designing innovative health education interventions using communications technology must be relevant and usable for the intended targeted audiences and the specific purposes.[7] The purpose of an e-health readiness assessment is to examine the preparedness of health care institutions or communities for changes if programs that entail information and communication technology use are introduced.[6] E-health readiness assessments have been conducted in various geographical regions of the world to identify the extent to which e-health strategies would fit with existing systems, cultures, and other external contexts, eg, resources, skills.[4,8,9] The purpose of this paper is to describe the findings from a rapid qualitative assessment procedure aimed at assessing the fit and capacity of RMI, as a small island nation, to disseminate technology-based health interventions to prevent non-communicable diseases.

Methods

Setting

In September 2014, two Centers for Disease Control and Prevention (CDC) sponsored projects were funded by collaborating academic institutions. The University of Hawaiʻi (UH) was awarded the Racial and Ethnic Approaches to Community Health (REACH) grant to work with the US Affiliated Pacific Islands (USAPI) on tobacco and nutrition interventions. A requirement for each of the USAPI jurisdictions is a communication plan and strategies regarding reduction of second-hand smoke exposure and improving nutrition. Additionally, the University of Rochester Medical Center (URMC) was awarded a Prevention Research Center-sponsored program as the CDC's Global and Territorial Health Research Network Coordinating Center (GHTRN). This project collaboratively conducts, shares, and translates innovative chronic disease prevention research in low-resource settings, particularly those relevant to the USAPI, Puerto Rico, and the US Virgin Islands.

In June 2015, the UH REACH and URMC GHTRN partners conducted an initial assessment of priority health issues and e-health readiness of the USAPI via surveys and questionnaires at a biannual face-to-face meeting of the USAPI Cancer Coalition and REACH representatives in Hawaiʻi. The preliminary assessment results revealed NCDs as a priority health issue across the Pacific and a general readiness toward e-health initiatives. The RMI was selected as a site to pilot a research project on an e-health initiative.

Instrument Development and Testing

The team developed a focus group guide and questionnaire to assess e-health readiness. Focus group questions were aimed at identifying sources of major NCD burden in Majuro as well as perspectives on the causes of NCDs. The e-health readiness questionnaire was adapted from previously published instruments assessing self-reported content and processes that have been purported to describe various organizational and geographic regional levels of "e-readiness."[10] The e-health assessment included data gathering on current health communication initiatives, as well as questions on barriers and facilitators of e-health programs on the island. The tool was pilot tested via emails and video conferencing between the researchers and local Majuro team members. Two key contacts in health from Majuro participated in the pilot testing of the focus group guide via videoconferencing by responding to the questions and providing suggestions to tailor questions according to relevancy.

Data Collection

The objective of this formative research project was to conduct a Rapid Assessment Procedure (RAP)—an intensive, team-based qualitative inquiry using triangulation, iterative data analysis, and additional data collection to quickly develop a preliminary understanding of a situation from the insider's perspective—to better understand the enabling factors, challenges, and opportunities related to health, technology (high and low, e-health), and communication in Majuro to help address chronic disease.[11] In August 2015, a RAP was conducted in Majuro to identify the community's priorities related to NCD prevention in order to address national and regional goals toward NCD reduction. The community's e-health readiness was assessed for opportunities to pursue information and communication technology (ICT)-based chronic disease prevention initiatives.

Focus group participants were selected from a local convenience sample of community members. The academic partners subsequently used chain sampling during the visit to identify key people in community health outreach or local communication. The focus groups and e-health assessments were conducted at convenient site locations, eg, health department, health clinic, and church, and facilitated by a URMC or UH researcher and audio-recorded with field notes taken. At the end of each day, the field team convened to debrief impressions and complete their notes from the day's focus groups. No identifying information was collected on individual participants. The project was approved by local stakeholders and the Institutional Review Boards of both UH and URMC.

Data Analysis

The inductive coding process began with a review of field notes and audio recordings to develop a coding tree. Dedoose qualitative analysis software program was used to support the coding for key themes and constructs by an initial reviewer. Dedoose is a cloud-based qualitative data analysis program using cloud-based data storage in a HIPAA compliant SAS 70 type II data center and utilizes SSL-EV and AES-256 encryption (www.dedoose.com), thus allowing multiple coders with the cloud-based platform.[12]

Content thematic coding examines for patterns or themes in participants' discussions. Content thematic coding was compatible with the aims of most qualitative health research in presenting the key elements of participants' accounts. Themes were coded as recurrent concepts to be used to summarize and organize the range of topics, views, experiences, or beliefs voiced by participants.[10] The thematic codes were then reviewed by two additional reviewers for corroboration, with any discrepancies discussed and resolved by the team.

Results

Fifteen men and 15 women representing different employment sectors, including the healthcare sector, participated in the group and individual interviews which averaged 39 minutes each. The team additionally completed four hours of meetings with officials and engaged in 12 hours of community introduction, cultural activities, and site visits.

Non-communicable Diseases in RMI

While the local participants mentioned a range of NCDs, diabetes emerged as a main priority across employment sectors and among local individuals. Participants described dramatic shifts in community diet away from traditional, island- and sea-generated foods such as breadfruit, fish, pandanas, and coconut toward more conveniently available and quickly prepared foods like canned tuna and meats, ramen noodles, and sugary beverages. Shifts away from traditional economic activities like fishing and active transportation were also seen as responsible for the increasing rates of diabetes in the RMI. A church pastor offered his perspective on the roles of modernization and globalization on diabetes in the RMI:

> "All the local foods, they keep people healthy, and there was no diabetes in the Marshall Islands but after we depend on the store-things from the store. That's how we got diabetes."

Furthermore, participants relayed experiences of embarrassment and fear related to learning of one's diagnosis with diabetes, interfering with timely treatment and secondary and tertiary prevention of additional diabetes-related morbidity. Participants were generally knowledgeable about the roles of physical activity and diet as diabetes risk factors. However, participants also cited challenges to translating that knowledge into behavior change, such as the increasing preference for food that is convenient and a desire for a more modern lifestyle. Nevertheless, the significance of traditional practices and values of the community elders were emphasized.

Information and Communication Technology on Majuro

Perspectives from the local participants were obtained regarding the ICT available in the community and the role of ICTs in health education, outreach, and care. Participants explained that technology infrastructure was present on the island in general, with the majority of public offices and buildings on Majuro using landline, cable-based internet connections. Fiber optic cable connections were noted to be available on eight of the islands in the RMI. Participants also reported that less than half of the population has internet access in the home which is primarily through a Wi-Fi connection.

Participants reported that most of the population has access to mobile phones, though not necessarily smartphones, but all with basic text messaging capabilities. The National Telecommunication Authority sends mass text messages that include alerts of importance or interest to the population, eg, power outages, bingo announcements, celebrations, and sales or specials at stores. As a result, mass text messaging was noted to be an effective method of disseminating information throughout the community. One participant noted:

> "There is also a mass text on cell phones….For example, it was world TB [tuberculosis] day a couple of months ago and a message was sent out to everybody's cell phone that there was an activity going on and just a little bit of information about TB…"

There are also some initiatives to incorporate technology into community outreach. One local clinic coordinator reported:

> "We put everyone on our team on 'Evernote' because we all have smartphones so we keep track of what's going on. It is shared calendar or schedule…You can share notes,you can share data, and you can share schedules…"

The participant described examples of outreach activities, which could be advertised through a phone-based app system, including community events like cooking demonstrations. Nevertheless, issues with connectivity in the home setting were noted as a major barrier to the success of e-health interventions. One participant noted other barriers like the initial capital costs and the lack of sufficient personnel support for maintaining the technology required for e-health programming and initiatives.

E-health Expansion in Majuro

There is interest in expanding e-health initiatives on Majuro and converting health materials to electronic communication formats. One participant noted:

> "....If you give us the content, we can translate it into the TV. We can translate it so you can put it on Facebook, the social media—the driving engine of the country…Just give us the content and we can pump it up for free."

There is also interest in increasing individual access. A participant described a generational gap in ICT use with the younger generation having more interest and ability to use various communication and social media platforms than older generations.

Social Media in Majuro

All participants viewed NCDs as an important issue in the community that should be addressed, and most felt that social media was an acceptable way of engaging most of the population in health education. One participant suggested mass texting as a means of community health messaging:

> "For two hours, you would send out a mass text that said 'everyone get up for 15 minutes and walk around'."

A major finding on social media was that island residents commonly use social and electronic media to communicate within and across islands and to other geographic regions to receive information, engage in electronic social interaction, and learn information about others. Facebook was noted as the most popular platform by several key informants:

> "Everybody is on Facebook out here."

Participants also noted personal examples, stories, and testimony delivered electronically or face-to-face as being preferred content of health messages.

> "We've had people who have changed their lifestyle and improved their health, go on the radio and tell their story, and that influences other people—if this person did it, I can do it."

Engaging health champions in media outreach was viewed as an important component in changing habits and preventing and treating diabetes. As one participant was quoted:

> "People just cannot make changes until they see something."

Other suggestions for using texting to reach out to the community included a health promotion campaign that consists of text messages with questions to get people thinking and stimulate follow-up discussion.

Discussion

The RMI, like other LMICs, experienced shifts in diet and activity that can be attributed to social, political, economic circumstances that lead to chronic disease. Diabetes was found to be a key issue for the Marshallese. This study suggests a need for outreach and prevention staff to be trained in delivery of key health promotion and disease prevention messages that include the nutritional value of foods, as well as the prevention and self-management of diabetes and its complications.[3] In addition, since social media has become important in many aspects of daily living including advertising, it has the potential to be used as a tool for health messaging promotion that enhances local health communications efforts.

Discussion from e-health assessments revealed that e-health readiness was high. A social media based, culturally-relevant and engaging diabetes prevention/intervention that enhances existing NCD initiatives and policies and features local content and activities of interest would enrich efforts to prevent the high-risk of diabetes expressed by participants. There is increasing support for Facebook-based interventions in delivering evidenced-based prevention messages.[13-16] More research needs to be done to improve the duration of the positive effects.

The majority of the population on Majuro has access to text messaging, which can be used to broaden the reach of a social media health education and behavior change campaign, especially as a tool for follow-up and ongoing encouragement of participants. This approach is consistent with current literature which suggests that text messaging campaigns positively affect health outcomes both in conjunction with other intervention components and as stand-alone initiatives.[14,17] In addition, due to the significant burden of disease in LMICs and comparatively fewer available resources, e-health-based interventions can often have a greater overall impact.[17] Although mass texting for residents in Majuro has been criticized for its use beyond emergencies, it remains a very effective means to reaching out to the general public.

Preliminary results from the qualitative assessments underwent a further validation via a presentation at another biannual face-to-face meeting of cancer control and other public health leaders from the USAPI. The local partners from the RMI corroborated the preliminary qualitative findings and contributed to the interpretation of results. Given its popularity and reach within Majuro, Facebook was identified as an appropriate and viable communication method for the majority of Marshallese with specific health messaging.

A project to conduct and evaluate a diabetes prevention intervention using Facebook as a means to deliver primary, secondary, and tertiary diabetes prevention health messages is being pilot tested. As with the assessment phase, continuous engagement of the local Majuro partners in the research intervention planning and implementation reflected and resulted in a collaboratively developed, feasible pilot intervention. Potentially positive results from the pilot research study may be scaled up in the RMI, other Pacific jurisdictions, and other LMICs. The continued community engagement will better ensure that social media and other e-health approaches will be relevant and sustainable as an overall strategy in NCD prevention in the Marshall Islands.

Strengths and Limitations

Strengths of the project were related to the academic and community partnerships, the ability to meet with many local key informants onsite, and the qualitative coding methods. The chain sampling approach to recruitment allowed researchers to further engage with the community by allowing focus group participants to identify additional key informants for this study. In addition, the sectors represented in the focus groups indicated saturation of responses suggesting that there was no need for "more of the same" participant representation. Thanks to existing partnerships from previous and current collaborations, the research team was able to meet with local participants with different levels of influence within the local government, and completed the qualitative assessment in five days. The qualitative analysis used direct thematic coding from the audio transcripts with the Dedoose software, which decreases the risk of information loss from inaccuracies in written transcription of the audio, associated with more traditional coding processes.

This study is not without its limitations. The short duration of the initial field work did not allow for alternate networks of key informants. For example, interviews of members of inner community networks or sectors who may provide alternative perspectives, eg, village leaders and traditional healers, could not be quickly arranged even though these individuals had been recommended. Although these key community individuals were identified during the discussions, the protocols including securing trusted English and Marshallese translators would have required much advance planning that was not possible while the team was already onsite. However, through the careful use of chain sampling strategies, the discussions involved professionals and community members who would also serve as potential future partners in implementing the resulting pilot Facebook intervention and other community-based initiatives.

Implications

Social and economic determinants of NCDs that affect the ability to practice healthy lifestyles will need to continue to be addressed to reduce the NCD burden in RMI. While issues surrounding social and economic determinants of health were discussed, suggestions to address resulting obesity and diabetes prevalence emphasized primary prevention through healthy lifestyle messaging.

A Facebook-based communications intervention may provide an acceptable and engaging opportunity to shape health promotion and disease prevention norms and behaviors to prevent diabetes and its complications, especially as other isolated and remote small island nations face dramatic shifts in diet and activity and burgeoning NCD epidemics. Combining such efforts with available mass media avenues such as mass text-messaging and the local radio station could further expand the reach of diabetes prevention initiatives. The health communications approach would focus on primary and secondary messaging integrating local experiences, images, and examples to enhance message internalization and behavior adoption. Furthermore, by providing a venue for participants to contribute their own content, a Facebook-based intervention has the potential for evolving self-sustainability. Further research will determine the types of electronic health messages that may enhance health communication and education efforts in small island communities like Majuro in the Republic of the Marshall Islands.

Conflict of Interest

None of the authors identify a conflict of interest.

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Authors' Affiliations:
- John A. Burns School of Medicine, University of Hawai'i, Honolulu, HI (AS, TT, LB-L)
- Environmental Medicine and Public Health, Icahn School of Medicine at Mount Sinai, New York, NY (CT)
- Clinical and Translational Science Institute, University of Rochester Medical Center, Rochester, NY (MD, TD)
- Department of Public Health Sciences, University of Rochester Medical Center, Rochester, NY (SM)
- University of Rochester Medical Center, Rochester, NY (JM, TF)

Correspondence to:
Timothy Dye PhD; University of Rochester Medical Center, 601 Elmwood Ave,
Box CU420708, Rochester, NY 14642; Email: tim_dye@urmc.rochester.edu

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A Rapid Assessment Procedure to Develop A Non-Communicable Disease Prevention Pilot Health Communications Project Using E- and M-Health Communications in Pohnpei State, Federated States of Micronesia

Angela Sy DrPH; Jahron Marriott MS; Candace Tannis MD, MPH; Margaret Demment PhD; Scott McIntosh PhD; Johnny Hadley BA; Pertina Albert; Lee Buenconsejo-Lum MD, FAAFP; and Timothy Dye PhD

Abstract

Pohnpei State of the Federated States of Micronesia, located in the Northwestern Pacific Ocean, has limited health research infrastructure; chronic non-communicable diseases (NCD) such as diabetes, heart disease, and cancer are a concern. Over 73% of Pohnpei's population is overweight or obese. E- and m- (mobile) health interventions are becoming more popular in low and middle income countries. A Rapid Assessment Procedure was conducted for formative research to identify the enabling factors and challenges related to health communication and technology in Pohnpei to address NCD prevention.

Thirty-seven local stakeholders were identified through snowball sampling for interviews and group discussions about e-health readiness and NCD priorities, held in local settings. Interviews were audio recorded, with field notes taken. Data were iteratively coded using DEDOOSE.

Diabetes emerged as the most serious NCD issue because both the health system and local community are having to deal with the complications and consequences. Stakeholders recommended that prevention should be integrated with diabetes treatment. Local health workers' teaching evidence-based diabetes prevention and other health promotion education were through handheld (mobile devices) was identified.

The ability to readily access evidence-based health education materials and modules is compatible with community approaches providing tailored, individual and small group education and social support. This approach may serve as a key component of local NCD prevention communications initiatives integral to prevent diabetes and its complications as remote Small Island Nations face burgeoning NCD epidemics and dramatic shifts in diet and activity.

Introduction

Pohnpei and Health Priorities

The Federated States of Micronesia (FSM) contain 607 volcanic islands and atolls scattered over 1 million square miles of the Northwestern Pacific Ocean. The land area totals 704.6 square kilometers, with 7192 square kilometers of lagoon area. The FSM consists of four geographically separate states: Chuuk, Kosrae, Pohnpei, and Yap.[1]

The FSM receives revenue from the Compact of Free Association, the agreement with the United States of America by which Micronesia received $1.3 billion in financial and technical assistance over a 15-year period until 2001, with smaller funding in succeeding years. Economic activity in the FSM consists primarily of subsistence farming and fishing.[1]

The State of Pohnpei consists of the main island of Pohnpei and eight outer atolls. The island of Pohnpei is roughly circular in shape, is approximately 13 miles long, has a landmass of 133.3 square miles, and is the largest island in the FSM. Based on the 2010 Census, Pohnpei has a population of 35,981. The mean household income was $11,249.[2]

Heart disease, diabetes, cancer, and hypertension were some of the leading causes of death among the residents of Pohnpei.[2] Over 73% of the population was overweight (30.5%) or obese (42.6%).[3] A classification for non-communicable disease (NCD) risk using specific risk factors found that 56.7% of the study population in Pohnpei was at high risk of NCDs.[2]

Human resources are a critical area in the health care setting nationally, as many of the current workforce will be retiring in five to 10 years, and their replacement is not imminent. Development of the health workforce therefore remains a government priority. Government health services also lack specialized allied health professional workers, particularly hospital administrators, epidemiologists, medical record administrators, pharmacists, laboratory technicians, radiologists, and environmentalists.[1] There is also a need for staff training on health education strategies using behavior change theories such as the Stages-of-Change model, Self-Management Skills, and Lifestyle Behaviors.[2]

The high incidence of NCDs with a small and diminishing health workforce in Pohnpei mirrors global health trends in developing countries. The WHO declared that in developing countries, there is a "critical health workforce shortage" which includes hospitals that are understaffed as well as gaps in patient physician communications.[4,5] NCD prevention as a means to address gaps in healthcare workforce has been identified as a "major health challenge of the 21st century" in low and middle-income countries (LMIC).[6,7]

E- and M-Health in LMICs

Standardized definitions of e- and m-health have not been established with terms used inconsistently and interchangeably with varied understanding.[8] E-health uses information and communications technologies while m-health uses mobile devices (on- or off-line) for communications and information. For m-health, the WHO definition is used: "communications technology using mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other technologies to support medical and public health practice".[5] E- and m-health encompass communications strategies covering the range of low and high tech media, and all have the goal to more efficiently and effectively deliver health communication and information to targeted audiences.[9] Examples include devices to access electronic or mobile information, eg, radio, digital camera, DVDs, tablets, telehealth, and forms of information delivery: email, websites, electronic health records, and social media.[10]

Information and communication technology strategies such as telemedicine, internet-based programming, and mobile platforms have been shown to be feasible in reaching populations that would otherwise have limited or no access to care resources within the United States and abroad.[11] "E-health" or "m-health" often use fewer resources and require less infrastructure for sustainability, making e- and m-health ideal, and these health communication strategies have been successfully used in low resource countries.[12,13] As highlighted by the United Nations at an NCD meeting, the use of m-health is a key strategy to address NCD prevention and reduction in developing countries by improving health programming and services, particularly in LMICs.[5,6] The literature review on m-health strategies most appropriate for LMICs found that health promotion and raising awareness and the use of mobile phones and PDAs were among the eight most common m-health areas and types.[5]

A literature review conducted on the use and areas of use of m-health found that though diabetes was the most commonly addressed health area, this, along with other NCDs, is still not adequately addressed. The authors conclude that for LMICs, m-health needs to extend globally outside of Asian countries, where m-health is more popular, and particularly address NCDs and diabetes.[5] In Pohnpei, the identified health priorities are the need to shift the health education paradigm from signs and symptoms of diabetes, nutrition, and physical activity to lifestyle behavior changes, self-management skills, and personal accountability.[2]

Like the use of traditional mass media, designing innovative health education interventions using mobile technology must be relevant and usable for the target audiences and the specific purposes.[6] The purpose of e- and m-health readiness is to assess the preparedness of health care institutions and communities for changes if programs that entail information and communication technology use are introduced.[9] An m-health assessment in the Republic of Seychelles, a developing small island state, found that such an assessment is necessary and should be conducted prior to m-health implementation for other small island, middle income developing states or countries.[6] E-health readiness assessments have been conducted in various circumstances and geographical regions of the world to identify the extent e- (or m-) health strategies would fit with existing systems, cultures, and other external contexts, eg, resources, skills.[4,6,9]

Purpose of Project

The Racial and Ethnic Approaches to Community Health (REACH) is a US Centers for Disease Control and Prevention (CDC) funded initiative to support public health efforts to reduce NCDs by promoting healthier lifestyles, to reduce health disparities, and to ultimately improve health outcomes for minority populations. In September 2014, the University of Hawai'i (UH) at Manoa received REACH funding to develop and implement in Pohnpei State a public communication campaign to reduce smoking, secondhand smoke, and sugar-sweetened beverage consumption. Additionally, the University of Rochester (UR) was awarded a Prevention Research Center-sponsored program as the CDC's Global and Territorial Health Research Network (GTHRN) Coordinating Center. This project collaboratively conducts, shares, and translates innovative chronic disease prevention research in low-resource settings, particularly those relevant to the US Affiliated Pacific Islands, Puerto Rico, and the US Virgin Islands.

The goals of the collaborative REACH and GTHRN project are to explore innovative approaches to health communications including e- and m-health approaches and develop qualitative and quantitative methods for measuring and evaluating communication efforts through the REACH program in Pohnpei. The objective of this formative research was to conduct a Rapid Assessment Procedure (RAP)—an intensive, team-based qualitative inquiry using triangulation, iterative data analysis, and additional data collection to quickly develop a preliminary understanding of a situation from the insider's perspective—to better understand the enabling factors, challenges, and opportunities related to health, technology (high and low, e- and m-health), and communication in Pohnpei to help address chronic disease.[14]

Methods

RAP is appropriate when there is a need for "actionable feedback" and has been used to quickly deploy recommendations to sponsors in a short amount of time available for a clinical informatics intervention. This RAP involved the development and refinement of procedures and then collection and analysis of interview data, field notes, and direct observation.[15] RAP was used to conduct formative research to better understand the enabling factors and challenges related to context, experience, results of current NCD-related communication efforts of REACH and related projects from local stakeholder perspectives in Pohnpei. The stakeholders included health workers, administrators, key institutional representatives and opinion leaders in the community, and community members.

Setting and Recruitment

REACH in the USAPI supported community and culturally relevant public health efforts to reduce NCDs by promoting healthy eating and preventing tobacco use. Pohnpei State was one of three USAPI locations that were identified by preliminary assessment, local expressed interest, and purposeful selection to conduct a pilot research project on e-health readiness via an intervention. Snowball and convenience sampling were used to identify people to include in qualitative interviewing and group interviews. Of interest were people whose jobs were related to health or communication and capturing a representative sample of community members impacted by potential messages.

Domains

Two domains were assessed for e-health readiness and NCD priorities: (1) Current health communication efforts, barriers, and facilitators and (2) multilevel conceptions of NCDs. Each domain was guided by questions developed in a semi-structured interview guide, eg, How would stakeholders like to see messaging done differently? What modalities are used (eg, radio, text messages)? What are the challenges and the recommendations that you would make to improve communication efforts around these NCD issues? The focus group questions were aimed at identifying sources of major NCD burden in Pohnpei as well as perspectives on the causes of NCDs. The semi-structured questions for the focus group were pilot tested via emails and video conferencing between the researchers and local team experts from a partner site in the Republic of Marshall Islands. They provided suggestions to tailor questions according to relevancy.

Data Collection

The REACH Local Project Assistant identified focus group participants from an initial local convenience sample with subsequent chain sampling. The participants were identified by the local partners during the visit as people who had key roles in community health outreach or local communication. The focus groups were conducted at convenient site locations (eg, health department, health clinic, and church), facilitated by a UR or UH researcher, and audio recorded with field notes taken. At the end of each day, the field team convened to debrief impressions and complete their notes from the day's focus groups.

Coding and Analysis

Thematic coding of the qualitative data was used to assess and gain insight on potential REACH communication activities to targeting healthy behavior change. Content thematic coding examines for patterns or themes in participants' discussions. This approach was chosen because it was compatible with the aims of most health qualitative research in presenting the key elements of participants' accounts. Themes were coded as recurrent concepts to be used to summarize and organize the range of topics, views, experiences or beliefs voiced by participants.[16] A coding tree was drafted after debriefing in the field and reviewing field notes (TD, AS, SM, MD), and a codebook was developed. Dedoose is a cloud-based qualitative data analysis program using cloud-based data storage to a HIPAA compliant SAS 70 type II data center and utilizes SSL-EV and AES-256 encryption (www.dedoose.com) thus allowing multiple coders with the cloud-based platform.[17] Dedoose qualitative analysis software program was used to support the coding for key themes and constructs by an initial reviewer. The initial reviewer had expertise in qualitative analysis and use of Dedoose for coding but was not involved in the RAP so that thematic codes identified could be purely inductive, ie, no familiarity of the context and topic. The coding tree (ie, themes and subthemes) was piloted on audio files by three independent coders to the cloud-based transcripts files and discrepancies in coding were discussed and resolved by the coding team (JM, CT, MD).

Results

Twenty-one men and twenty-two women participated in focus groups and key informants interviews (group and individual interviews), and they represented different employment sectors including health disciplines. The interviews averaged 40 minutes in length and took place within a variety of local settings including hospitals, churches, homes, and at community events. The team additionally engaged in 4 hours of community introduction, cultural activities, and site visits (Table 1). Results address the two domains of which participants were queried: (1) Current health communication efforts, barriers, and facilitators and (2) multilevel conceptions of NCDs, and reported below.

Diet

Change in diet since World War II was indicated as a major contributing factor to the increased rate of NCDs. Participants explained that this change arises from a sociocultural shift in time management that prioritizes speed and convenience in food preparation over the longer time it takes to prepare traditional meals. Ease and affordability of canned foods was an incentive to forgo traditional meals.

Table 1. Descriptive Information on RAP in Pohnpei

Interview and Activity Characteristics	n
Gender	
Male	21
Female	22
Local	
Yes	38
No	5
Average length of interview/meeting (minutes)	60 minutes
Community activity (hours)	4 hours

The influx of imported food items, such as rice or other foods foreign to the traditional diet, has been explained as a contributing factor of diabetes and other NCDs (Table 2). All but one interview or focus group discussed diet change as a major contribution to NCDs in Pohnpei. Participants expressed the belief that by going back to one's "roots", traditional diets and ways of preparing food, health issues, such as NCDs, may decrease.

Physical Activity

The changes in physical activity levels of residents were described as the result of the flow of modernization reflected in having less time devoted to food preparation. Participants explained that the ease and convenience of food preparation takes away one of the outlets that islanders have to get exercise with one participant noting: "*Need to get back to doing physical work. Need to sweat it out!*" On Pohnpei, people are more willing to drive cars or get a ride to their destination instead of using more active means of transportation. Nevertheless, there seems to be a desire to get people more active through engagement in sporting activities. In three of the interviews and focus groups, participants discussed physical activity and its relationship to NCDs.

Diabetes

Diabetes is a visible part of Pohnpeian life, but it has been resistant to intervention:

> "*We are struggling to deal with this*."

Diet has been identified as a contributing factor to diabetes. White rice was mentioned as a commonly consumed imported food and most responsible for the increase of diabetes on the islands. Also, many people felt the scope and impact of NCDs in Pohnpei is overwhelming:

> "*NCDs are so big, we can't see what it is*."

Participants discussed themes related to diabetes as a problem in every interview and focus group and expressed that diabetes is the most serious NCD issue because both the health system and local community are having to deal with the complications and consequences. Furthermore, participants explained that Pohnpei is not able to prevent diabetes or treat complications. However, they also recommended that prevention should be integrated with the diabetes treatment (Table 3).

Summary of Diabetes-related Themes

Further analysis of the constructs of diabetes, physical activity, and diet within this study seem to suggest a strong connection between all three constructs. A tripartite reciprocal model in which each construct impacts the other may capture the interconnected relationship between diabetes, physical activity, and diet. There is a strong interaction between these three constructs.

Communication Efforts

Participants were asked about health communications including the use of communications technology in Pohnpei. Three themes regarding health communications emerged, with one addressing technology (in general) for health communications. One salient theme was that the most effective intervention to communicate NCD prevention messages was community engagement and outreach, deployed through mobile teams and events and with testimony provided by affected populations. Another theme was that health education training was needed for community health workers to deliver accurate NCD prevention messages. The third theme is a hope that some type of technology could facilitate an intervention because people like to *"play with their electronic toys"* (Table 4). Educational modules for use in mobile devices with content and teaching strategies to help health workers use in the field when providing diabetes prevention and management education were identified as an intervention to address diabetes.

Table 2. Themes Related to Diet

Theme	Quotes
Diet rapidly changed in response to colonial periods - introduction of rice as staple, canned foods, and priority on speed and convenience	*"Now people want to cook what's easy – just open a can…"*
Diet habits are difficult to shift	*"[Kids] spend their life eating rice, it's hard to change."*
Impact of modern economy	*"We prefer to have money to buy what we want… People sell fish to buy canned meat!"*

Table 3. Themes Related to Diabetes

Theme	Quotes
Diabetes is overwhelming the health system and community	*"When you talk about a boat crash, the boat is already sinking."* *"We're losing the battle."*
Inability to prevent or treat complications	*"Here if you have kidney problems from diabetes, you're going to die"*
Need to integrate prevention and treatment	*"Public health and curative services are like two legs… If you tie them, you can't go anywhere. Too far apart, and you fall down."*
Attitude of fatalism, fear, and denial of potential medical consequences	*"Our perception of disease is pain. Diabetes doesn't have the cardinal features of illness that we know – fever, pain, etc. People feel OK."* *"They think it's God's Will. That's hogwash, it's not God's Will at all."*

Table 4. Themes Related to Technology

Theme	Quotes
Health education training was needed	*"We've never been trained in health education and behavior change – it's all learning on our own. Would like to know how to do this right."* *"People need to see and learn. To get something done, need to show people it works first."*
Technology could facilitate an intervention	*"I hope technology can help us."* *"People here really play around with their [electronic] toys."*
Interventions that engage community members in groups, with personalized stories, and with local theming were preferred	*"They can associate it with how people lived in the past...like a song...keep your roots...something that would identify themselves with the past. Especially in terms of eating or in terms of how do they approach health."*

Discussion

A Rapid Assessment Procedure was conducted with key community members representing health and other key sectors in Pohnpei State, FSM to assess NCD priorities and e- and m-health readiness, similar to e- and m-health readiness assessments conducted in other LMICs.[4,9] Pohnpei, like other LMICs, is experiencing shifts in diet and activity that lead to chronic disease. Diabetes was found to be a key issue for Pohnpeians.

Discussion from e-health assessments revealed needs for health professionals at all levels (ie, local health workers and trained clinicians) to accurately communicate prevention education as a priority. Educational modules for use in mobile devices with content and teaching strategies to help health workers use in the field when providing diabetes prevention and management education were identified as an intervention to address diabetes. Providing decision support tools via mobile devices is an asset for community health workers in LMICs. Additionally, use of e-health interventions for management of chronic diseases like diabetes has also been found to be cost-effective.[5,11,12] Use of a simple mobile device to access the educational materials for disease prevention at all stages should be locally feasible in multiple settings, especially if the modules are designed to be self-contained without the need for internet access. A mobile, solar charged offline device used by the US Peace Corps volunteers in the field would be the ideal m-health platform because of its ease of transport.

Preliminary results from the qualitative assessments underwent a further validation process via presentation at another biannual face-to-face meeting of cancer control and other public health leaders from the USAPI. The local partners from Pohnpei corroborated the preliminary qualitative findings and contributed to the interpretation of results.

These findings are consistent with the literature that found that health priorities in Pohnpei include a need for training of health professionals in general and trainings on how to conduct health education while aligning with global health priorities.[2,5,6] Though the RAP aims and procedures differed from previous assessments which only focused on health priorities, these findings were still well aligned regarding health priorities on health professional trainings. Finally, the need to provide easily accessible health professionals training and health education materials aligns with LMICs using mobile devices in health communications. This project found that a mobile device may serve as a tool to access health education and trainings when health workers are providing their education and services.

Strengths and Limitations

Strengths of the project were related to the academic and community partnerships, ability to meet with many local key informants onsite, and the qualitative coding methods. The RAP was feasible for focus group opinions from participants with varying levels of healthcare and technology related experiences and consistent with the recommendation to conduct e- and m-health assessments encompassing technological, resource, and cultural readiness. The recruitment approach identified additional key informant participants recommended by the focus group participants. Thanks to existing partnerships from previous and current collaborations, local participants with different levels of influence within the local government were met and qualitative assessments were completed in five days. The qualitative analysis used direct thematic coding from multiple coders from the audio transcripts with the Dedoose software. In contrast, coding of transcribed audio in written form may increase the risk of inaccurate transcriptions through the transcription process. Finally, these findings aligned with previously conducted assessments that identified similar health priorities for Pohnpei and global health trends, eg, diabetes and NCDs, limited health workforce.

Though the sectors represented in the focus groups indicated saturation of responses and this study did not need "more of the same" participant representation, the short duration of the initial fieldwork did not allow for alternate networks of key informants. For example, inner community networks or sectors that may provide alternative perspectives, including village leaders and traditional healers, were unable to participate in the focus groups due to time limitations associated with identifying them prior to arrival. Although these key community individuals were identified during the discussions, the protocols including securing trusted English and Pohnpeian translators would have required much advance planning that was not possible while the team was already on-site. However, through careful use of chain sampling strategies, professionals and community members that would also serve as potential future partners in the project planning and implementation phase of this project were involved.

Implications

A pilot research project to develop, implement, and evaluate a mobile based platform to deliver educational modules for health workers in their prevention work will be conducted. As with the assessment phase, continuous engagement of the local Pohnpei partners in the research intervention planning and implementation will reflect and result in a collaboratively developed feasible intervention reflecting community needs. Potentially positive results from the pilot research study may be scaled up in the FSM, other Pacific jurisdictions, and other LMICs. The continued community engagement will better ensure that a social media and other e-health approaches will be relevant and sustainable as an overall strategy in NCD prevention in the Pohnpei.

A mobile health training based intervention for health workers will help those who have reach into communities to educate the community on evidence-based diabetes prevention and management strategies. The role of community health workers and their ability to connect with community members in health education is key to prevent diabetes and its complications as more isolated and remote Small Island Nations face burgeoning NCD epidemics and dramatic shifts in diet and activity. Further research will determine the types of evidence-based diabetes and health education content to include to enhance health communication and education efforts in small island communities like Pohnpei State in the Federated States of Micronesia.

Conflict of Interest

None of the authors identify a conflict of interest.

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Authors' Affiliations:
- John A. Burns School of Medicine, University of Hawai'i, Honolulu, HI (AS, LB-L)
- Department of Obstetrics and Gynecology, University of Rochester Medical Center, Rochester, NY (JM,TD)
- Environmental Medicine and Public Health, Icahn School of Medicine at Mount Sinai, New York, NY (CT)
- Clinical and Translational Science Institute, University of Rochester Medical Center, Rochester, NY (MD)
- Department of Public Health Sciences, University of Rochester Medical Center, Rochester, NY (SM)
- Pohnpei State Cancer Control Program, Pohnpei, Federated States of Micronesia (JH, PA)

Correspondence to:
Timothy Dye PhD; University of Rochester Medical Center, 601 Elmwood Ave,
Box CU420708, Rochester, NY 14642; Email: tim_dye@urmc.rochester.edu

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Cultural Considerations for Conducting the Health Information National Trends Survey with Micronesian Communities: Lessons from a Qualitative Study

Kevin Cassel DrPH; Hye-ryeon Lee PhD; Lilnabeth P. Somera PhD; Grazyna Badowski PhD; and Megan Kiyomi Inada Hagiwara DrPH

Abstract

A critical barrier to addressing health disparities among minorities is the lack of data, particularly on Pacific Islanders. Typically, national health surveillance systems do not have the resources to ensure proper representation of these small population groups. This study reports factors that guided the cultural adaptation and administration of the National Cancer Institute's Health Information Trends National Survey (HINTS) for a United States-dwelling Pacific Islander population in Hawai'i. To adapt the survey, four focus groups were conducted with 32 purposively-selected Micronesian migrants. Themes on health, healthcare barriers, cancer and methods to implement the survey were extracted from the analyses of the focus group narratives. Key cultural factors were identified that impact health practices, including religious and cancer fatalism, racism, health locus of control and other barriers. Using information from the focus group participants, the HINTS questionnaire was modified and the survey was implemented. The survey data provided will inform the future delivery of health promotion strategies for this unique medically underserved population.

Keywords

Cancer epidemiology, health communication, health promotion, qualitative research, health equity, cultural appropriateness, Micronesian

Introduction

According to the 2010 Census, 1.2 million people in the United States (U.S.) identified themselves as Pacific Islanders, one of the fastest growing U.S. populations.[1] Pacific Islanders represent a broad category of ethnically and culturally diverse groups. Although Micronesians are the third largest ethnic group, comprising 15% of U.S. Pacific Islanders,[1-3] they continue to be "invisible" in the U.S. There are tremendous gaps in knowledge about factors that influence their health and quality of life.[1,2]

The majority of Micronesians have come to the U.S. under a series of treaties known as the Compact of Free Association (COFA). COFA was negotiated in the 1980s with three Micronesian nations, the Federated States of Micronesia, the Republic of the Marshall Islands, and the Republic of Palau, giving the U.S. certain rights and responsibilities. Citizens from these nations have unlimited entry into the U.S. without visas or limits on length of stays.[4] Inadequate economic opportunities combined with insufficient healthcare systems in COFA jurisdictions are driving the Micronesian exodus, specifically to Hawai'i and Guam.[5] This migration is also fueled by complex historical and political relationships, including substantial nuclear weapons testing conducted by the U.S. military in the Pacific region between 1946 and 1958.[5]

Limited data is available on the health status of Micronesians in Hawai'i, Guam and the continental U.S. because of their inadequate representation in U.S. healthcare assessments and surveys.[3] In Hawai'i, the Centers for Disease Control and Prevention (CDC) Behavioral Risk Factor Surveillance System (BRFSS) captures limited data on Chamorro or indigenous Guamanians, but remains inadequate in reaching other groups of Micronesians.[3] This underrepresentation is in part due to the survey's sampling strategies, including the use of only landline telephones, which unintentionally excludes many Micronesians.[3] Therefore, more appropriate survey methods are needed to assess disease risk, health status, health information seeking and healthcare utilization among Micronesians in Hawai'i.

Despite this lack of population-based data, indications are that Micronesians living in the U.S. and their home nations represent a large medically underserved population.[3,4] High rates of both infectious and chronic diseases experienced by Micronesians in their homelands contribute to overall low life expectancies, averaging 12 less years of life than U.S. residents.[5] Micronesian migrants to the U.S. continue these high disease burdens with significant prevalence of tuberculosis, obesity, diabetes and cancer. Recent study data and anecdotal evidence from organizations that provide healthcare to Micronesians in the Pacific including Tripler Army Medical Center, and Hawai'i's community-based health centers reveal a high and unequal burden of both chronic and infectious diseases, including cancer, diabetes, and cardiovascular disease.[3] Micronesian women experience some of the highest rates of cervical cancer in the world with an incidence rate of 18.3 /100,000 compared to the U.S. rate of 7.2/100,000, which illustrate lack of access to routine cancer screening and prevention. Additionally, the unique cancer risk behaviors of Micronesians including tobacco and betel nut use are correlated with the incidence and mortality rates for lung, nasopharyngeal and liver cancers in this ethnic group.[6]

Improved assessment of the healthcare needs of this growing U.S. population can support appropriate health promotion and the strategic allocation of resources to reduce health inequities. One possible tool to help reach this goal may be the use of the

Health Information National Trends Survey (HINTS).[7] HINTS was created in 2003 by the National Cancer Institute in an effort to assess the access and utilization of health information technology to promote health behaviors. However, HINTS has limited sampling data on Micronesians.[7] As Micronesian migrants may have different needs and protocols than the general population, focus groups with Micronesian community members were conducted to identify the appropriate adaptations needed to successfully administer HINTS to this group.[8,9] Key factors to understanding the health behaviors and perceptions of Micronesians were identified. Findings from the preliminary qualitative research are reported here.

Methods

This study was approved by the University of Hawai‘i's Office of Research Compliance. Focus groups (n=4) were conducted from 2012-2013. Thirty-two migrants from either Chuuk (a state within the Federated States of Micronesia) or the Republic of the Marshall Islands participated. These populations were chosen as they represent the largest Micronesian demographic groups in Hawai‘i.[10]

Participants were referred from the Hawai‘i Department of Health's Bilingual Health Services' Easy Access Program (DOH-EAP), which provides linguistically- and culturally-appropriate healthcare assistance to Hawai‘i's immigrants.[11] People who had vocational or positional influence within Hawai‘i's Chuukese or Marshallese communities were given priority for inclusion because of their capability to provide rich information about community members in their respective groups.[9,12,13] Focus groups were stratified by ethnic group (separate sessions were held for Marshallese and Chuukese groups) and gender to accommodate language differences and gender norms that might otherwise deter free conversation in Pacific Island cultures.[14-16] Trained moderators, recruited from the Hawai‘i DOH-EAP and matched by ethnicity and gender, led the groups and signed non-disclosure agreements. All participants provided written and oral consent to voluntarily participate.

Focus groups were held at a health center serving Honolulu's Chuukese and Marshallese communities and were audiotaped. Interview questions were designed to obtain data about: the relevance of health and cancer including cultural factors related to health; how health information is disseminated; willingness to participate; and the culturally-appropriate methods for administering a health survey within the Marshallese or Chuukese community (Table 1).

Table 1. Questions Used for Discussion Group Interviews

Section 1 – General Health and Cancer:
1. What does health or being healthy mean to you?
2. What does cancer or a cancer diagnosis mean to you?
3. How does cancer impact your community?
Section 2 – Health and Culture
1. What are the customs in the Chuukese/Marshallese culture that would make you feel uncomfortable answering questions surrounding cancer and health?
2. What could be done to help make you feel more comfortable?
3. Do you or how do you share health/cancer information with the public in Chuuk/ the Marshall Islands?
4. How have you ever answered questions about health/cancer?
5. How could we best ask questions about health with Chuukese/Marshallese people
6. How could we get Chuukese/Marshallese people together to ask health questions?
7. What has been your experience in obtaining healthcare, have you experienced discrimination in this setting?
Section 3 – Survey Design and Administration
1. What customs in the Chuukese/Marshallese culture would support people answering a survey about health and cancer?
2. What do you think is the best way we can reach people from the Chuukese/Marshallese community to promote taking a survey?
3. What would make you and other Chuukese/Marshallese people more likely to agree to answer survey questions surrounding cancer?
4. How important would it be to administer the survey in the Chuukese or Marshallese language?
5. If a written survey is used, how much help would people need to complete a survey?
6. How important would it be to have someone who is Chuukese/Marshallese help administer the survey?
7. How much time would people be willing to give to complete a survey?

All dialogue of the four focus groups were translated into English by the bilingual moderators and subsequently transcribed by the study team. Analysis of the transcribed interviews was inductive.[12,16] Members of the study team independently read the transcripts to identify potential themes and structures. Consensus was established among the study team for a structural framework that encompassed themes and underlying meanings and was then used to establish a coding structure for investigator co-coding.[8,12] The study investigators then reread the transcripts, highlighting illustrative passages. There was high agreement among the investigators on themes and any disagreement was discussed until consensus was reached. The results of the investigators' analysis of the transcripts were reviewed by the focus group moderators and transcript translators who, as representatives of the Marshallese and Chuukese communities, supported this study's use of a member-checking procedure to ensure the accuracy of the findings, and to provide any additional insights concerning the data.[12,13]

Results

A total of six Chuukese and six Marshallese women, and 10 Chuukese and 10 Marshallese men participated (Table 2). Five major themes were identified: (1) perceptions about health; (2) communications about health; (3) cultural factors influencing health; (4) perceived racism in healthcare; and (5) survey method considerations. Each is discussed in more detail below.

Perceptions About Health

Definitions of health were wide ranging. For instance, some saw the absence of medical care as a sign of health. A Marshallese man stated, "One is healthy if he is not being treated by the doctor or doesn't have to take medication." A Chuukese woman linked health to financial well-being and having a social support system, stating, "Knowing that I have a home, a job and family support is healthy to me."

Perceptions about cancer differed between the two groups. Marshallese discussions focused on the role of nuclear testing as a causal factor of cancer. A male Marshallese stated, "Our community suffers because of the nuclear bombs dropped on our homes." Another Marshallese man reiterated and expanded this concept:

> We think cancer in the Marshalls is related to the bomb testing. I have seen many Marshallese coming to Hawai'i for cancer-related medical treatment; and some did not make it… Back home we have seen babies born without bones because of the fallout.

On the other hand, Chuukese participants saw cancer as a rare disease, possibly related to the limited access to treatment and the non-disclosure of patients' disease in their community. A Chuukese man stated emphatically for the group, "Cancer is rare for us, it is not common."

Table 2. Discussion Group Demographics

	n (%)
Chuukese	
Male	10 (31)
Female	6 (19)
Marshallese	
Male	10 (31)
Female	6 (19)
Total	**32 (100)**

Participants across all groups had remarkably fatalistic attitudes toward a cancer diagnosis: most associated cancer with impending death, and the few patients that survived were considered lucky. Early stage cancers were not associated with better survival rates or cures. One Marshallese man stated, "Getting diagnosed with cancer means that you are going to die soon; that you don't have much more time on Earth."

The financial costs of cancer care also seemed to frame participants' attitudes. A Marshallese man stated, "I think about the money and the debt; because if you have money, you have a big chance of surviving the cancer, but if you don't have money, I'm sorry, bye-bye."

Communicating About Health

Communication about health is often restricted among these populations. One Chuukese woman said, "Cancer is not talked about even among family members. Some have cancer but we don't know because we don't get treatment." Across all groups, participants emphasized that cancer and the notion of death from cancer are uncomfortable topics. However, younger generations could be more willing to talk about health and cancer. A Marshallese woman stated, "There are youth-to-youth programs that use skits and music to talk about health."

Similarly, all participants shared that certain topics are considered taboo in discussions, particularly in mixed gender groups in Micronesian culture. Participants stated that open discussions about breast, cervical, prostate and colorectal cancers as well as the associated screening tests are inappropriate in mixed gender groups. A male Marshallese emphasized, "You'd have to frame questions and information related to sexual organs in a certain way. In the older generation, [cancer] might be taboo to talk about; the younger ages are more willing." The norms supporting gender concordance extend to personal interactions with healthcare providers. Another Marshallese woman explained, "Females would prefer to see a female physician, especially when talking about reproductive parts. Otherwise it is very uncomfortable to talk about these things."

A wide range of communication channels was used to obtain and disseminate health information in both communities. Popular health communication channels included use of the Internet, radio, television, brochures, and posters. Among Marshallese participants, churches were described as a setting to discuss health information. One Marshallese man stated, “Churches might be a good place to share cancer information. The Marshall Islands government had a church-based program teaching people about cancer.” By contrast, some Chuukese people felt uncomfortable sharing personal health information in church-based groups. One Chuukese man stated, “We don’t like to share the secrecy of our own health in groups, churches may not work for that reason.”

Cultural Factors Influencing Health

The discordance between Western and Micronesian perceptions of large body sizes was common across all discussions. A Chuukese female stated, “In Chuuk, the mentality of being healthy is being chubby. They tell you to feed your kids so that they look healthy, but we know that’s not true.” Another Chuukese woman stated, “In Chuuk if you are fat you are healthy, otherwise people will worry you are sick or your husband isn’t treating you well. Skinny is not healthy.”

There were also conflicting beliefs about Western and traditional medicine. One Chuukese male shared that he put his faith in Chuukese traditional medicine, “I don’t go to church or to the doctor, I go to the person…[who] knows how to make medicine. . . I believe in the ingredients in the plants to heal.”

Perceptions of Racism in Healthcare

Perceived racism emerged as an important factor which not only influenced health care decision making but dominated other aspects of migrants’ daily lives in Hawai‘i. A Marshallese woman raised her concerns of racism in the healthcare system by stating, “There is like a stigma with the government, the healthcare system in Hawai‘i…When we get sick and we need services, but we are not eligible. We have an agreement with the U.S. to be here and to work here. Yet we are still treated like you know [inferior].”

A Chuukese woman said, “We breathe racism, we experience it every day of our lives here. Just wearing our dress is a big turn-off for people, but some of us make a point to wear it so you cannot forget us.” Male respondents had similar views of racism in health care settings. One Chuukese man explained that he felt like his doctor ignored his concerns, “…so my concern is he didn’t listen to me and check me for my prostate when I say this has been my problem. So I was thinking, I am not like him.” This view is shared by the Marshallese men. One Marshallese man said, “They talk to us like we are stupid and we don’t understand anything.”

Survey Methods Considerations

Participants emphasized that surveys should be brief and easy to use. A Marshallese man indicated that it was essential to deliver the survey face-to-face, translate it into their language, have community leaders administer them and provide refreshments and transportation. The location for the administration of the survey and transportation to the site were of utmost importance to all participants. One Chuukese man stated, “Trying to find a central place is hard because the Chuukese community is spread out across the island. The only reason I’m here is because…I live close to here.”

All participants emphasized that the research be conducted in an open fashion using groups and that investigators should take time to become acquainted with participants during the survey administration sessions. As a Marshallese man noted:

> It is hard to get people to come out for focus groups and surveys because many people want to do research on us. It is important for us know how it will benefit our community. If people know it will help them get better cancer services they will be more willing to answer questions.

Finally, participants suggested gift cards from a local supermarket were appropriate incentives. According to a Marshallese woman, “If you are going to give gift cards, then people will be more willing to answer a three- or four-page survey. We would stay for two hours but with incentive. More than an hour with no incentive [is not good].”

Discussion

The present study illustrates attitudes among Marshallese and Chuukese people residing in Hawai’i about health, cancer, racial discrimination and participation in health-related surveys. Previous studies have identified the role of socioeconomic and political factors contributing to the health disparities found in Micronesians, including the legacy of U.S. nuclear testing contaminating subsistence resources and leading to dietary risks for disease as well as the resulting cancers caused by fallout. Within the jurisdictions, inadequate employment, educational opportunities and healthcare systems remain, despite the requirements of the COFA to provide these services in remuneration for the U.S. military presence. These factors contribute to poor health outcomes and drive the current migration of Micronesians. Once in Hawai‘i, Micronesians experience discrimination in the society at large and in the health care system.[18] In the past, the state of Hawai‘i has discriminated against Micronesians by unconstitutionally attempting to dis-enroll them from Medicaid.[18] Our study sought to identify these additional social determinants of health unique to Micronesians in Hawai‘i to include in the survey design to provide a more robust assessment of health. Results from the group discussions were instrumental in guiding the modification and implementation of HINTS to fit Micronesian migrants living in Hawai‘i. Items added to the original HINTS instrument included measures of cancer fatalism, health locus of control, religiosity, perceptions of racism, and acculturation. Appropriate instruments to assess these factors were selected through a review of published scales.

In many ethnic minority populations, fatalism towards cancer or the belief that death is inevitable when cancer is present is thought to influence cancer screening practices and treatment adherence.[20] The analyses found that this attitude was prevalent for the study participants. Therefore, items derived from Powe Fatalism Inventory were included for this audience.[21] Related to the findings from the focus groups, distinct health locus of control (HLC) perspectives may be a major factor in Micronesian populations. Participants expressed differences in their attribution of cancer causes; some participants focused on external causes (nuclear testing) while downplaying internal factors (tobacco and betel nut use). For this reason, an HLC instrument was included to assess these differences across Marshallese and Chuukese groups.

Religious practices and spiritual life are considered important aspects of health in many Pacific Islander communities and may affect health seeking behaviors.[15,16] According to the World Fact Book,[17] 94% of Micronesians identify themselves as Christian (Catholic or Protestant).[19] Those beliefs exert a positive influence in coping with illnesses by providing mechanisms for social support. In the focus groups, spiritual health was commonly mentioned as an important feature of overall health. Given this finding, items for positive and negative religious coping as measured by the Religious Coping Activity Scale (RCOPE) [22] were added to the modified HINTS instrument.

During the four focus group discussion sessions, most participants said they had experienced some form of racial discrimination. This finding supports a need to quantify experiences of racial prejudice in this group, as racism may affect their healthcare seeking behaviors and overall health.[23] Items from a scale developed by Carty, et al, (2011) were added to explore how perceived racism potentially affects health outcomes in this group.[24] Additionally, because many Micronesian people said they experienced racism due to their immigration status, items from an acculturation scale for Pacific Islanders were added.[25] It was anticipated that the use of these scales might help characterize the effects of racism and acculturation on the health and health seeking behaviors of Micronesians in Hawai‘i.

Findings regarding the survey administration procedures suggested that the survey should present questions in a bilingual format, displaying content in both English and the appropriate Micronesian language, side by side. Participants suggested administering surveys to a group, allowing the study team to explain the purpose of the survey and to build trust with participants. To adhere to these recommendations, collaboration was extended to the DOH-EAP, asking for help to create bilingual versions of the modified HINTS survey, provide guidance on potential venues to administer the survey and serve as facilitators during the planned group administrations of the survey.

There were several limitations in this research. First, there was a lack of cultural concordance between the research team (none of the research team members identified as Pacific Islander) and the community of interest. A second limitation was that participants were recruited through one government program. This method may have introduced response bias, as recruited participants may have had an affinity towards the research topic or commonalities on factors related to the inquiry. Also, despite efforts to segregate focus group members by age and gender, some interviewees may have deferred their comments to accommodate members of higher status in the community.

However, the rich detailed data provided by the interviewees in this study met the exploratory purpose of this research.[26] The use of an inductive approach to the data analysis was intended to address any limitations relative to sampling by allowing the findings to emerge from the data rather than adhering to a prescribed framework.

Conclusions

Participants highlighted several factors including religiosity, fatalism, and racism that may potentially contribute to Micronesians' knowledge and use of health information and services. These factors informed the modification of the HINTS instrument. Information shared during the focus groups led to the delivery of the survey in group settings and in nontraditional administration venues including public parks, which were more in line with cultural protocols. These findings are especially consequential for those conducting national surveys in that to reach elusive or underrepresented populations, such as Micronesians, it is important to include them in the research planning process.

Conflict of Interest

None of the authors identify a conflict of interest.

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Authors' Affiliations:
- University of Hawai'i Cancer Center, Honolulu, HI (KC, MKIH)
- University of Hawai'i at Mānoa, Honolulu, HI (HL)
- College of Liberal Arts & Social Sciences, University of Guam, Mangilao, Guam (LPS)
- College of Natural & Applied Sciences, University of Guam, Mangilao, Guam (GB)

Correspondence to:
Kevin Cassel DrPH; University of Hawai'i Cancer Center, 701 Ilalo St., Honolulu, HI 96813; Email: kevin@cc.hawaii.edu

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Attitudes Towards Family Planning among Bhutanese, Burmese, and Iraqi Refugee Women: A Qualitative Study

Komal S. Soin MD, MPH; Kathryn Beldowski MD; Elizabeth Bates MD;
Kristine Pamela Garcia MD; Sapna Naik MD; Ellen Plumb MD;
Rickie Brawer PhD, MPH, MCHES; Abbie Santana MSPH; and Marc Altshuler MD

Abstract

The number of foreign-born people living in the United States continues to increase yearly. Foreign-born women in the United States, a group that includes both refugees and immigrants, continue to have higher birth rates when compared to their US-born counterparts. This study examines the cultural and socioeconomic factors influencing family planning choices of resettled refugee women living in the United States. Thirty-two Bhutanese, Burmese, and Iraqi women living in Philadelphia participated in interviews and focus groups. A grounded theory approach was used for analysis. Three overarching themes were identified: knowledge acquisition and experiential learning with trans-border migration and resettlement, changes in gender roles and family relations, and provider relationships and provision of care. Findings from the study show that a stable environment results in increased opportunities and personal freedoms, a sense of empowerment, and the desire for family planning. Women want to discuss options, but healthcare providers must begin the conversation. As health care providers in Hawai'i, a state with about 18% of residents being foreign-born, what can be learned from the Philadelphia refugee experience and family planning?

Keywords

Refugee, immigrant, foreign-born, contraception, family planning, resettlement, United States, providers, physicians, empowerment

Introduction

Approximately 50,000 to 80,000 refugees resettle in the United States annually, about half of whom are women and children.[1] Refugee women face many challenges as they resettle in a new country, including obtaining sexual and reproductive health services that meet their needs. Barriers to these services include limited knowledge of sexual and reproductive health, culturally influenced gender roles (eg, male dominance in decisions making), socioeconomic demands, provider attitudes and practices, and poor healthcare access.[2-6]

Although overall birth rates are declining in the United States, foreign-born women (those that are not citizens at birth and include both immigrants and refugees) continue to have higher birth rates when compared to their United States counterparts.[7] The 2010 birth rate for foreign-born women was nearly 50% higher than the rate for US-born women.[7]

The World Health Organization defines family planning as allowing people to attain their desired number of children and determine the spacing and timing of their births.[8] Family planning services play a critical role in a woman's sexual and reproductive health, including access to modern contraceptive methods. However, as indicated by higher birth rates in foreign-born women, the availability of these services alone may be inadequate for meeting family planning needs. Little is known about what factors influence family planning choices for resettled refugees, including the role of health care providers in providing family planning counseling and services. From 2012 to 2017, the Bhutanese, Burmese, and Iraqi people have been among the largest resettled refugee populations in the United States.[1] However, very few qualitative studies from the United States have focused on family planning choices of these populations. Two studies done in the United States with Bhutanese refugees demonstrated that poor sexual and reproductive health knowledge, socio-cultural norms, and stigma around sexual health dictated decisions regarding family planning.[2,9]

In light of limited literature about family planning for Bhutanese, Burmese, and Iraqi refugee women in the United States, the objective of this study was to learn about the family planning practices of resettled refugees and the factors that promote and/or hinder contraceptive use. As health care providers, there is an opportunity to learn about the patient-provider relationship and the counseling practices that are considered effective from the patient's perspective. With this information, the goal was to understand how to effectively counsel and provide culturally sensitive family planning care to resettled refugee women.

Methods

Ethical approval to conduct the research was obtained from the Thomas Jefferson University Internal Review Board. Women 18 years and older of Bhutanese/Nepalese, Burmese, and Iraqi nationalities were recruited for in-depth interviews (IDIs) and focus group discussions (FGDs) from an urban Family Medicine Clinic in Philadelphia and the surrounding community. Women of these specific nationalities were purposefully selected, as they were the predominant refugee groups resettling in Philadelphia at the time of this study. Additionally, women 18 or older were included along with those who were not of reproductive age, as they could offer insight on family planning practices specific to their country and ethnicity. Recruitment was through convenience sampling by community navigators who were proficient in the woman's language and by the co-investigators of this study with the aid of trained bilingual translators. Further recruitment was conducted through snowball sampling.

Interviews and focus group discussions were conducted over an 11-month period from May 2013 to April 2014. Verbal consent from participants was obtained by trained female bilingual translators. Female co-investigators led the IDIs and FGDs with the assistance of the translators. All sessions were semi-structured, and a discussion guide was followed for both the IDIs and FGDs (Table 1). Focus groups and in-depth interviews were arranged according to ethnicity. IDIs and FGDs were audio-recorded and transcribed. Broken English spoken by the translators and participants was transcribed word for word in the transcription. Since most discussions were through a translator, translations often alternated between the first and third person. For standardization and ease of reading, third person translations have been converted to the first person in this paper.

IDIs and FGDs were conducted until theoretical saturation was reached. Two investigators independently coded the transcripts using the Charmaz grounded theory approach.[10] With this approach, theories were constructed based on the data itself. Analysis of the data began by each of the two investigators manually coding the interviews line-by-line. These codes were entered into Microsoft Excel to form a code list. The two investigators discussed the code lists and grouped codes into concepts. Major themes were developed from these concepts. Discrepancies between the two investigators were resolved through discussion.

Table 1. Discussion Guide
1. Demographics: Can you tell me your age, how long you have lived in the United States, and how many children you have?
2. Can you tell me about your experience with resettling, as in what country you are from, where you resettled through, and if you lived in a camp(s)?
3. How do you decide about how big your family is going to be? (Probe for cultural norms around family size and whether this is changing now that they are in the US.)
4. When do you have this discussion? Who is involved in the discussion?
5. How are these decisions made?
6. How soon after you are married do most people have their first child?
7. Does it matter whether you have a boy or girl? To you? Family? Culture?
8. Now let's talk about planning for your second child? How long do most people wait before having a second child? How successful were you with your plan? What kinds of things do you do not to get pregnant too soon? (Probe for no prevention, rhythm, condoms, etc., herbal/non-traditional meds). Has this changed in any way since coming to the US? If so, how? (probe for if they know about contraception methods)
9. In school or camps were there sessions on sexual education that you attended or knew about? What did they talk about?
10. So, you mentioned that you used ______ methods to try to not get pregnant too soon. Why did you choose this method? How do you feel about it? What do you like or dislike about it? Did they work for you? If so how, or if not why not? How long have you been using it? (Probe for prior to arriving in US or since coming to the US).
11. What other things do people do that can help them plan when to have another child? (Probe for medicines, herbal, non-traditional, other methods, etc.) a. How did you learn/hear about these methods? What do you know about them? How do they work? (probe about whether it was explained by doctor or learned through the community) b. How do you feel about these methods? Would you use them? Why or why not?
12. Some of you mentioned that you have heard about medicines that can help you to plan when you want to get pregnant. What kind of medicines have you heard about? (Probe for different types –pills, injections, patches, medicines that can be inserted in your skin or inside your body that stay there for a few years, TL, vasectomy). a. How do you feel about using a medicine to plan when you have your next child? (Probe about cultural beliefs, discussions with friends?). Would you use a medicine? Why or why not? b. Have you used any of these medicines? How did you decide which medicine to use? – (probe for discussion with friends/family, discussions with doctor or other health care provider, read about it in an article or on the internet, etc. Was decision/choice made with family, partner, or by themselves?) c. What were these discussions like? What did you talk about? (Probe for how contraception works, etc.) What kinds of questions did you have? How easy was it to discuss this with the doctor/nurse? What would have helped to make this discussion better? d. How easy or difficult was it to get the medicine once you made a choice? (Probe about whether access is easy or difficult and why – cost, embarrassment, availability, etc. Probe for access issues prior to and after coming to the US.)
13. What if you become pregnant and don't want the child? What do you do then? Who is involved in the decision (probe about thoughts on abortion)
14. Some women want to get pregnant but can't… what do you think about that? What do your families think about that? (probe about infertility)
15. So now that you are in the United States, have your thoughts on family planning changed since resettlement or are they the same as when in your native country? (Probe about methods, more active planning.)
16. Do you have discussions with your children about their health – especially in regard to sexual health, menstrual cycle?
17. Now let's talk about your visits with a doctor. How is it to discuss your health including planning for a family with your doctor in the United States? Do you feel comfortable bringing up the discussion with your doctor? How is it compared to discussions prior to resettlement? (probe about difficulties, ease of use of translator, sex of physician, access to methods and physician, cost)
18. Is there anything else you want your doctors to know regarding your healthcare or the relationship with the doctor? Is there anything you would want your doctors to do differently? (probe about culture, religion, language, access)

Results

Thirty-two women from Bhutan/Nepal, Burma, and Iraq, with an average age of 40.7, participated in the study (Table 2). Bhutanese and Nepalese women often identified themselves as either nationality because of their displacement to camps in Nepal. Therefore, these women are referred to collectively as Bhutanese in this paper.

Participants reported limited knowledge of family planning methods prior to arrival in the United States, but they described an evolution of their beliefs regarding family planning through the resettlement process. Several overarching themes emerged regarding attitudes towards family planning. These included: (1) knowledge acquisition and experiential learning with trans-border migration and resettlement; (2) changes in gender roles and family relations throughout the resettlement process; and (3) provider relationships and provision of care.

I. Knowledge acquisition and experiential learning with trans-border migration and resettlement

Knowledge about sexual and reproductive health and specifically family planning evolved through the resettlement process. Resettlement involved migrating as a refugee from a country of origin to an initial country of displacement such as Nepal, Thailand, Malaysia, and Jordan, and finally to the United States. Participants' knowledge was based on both formal and informal education modalities, such as workshops in camps to conversations with friends and family. Many women reported that during the resettlement process their access to information increased and influenced their decisions about both contraceptive use and preferences.

Country of Origin

Participants indicated that they received inadequate education about family planning prior to initial displacement. Barriers included geographic isolation and conflict, which often led to limited access to resources. One Burmese woman expressed frustration with the education in her home country:

> 'No choice [in Burma]. I have no choice because nobody educate us to have the first baby, second baby. How long do you have to take time? No one educates [in Burma], so that is a problem for me.' (Burmese, 43 years old)

Societal norms and culture also influenced the depth of education regarding family planning. Iraqi participants, who came from a higher socioeconomic status compared to other participants in the study, had access to advanced education prior to resettlement where they had learned about human anatomy. This school curriculum did not, however, include education on sexuality and contraception, so they acquired this knowledge from friends and family members. One Iraqi woman stated:

> 'No [in school], they teach only about the human body, not about having sex…a neighbor, I think, she tried to teach me these things.' (Iraqi, 45)

Displaced Settings

Refugee camps were reported to be many participants' first introduction to family planning, particularly those from Bhutan and Burma. Educational interventions in the camps included group workshops, clinic services, and home visits by community health workers. These programs were often implemented by international non-governmental organizations, such as the United Nations High Commissioner for Refugees, but also included host governments. Respondents explained how they learned about family planning:

> 'In Mae la or Mae La Oo [camps], every week there was formal teaching on birth control methods…before giving us prenatal vitamins or food, they tell us about birth control. Even if we don't want to hear about it, they still do.' (Burmese, 41)

> 'In the camp - [they had] workshops and meetings. Family planning was all free because the population was growing and Nepal [government] wanted to stop that. Health workers…went to people's homes especially for those having kids.' (Bhutanese, 30)

> 'After we went to Jordan, I attended a lot of workshops on family planning through the UN…they told us about how we should raise the child at different stages of life…I wish that I only had one child to really give all my attention to, so I decided no more, so I started using more protection.' (Iraqi, 40)

Table 2. Demographics of Participants Involved in the In-depth Interviews (IDIs) and Focus Group Discussions (FGDs)

	Nepali/ Bhutanese	Burmese	Iraqi	Mean
# of IDIs	0	1	3	2
# of FGDs	2	3	3	2.67
# of IDI and FGD Participants	10	12	10	10.67
Age Range	19 - 53	24 - 65	19 - 73	
Average Age	39	42	41	40.67
Range of Time in the US	2 months - 2 years	1 month - 6 years	3 months - 6 years	
Average Time in the US	11 months	2 years 2 months	3 years	2 years
% with Children	100	92	70	87.33%

Resettlement in the United States

Following arrival in the United States, participants received counseling about contraception from medical providers and friends. Women indicated collective efforts to inform each other about contraceptives and suggested additional interventions to enhance education, such as monthly community meetings. The shifting cultural landscape of life in the United States influenced attitudes regarding sexual health, including a desire to discuss these issues with physicians, family, and community members.

> 'In our country, the older people don't talk about sex. We learned more about the reproductive cycle and sex here in this country.' (Burmese, 43)

Women indicated a divergence from traditional cultural norms now that they were in the United States. This was considered a positive change because it reduced barriers to family planning that were previously encountered either in their home countries or in refugee camps.

> 'It is harder in the camps. It is frustrating asking for even condoms. I think it's cultural, because they don't talk about sex. We're shy to ask and talk about it there. It is easier here.' (Burmese, 37)

II: Turning the Tide: Changes in gender roles and family relations throughout the resettlement process

With resettlement, women felt empowered to take control of their lives. They rejected oppressive customs from their past and acknowledged an increase in women's rights. Many participants mentioned the institution of early marriage in their countries of origin. Young age and lack of education contributed to limited contraceptive use and unwanted pregnancy.

> 'When I first got married I was very young. I was 15. I had 2 miscarriages…and couldn't really handle it. I didn't know about any protection methods at all…and was just too young to comprehend even what pregnancy means.' (Iraqi, 40)

> 'I didn't really want to have a kid when I was 16, I was really young. But after I got married there was no choice, and I was already pregnant, so I was forced to have the kid.' (Bhutanese, 40)

Participants suggested that limiting family size became increasingly appealing during displacement. As they traveled to larger camps, they became exposed to increased economic opportunities, expanded education programs, and greater cultural diversity. Participants suggested that contraception was a method they employed to regain control over financial and social instability, which occurred during migration and conflict.

> 'In Mae La…a little bit open our eyes. Mae La was the biggest camp, that's a lot of culture there. Some [women] are going to work in Bangkok…they know if you have kids, you can't do business…so they not interested in getting too many babies.' (Burmese, 42)

> '[In Iraq] you don't decide to have a child, it just happens…but when we left Iraq, we saw that people had a different lifestyle and different expectations…I wished I would have waited and didn't have as many kids, just spaced it out.' (Iraqi, 43)

Limiting family size often continued upon resettlement in the United States, although some women indicated an eagerness to have a child in America that reflected a belief in enhanced opportunities in the United States.

> 'They want to have children here. Some women, some family, they want their kids to be president or something like that. They have very high visions.' (Burmese, 43)

With resettlement, many participants portrayed a change of individual thought regarding contraception in particular and women's rights in general. When asked if it was empowering to make family planning decisions, one participant replied:

> 'When we come here, he want another baby and I say no…I say women's rights in here.' (Burmese, 43)

An Iraqi woman was poignant about women's rights, reflecting on differences between Iraq and the United States:

> 'I'm just so fascinated by how much power women have here and I really like it…I wish I had come here at a younger age so I could have advantage of that too…I always rejected the idea of women being so powerless and men having all the power and I always thought it was backwards. But I couldn't do anything about it [in Iraq].' (Iraqi, 41)

III: Provider relationships and provision of care

Participants described the process of assimilation that occurred along with their resettlement in the United States, noting that differences in culture and language were barriers in their relationships with medical providers, and in receiving care. Women expressed embarrassment in discussing their sexual and reproductive health with their physicians, especially through an interpreter. They also continued to struggle with the language barrier, despite interpretation services.

> 'More comfortable in camp talking to doctor, because he was a Karen [speaking Burmese] doctor. Here [in the US] I am shy because we have to go through interpreter phone. Still shy to talk about.' (Burmese, 42)

> 'When [we] talk face to face with the doctor about the family planning measures its easier. But if we have to talk to someone else (translator) – a person in between [the physician], it gets a little embarrassed and we don't feel comfortable talking about it.' (Bhutanese, 31)

Some participants became more comfortable voicing their concerns to their providers over time.

> 'The environment here when we go to the doctor, it's comfortable to speak up, because now we learned that people talk and it's comfortable, and it's ok to talk.' (Bhutanese, 30)

However, a majority of women expressed that they preferred the provider to initiate the conversation regarding their family planning needs, as they felt uncomfortable approaching the subject on their own.

> 'It's easier and comfortable if doctor directly asks the question rather than answering to [the doctor's question] why are you here.' (Bhutanese, 31)

> 'It's very embarrassing to talk about it with doctors, to actually bring it up even though it's very important.' (Bhutanese, 30)

Most women did not have a preference for either a male or female physician for their general medical care but felt that concerns about reproductive health were best articulated to female physicians. Iraqi women often preferred a female provider, but this was not a universal requirement. Burmese and Bhutanese women did not state a preference.

> 'I prefer a female doctor. [For] a general doctor, a male is fine, but if woman issues, prefer female. I just can't let go of all my cultural beliefs.' (Iraqi, 40)

> 'We feel good talking about this with doctors here in the US. It is harder in the camps…It is easier here because the American doctors ask us. And it is usually a woman doctor.' (Burmese, 37)

> 'For me, a male doctor is not a problem.' (Burmese, 41)

Participants were asked about specific cultural attitudes and sensitivities that physicians should consider when providing reproductive health care. Some shared negative experiences about encounters in the United States, reporting that cultural differences and norms could often be misinterpreted by the provider.

A 21-year-old woman spoke about her first visit with an American Ob/Gyn. She commented that the visit could have been different if culturally competent, humbled, and appropriate care had been provided.

> 'When I first turned 21, my family doctor referred me to a GYN physician. I had the worst experience…I had never been to an Ob/Gyn before, and I did not know what to expect. I saw the nurse for about 15 minutes, during which she explained that I will be getting a pap smear…With no further explanations, the physician came in and started the procedure. I told her multiple times that I was uncomfortable and asked her to stop, but the doctor continued against my wishes. I got out of the office confused and in tears. I did not get another pap smear until last year when I found my current doctor and was able to talk to her about my terrible experience with the test. Unmarried girls/women in Iraq do not get pap smears…Needless to say, my first Ob/Gyn here in the US was completely insensitive to my cultural background.' (Iraqi, 26)

Another woman spoke about cultural norms and how they differ between generations. She spoke about how her mother's relationship with her physician was affected by these norms. As a result, she wanted physicians to be aware of cultural norms that may be misinterpreted, thus affecting the care of the patient.

> 'People who are older…it's hard for them to have conversation, to even have eye contact…if it's someone like a doctor, or a figure of authority. In Nepal or in Bhutan, if you have eye contact with people who are older than you or someone who needs to be respected, it's a bad thing…But here, if you don't have eye contact, then there's something wrong. It's a culture difference.' (Bhutanese, 30)

Discussion

Primary Objective

The primary objective of this study was to learn about family planning practices of the resettled refugee populations in the United States and the influences that promote or hinder contraceptive use. Similar to previous studies, this study demonstrated that refugee women have limited knowledge of sexual and reproductive health compared to women of the host population.[2-5] However, women in this study did report increased education on family planning through the migration and resettlement process, which influenced their family planning decisions. With improved knowledge of family planning and reproductive health, increased socioeconomic opportunities, and financial stability, women felt empowered to take control of their lives. This included pursuing educational and economic opportunities, choosing to be on contraception, limiting family size, and rejecting past norms of early marriage.

The impact of resettlement on empowerment and gendered roles is an important finding of this study. Very few studies have previously addressed the notion of empowerment in resettled refugee women and how it influences their family planning decisions. It is acknowledged that gendered roles in numerous cultures prohibit pre-marital sex and make sex and motherhood obligatory within a marriage, thus creating a barrier to education, access, and contraceptive use.[11] Studies have also noted that partner control can influence the contraception choices of refugee women.[4,12]

Our findings are consistent with Kabeer's definition of empowerment as "the process by which those who have been denied the ability to make strategic life choices acquire such an ability."[13] Additionally, the findings of this study align with the description of Upadhyay, et al, of the two most commonly cited measures of women's empowerment related to fertility: participation in household decision-making and mobility level (ability to travel outside the home).[14] Our study indicates that the evolution of empowerment in resettled refugee women is multifactorial. It is likely a culmination of increased stability and thus mobility, changes in socio-cultural norms due to living in the United States, enhanced awareness of women's rights and changes in gendered roles, and improved educational and economic opportunities. It is important for providers to be aware of this and support women through the process of decision-making whether individually or with their partner. Since attitudes about partners did not emerge as a clear theme in this study, further studies are needed with partners in this population to help elucidate attitudes and barriers towards family planning.

Secondary Objective

The second objective of our study was to learn about the patient-provider relationship and counseling practices that are considered effective from the patient's perspective. Participants reported multiple barriers arising during office visits with health care providers. These included speaking English as a second language, the need for an interpreter, and cultural norms. Due to these barriers, women felt embarrassed discussing their family planning needs with medical providers, although this improved with the length of time of having been resettled in the United States. Nevertheless, many noted the importance of the topic but needed the provider to initiate the conversation. Additionally, women felt it important that the provider learn about their culture and religion, as these factors strongly influenced their family planning decisions.

Several studies have reported similar barriers to obtaining sexual and reproductive health services.[4,5,12] A systematic review found that language and "inappropriate sex or culture matching between the woman and health care provider" led to inadequate healthcare.[15] Studies evaluating the perspectives of the health care providers delivering care to refugee women have mentioned that providers often assume that women have adequate knowledge and expect them to be able to navigate their own sexual and reproductive health needs.[4,12] In this study, refugee women specifically stated that they wanted providers to start a conversation regarding family planning. This important finding has not been reported elsewhere in the literature. However, refugees have made similar statements in studies on barriers to mental health care.[16,17] In these studies, refugees stated that they wanted the provider to initiate the conversation and ask direct questions regarding their mental health.[16,17] This desire was often secondary to cultural norms requiring deference to a doctor's authority.[16] It was inferred that similar norms are present when health care providers discuss a woman's reproductive health.

Current screening guidelines for resettled refugees developed by the Centers for Disease Control and Prevention recommend screening for pregnancy but do not provide guidance on screening for unmet contraceptive or family planning options specific to newly arrived refugee women. Often, family planning is not addressed until the woman is scheduled for a well woman exam and Pap smear collection, which may be months after arrival to the United States. Authors of evidence-based guidelines published in 2011 by the Canadian Collaboration for Immigrant and Refugee Health reported that they found no guidelines for immigrant screening related to contraception.[18] As a result, based on studies on sexually active women, they recommended screening immigrant women soon after their arrival for unmet contraceptive needs.[18] Our findings support this recommendation that refugee women should be screened for unmet contraceptive needs at their initial health-screening exam and at subsequent primary care encounters, and be provided education on family planning options. One simple way to address family planning at any visit is to ask the One Key Question: "Would you like to become pregnant in the next year?".[19] This one question can open up the conversation for patients to discuss their family planning needs, whether contraception or pre-conception care, in a patient-centered way.

Strengths and Limitations

This qualitative study adds to the limited literature on refugees who are currently resettling in the United States. New findings on the evolution of empowerment and provider-initiated care will assist in providing better care to refugee women. In addition, whereas most studies focus on one refugee population, this study examined three different nationalities. As a result, the main themes presented in this paper are likely to resonate with other resettled refugee women of differing nationalities.

As a qualitative study, we recognize that the specific social context that produced these findings has shaped the results, specifically what women were willing to say and how they said it. Inevitably, there were differences between the FGDs and IDIs since the focus groups produced discussion between the participants, while the in-depth interviews did not. However, we did not notice meaningful differences between the responses received in FGDs and IDIs and so do not discuss any in this paper. Additionally, the number of FGDs and IDIs were not equivalent among participants of the three nationalities. Further studies can be done utilizing either FGDs or IDIs to eliminate possible differences. The study was also conducted with the aid of translators, and thus translation error or misinterpretation could have occurred during the interviews.

Implications for Practice and/or Policy

This study was executed in three populations of refugee women from Bhutan, Iraq, and Burma who resettled in Philadelphia. The three groups are distinct from a standpoint of ethnicity and national origin. Similarities were identified in these populations of women regarding the association of environmental safety to empowerment and the use of family planning and contraception. What can be learned from this study that may be helpful for medical practitioners in Hawaiʻi as they work with the family planning needs of immigrant and migrant populations?

The percentage of foreign-born individuals living in Hawai‘i has continued to rise over the last decade, with people immigrating from Asia, the Compact nations, Samoa, and other countries in the Pacific.[20] Similar to the refugee patients in this study, foreign-born women in Hawai‘i face many of the same barriers and challenges to family planning care. Language, education, culture, and socioeconomic factors influence their attitudes towards health services[21-24] and family planning.[25,26] Similar to these interviewees, the Pacific Islanders' young age and lack of education contribute to limited contraceptive use and unwanted pregnancy. Teen births are more common in Pacific Islanders compared to the United States.[27-29] In the Federated States of Micronesia and the Republic of the Marshall Islands, a high percentage of teenage pregnancies are linked to low family planning knowledge and lack of access to reproductive health services.[26,30] For Marshallese women, a lack of knowledge surrounding contraception use and Marshallese customs of not discussing sex or family planning options lead to women expressing embarrassment in discussing their sexual and reproductive health.[23,26] Chuukese women are modest and culturally their spouses usually have primary roles on health care seeking behaviors.[31,32] With such similarities across cultures and ethnicities, the findings presented in this paper will likely resonate with foreign-born women in Hawai‘i who have also moved in search of enhanced opportunities in health care, education, and employment.

Foreign-born women who resettle in a safer environment with increased opportunities are empowered to take control of their lives. This includes making informed decisions regarding family planning. Health care providers have a unique opportunity to connect with refugees and all foreign-born women in the clinical context. Participants overwhelmingly stated that they want their provider to initiate the conversation regarding family planning and contraceptive use. Thus, it is important for providers to feel comfortable, create an environment that is conducive to this sensitive discussion, and most importantly, initiate the conversation with their patients.

An important step is to incorporate cultural sensitivity training in the medical curriculum and in the workplace with practicing physicians. Such training can increase provider knowledge and enhance communication styles, resulting in improved care and quality support for refugee and immigrant women. Identifying unmet family planning needs will lead to informed healthcare decisions and planned healthy pregnancies.

Conflict of Interest

None of the authors identify any conflict of interest.

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Authors' Affiliations:
- Department of Family Medicine and Community Health, University of Hawai‘i, Honolulu, HI (KSS)
- Department of Family & Community Medicine, Thomas Jefferson University, Philadelphia, PA (KB, EB, KPG, SN, EP, RB, AS, MA)

Correspondence to:
Komal S. Soin MD, MPH; Department of Family Medicine and Community Health, University of Hawai‘i, Mililani, HI. Email: ksoin@hawaii.edu

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Building Capacity for Caregiver Education in Yap, Micronesia

Ritabelle Fernandes MD, MPH; Pius You; Martina Reichhardt BJRN;
Christina Wang DNP, MPH, APRN; Daniel Langston MSN, CNS, NP; and Lam Nguyen MD

Abstract

The US Affiliated Pacific Islands have an urgent need for family caregiver education to prevent caregiver burnout and strengthen the existing culture where seniors are cared for at home by their families. The Pacific Islands Geriatric Education Center conducted a 32-hour family caregiver train-the-trainer workshop in partnership with the Yap Department of Health Services and the Yap Area Health Education Center (AHEC) from October 16 - 20, 2017. Twenty-seven participants including community health workers, peer educators, health assistants, nurses, and physicians were trained as instructors. Confidence in caregiving increased following the training and feedback was extremely positive. Competence in geriatric syndromes was improved after attending the workshop ($P < .001$). Lessons from the field revealed an immense value of adding home visits to the training practicum as well as the need to translate caregiving handouts into the outer island languages. Yap AHEC is committed to offering this course as part of caregiver education at the hospital and in the community.

Keywords

Micronesia, Yapese, caregiving, AHEC, educational program, family caregivers

Introduction

Yap is one of four states in the Federated States of Micronesia (FSM). These states were part of the United States Trust Territory of the Pacific Islands.[1] Yap State stretches from 6 – 10 degrees north latitude to 137 – 148 degrees west longitude and encompasses 500,000 square miles of area in the Western Caroline Islands. It consists of 78 islands, however only 22 are inhabited. Yap State includes Yap Proper, Ulithi, Woleai, and other atolls east of Yap. According to the 2000 FSM Census data, the population of Yap was 11,241 with 7,391 in Yap proper and 3,850 in the outer islands.[2] The population consists of 49.1% Yapese mainlanders, 36% outer islanders, and 4.8% Asians. Elderly population aged 75 years and above comprises 2% of the population.

Prior to colonization, Yap contained chiefdoms which consisted of sociocultural systems characterized by hierarchical social rankings. Bilineal descent determined social position, inheritance, kinship, residence, and land tenure. In a subsistence economy, women tended to the taro patches and yam gardens while the primary role of men was fishing. *Tabinaw* commonly referring to Yapese household, is the most basic concept of Yapese leadership and sociopolitical organization. Primary food and space goes to the oldest male followed by the oldest female, and on down through the hierarchy of the family.[3] Yap is known for its stone money or *Rai*, which are large doughnut-shaped carved disks of calcite measuring anywhere from 1 -12 feet in diameter.[4] Their value is based on the stone's size and history.

In traditional times, Yapese did not have specialized medical practitioners. In every family there were members who had knowledge of magic associated with controlling weather, warfare, or fishing and had knowledge with regard to health and disease. These magicians gained prestige based upon the effectiveness of their knowledge in curing those who were ill or in aborting or controlling potential natural disasters. Yap Memorial Hospital in the capital of Colonia is the only hospital in Yap. Due to limited transportation, residents living on the outer islands rely on the 17 outer island dispensaries and traditional practitioners.

All of the long-term care in Yap is provided by families. Filial piety is an important cultural value. Concepts of nursing homes, assisted living, care homes, or foster homes are non-existent. Yap has a high proportion of individuals with disabilities needing assistance with daily living. The 1,922 people with disabilities in Yap represented 16.9% of its population.[5] The islands of Yap, particularly the outer islands, continue to support one of the world's best traditional palliative care systems involving the immediate family, more distant relatives, and in many cases, the entire community.[6] However, there is concern that this system is weakening and one of the many suggestions for improvement includes regular home visits by a healthcare team combined with practical at home teaching.[6]

The Yap State Department of Health Services, through key informant interviews, identified a lack of skills and basic knowledge on caregiving for the elderly and disabled. There is difficulty in discharging persons from the hospital as families are ill equipped to care for them at home. There is an urgent need for additional training on caregiving for the elderly and disabled. This common need is also seen on other islands in Micronesia such as Palau.[7]

The Pacific Islands Geriatric Education Center (PIGEC) at the John A. Burns School of Medicine, University of Hawai‘i has a mission to promote training in geriatric education in the Pacific Islands to improve healthcare for the elderly and homebound. The goal is to support families in the acquisition of specific skills related to healthcare of the elderly and disabled. The objective of this project was to develop a family caregiver training program for Yap.

Methods

A Family Caregiving Certificate train-the-trainer workshop was conducted from October 16 - 20, 2017 at Yap Memorial Hospital. This workshop was modeled on prior successful training that was developed and implemented in Palau. In 2013, the Palau Ministry of Health, Palau Area Health Education Center (AHEC), Palau Community College (PCC), and PIGEC collaboratively designed the core curriculum of a Family Caregiving Certificate. Resources available in developed countries are not available in developing countries, and so the curriculum had to be tailored to the islander population. This Family Caregiver Certificate taught at PCC included 8 modules covering basic caregiving topics and skills. Since its inception, the Palau AHEC has coordinated a total of 37 postgraduate and undergraduate courses in general practice and public health in Palau, Yap, and the Republic of the Marshall Islands.[8]

The core curriculum of the Family Caregiving Certificate is divided into four main competencies: caregiver health literacy, mental health, hands-on training, and the field practicum. The training covered topics such as activities of daily living, common medical problems, wound care, proper use of durable medical equipment, managing difficult behaviors, and caregiver burnout (Table 1). The workshop integrated local culture and included: role play, the teach-back method, hands-on demonstrations, as well as field trips.

A train-the-trainer model was adopted by PIGEC. The workshop was designed collaboratively by Yap AHEC, Yap Department of Health Services, and PIGEC. The planning committee members requested home visits for the field practicum and standardized geriatric assessment tools were taught and utilized at the home visits. Another priority identified was to conduct community outreach during evening sessions at local churches.

Descriptive statistics with means and percentages were used to provide a description of the sample. A pre-post test containing 28 multiple-choice questions was administered to assess knowledge of core geriatric topics. To assess changes in knowledge and confidence to teach specific geriatric skills, values from the pre- and post- questionnaires were compared using paired t-tests. Data was analyzed using SAS version 9.1.3 (Cary, North Carolina).

Table 1. Core Curriculum of the Family Caregiving Certificate

Session	Module	Learning Objectives and Rationale
1	Normal Aging Cultural Aspects of Caregiving	• Understand the general principles in caring for the elderly. • Strengthen the cultural aspects of caregiving in Yap. • Increase knowledge on the physical changes associated with aging.
2	Gait and Transfer Training Fall Prevention	• Learn strategies to prevent falls at home. • Training on gait and transfers techniques. • Proper use of durable medical equipment such as canes, walkers, and wheelchairs.
3	Pain and Symptom Management Managing Difficult Behaviors	• Understand the WHO approach to pain management. • Learn non-pharmacological approaches to managing difficult behaviors. • Improve communication with persons who have dementia.
4	Activities of Daily Living – Part 1	• Learn the importance of proper hygiene. • Increase confidence in performing activities of daily living. • Competence in giving a bed bath.
5	Activities of Daily Living – Part 2	• Understand the importance of oral care and dental hygiene. • Learn dietary recommendations for chronic diseases. • Describe strategies to improve appetite.
6	Wound care and Bedsore Prevention Common Medical Problems	• Increase knowledge on prevention of bed sores. • Learn signs and symptoms of a heart attack and stroke. • Understand common medical problems affecting the elderly.
7	Relieving Family and Caregiver Stress	• Describe stress management strategies. • Recognize signs of caregiver burnout. • Increase knowledge of community resources available for the elderly and disabled in Yap.
8	Field Trip	• Practicum to provide trainees a real world experience. • Hand-on skills check and assessment. • Opportunity to work in an interdisciplinary team.

Results

Twenty-seven participants were trained as instructors and the training was 32 hours in duration. Participants included health assistants, community health workers, nurses, and physicians. The majority were Yapese, with 2 Kosraen, 1 Fijian and 1 German. Caregiving handouts were translated into Yapese and outer island languages. Demographic characteristics of the 27 participants are described in Table 2. Twelve were nurses, 8 were community health workers, 2 were peer educators, 1 was a physician and 2 were other professionals. Twenty-two participants were women and 5 were men. The majority were in the age range of 50 – 59 years with less than 10 years of experience.

Self-rated competency of the participants with regards to skills about common geriatric syndromes before and after participating in the workshop is shown in Table 3. Competency in geriatric syndromes was significantly improved after attending the workshop. Topics such as dealing with gait and fall prevention, pain and symptom management, activities of daily living, oral care, and nutrition had statistically significant improvements (*P*<.001) in scores.

Table 2. Demographic Characteristics of Workshop Participants (n = 27)

No.	Variable	Frequency (%)
1.	**Gender**	
	Male	5 (18.51)
	Female	22 (81.49)
2.	**Ethnicity**	
	Yapese	23 (85.2)
	Kosraen	2 (7.4)
	German	1 (3.7)
	Fijiian	1 (3.7)
3.	**Age**	
	20-29	3 (11.1)
	30-39	5 (18.6)
	40-49	7 (25.9)
	50-59	9 (33.3)
	60 or older	3 (11.1)
4.	**Health Profession**	
	Community Health Worker	8 (29.6)
	Health Assistant	1 (3.7)
	Peer educator	2 (7.5)
	Nurses	12 (44.4)
	Physicians	1 (3.7)
	Other professionals	3 (11.1)
5.	**Education**	
	High School Graduate	5 (18.6)
	Some College	12 (44.4)
	College Graduate	10 (37.0)
6.	**Years of Experience**	
	<5	9 (33.3)
	5 to <10	8 (29.6)
	10 to <15	4 (14.8)
	15 to <20	1 (3.7)
	20 to <30	5 (18.6)

Table 3. Differences in Knowledge Summary Scores Before and After Attending the Family Caregiving Certificate Train-The-Trainer Workshop (N = 23)

Training Module	Pre-Training Mean ± SD	Post-Training Mean ± SD	Change Mean ± SD	*P*-value[a]
Normal Aging	3.5 ± 0.67	3.6 ± 0.95	0.04 ± 1.06	.85
Gait and Fall Prevention	1.9 ± 0.98	3.3 ± 0.88	1.39 ± 1.08	<.001
Pain and Symptom Management	3.1 ± 0.92	3.8 ± 0.42	0.65 ± 0.83	**.001**
Activities of Daily Living	2.7 ± 1.01	3.4 ± 0.50	0.70 ± 0.97	**.002**
Oral Care and Nutrition	3.1 ± 0.79	3.9 ± 0.63	0.78 ± 1.00	.001
Common Medical Problems	3.8 ± 0.39	4.0 ± 0.21	0.13 ± 0.34	.83
Relieving Caregiver Stress	3.6 ± 0.65	3.9 ± 0.34	0.22 ± 0.60	.09
Overall Summary Scores	21.9 ± 2.63	25.8 ± 2.30	3.91 ± 2.81	**<.001**

[a] *P*-value based on paired t-tests

Table 4. Participant Satisfaction Survey After Attending the Family Caregiving Certificate Train-The-Trainer Workshop (N = 24)

Question No.	Training Evaluation	Mean ± SD[a]
1.	Handouts	4.5 ± 0.59
2.	Translations	4.0 ± 0.75
3.	Demonstrations	4.7 ± 0.46
4.	Audiovisuals	4.6 ± 0.65
5.	Content of the modules	4.8 ± 0.44
6.	Educational materials	4.6 ± 0.50
7.	Trainer's knowledge of the manual	4.8 ± 0.41
8.	Trainer's teaching skills	4.8 ± 0.41
9.	Activities such as role plays	4.5 ± 0.38
10.	Overall quality of the training	4.8 ± 0.38

[a] Likert scale of 1-5, where 1 = poor, 2 = fair, 3 = good, 4 = very good, 5 = excellent

Participants were very pleased with the overall quality of the workshop, with a mean score of 4.8 based on a 1-5 Likert scale (Table 4). Some of the comments were: "*All the topics are very useful and beneficial to my work,*" and "*Teachers were encouraging, inspiring and motivating all the time*." The self-rated confidence to teach geriatric topics pre workshop was 3.34±0.97 and post workshop was 3.64±0.58 showing significantly improved scores (*P*=.025) after attending the workshop (not shown in table). Participants felt it was important to improve caregiver training on Yap (3.96 out of 4). The participants were eager to implement family caregiver training on their islands and plan to teach caregivers at the hospital, on boats, churches, homes, clubs, dispensary, and women's meeting houses.

In addition, there were 4 evening sessions held on weekdays in the community churches to perform outreach and education to Yapese family caregivers. Over 125 family caregivers received education on the proper use of cane and crutches, signs and symptoms of heart attack and stroke, and ways to recognize and reduce caregiver stress and burden.

Discussion

Aging has been a main feature of population trends of the 20th century, with most elderly people living in developing countries.[9] By 2050, nearly 1.2 billion of the expected 1.5 billion people age 65 or older will reside in today's less developed regions.[9] Strengths of this study included that the training was well attended and very well received. PIGEC is one of the first organizations to bring formal caregiver education and training to health professionals in this region. There has been a well documented need for continuing education of health workers in the US Affiliated Pacific Islands.[10]

One of the lessons learned from the field was the immense value of health professional visits to the Yapese homes. On the final day of training, participants and faculty were divided into 4 teams according to geographic zones. Standardized home visit geriatric assessment tools such as medication reconciliation, home safety, and falls checklist were provided to the teams. This brought the week-long training into culmination in the home, where participants could provide caregiver education and receive mentoring at the same time. Community health workers and public health nurses are at the front lines of the delivery of healthcare across the islands. A survey of zone nurses in Fiji revealed that nurses had little awareness of geriatric assessment procedures.[11] This was similar for Yap too, hence the planning committee had requested for standardized home visit geriatric assessment tools.

A small sample size and lack of availability of culturally appropriate standardized questionnaires were some of the limitations of this study. While there are disease specific family questionnaires available, validated tools to assess general family caregiver knowledge and skills in caring for the elderly are limited. The PCC pre-post test containing 28 multiple-choice questions was used to assess knowledge of core geriatric topics. The caregiver handouts were translated into Yapese, but not into all of the outer island languages such as Satawalese and Ulithian.

Geriatric medicine skills and confidence to teach scores of the participants improved significantly after attending the workshop. Although the proportion of the aging population has dramatically increased in developing countries, there is limited data on the availability of geriatric care and skills of the healthcare workforce especially in the Pacific Islands. This article contributes to the literature by presenting an update on caregiving in Yap. This training curriculum is similar to the Italian caregiver educational program, which has been structured in lessons to analyze the deepening of chronic diseases related to different areas of medical interventions and in practical sessions guided to support the family in the acquisition of skills and competencies for the care management of patients at home.[12]

While the participants incorporated caregiver education into their work and communities, there has been no formal 32-hour course offered due to lack of funds. The administration and leadership at the Department of Health Services in partnership with Yap AHEC is committed to offering this course as a part of caregiver education at the hospital. PIGEC has recently been awarded another Geriatrics Workforce Enhancement Program (GWEP) grant and will partner with Yap AHEC in 2020 with the common goal of building an age-friendly health system in FSM. This will be accomplished by teaching and evaluating the curriculum, which includes principles of the 4Ms (Medication, Mentation, Mobility and what Matters).[13] Yap AHEC, either though in-person sessions or using video recordings, will disseminate this course to the other islands in Micronesia.

Conclusion

The culture of Yap honors and respects its elderly population. With empowerment of caregivers through family caregiver training programs, better care for the elderly and disabled can be envisioned. Reduction in caregiver stress and burden will facilitate smooth transitions of care from the hospital back to the community. Yap AHEC is committed to offering the Family Caregiving Certificate at Yap Memorial Hospital and in the community.

Conflict of Interest

None of the authors identify a conflict of interest.

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Authors' Affiliations:
- The Pacific Islands Geriatric Education Center, Department of Geriatric Medicine, John A. Burns School of Medicine, University of Hawai'i, Honolulu, HI (RF)
- Yap Area Health Education Center (AHEC), Yap, Federated States of Micronesia (PY)
- Yap State Department of Health Services, Yap, Federated States of Micronesia (MR)
- Hawai'i Health & Harm Reduction Center, Honolulu, HI (CW)
- University of California San Francisco, San Francisco, CA (DL)
- Pain and Palliative Care, The Queen's Medical Center, Honolulu, HI (LN)

Correspondence to:
Ritabelle Fernandes MD, MPH; Department of Geriatric Medicine,
University of Hawai'i; E-mail: fernandes.ritabelle@gmail.com

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Evolving Palliative Care Practices among Marshall Islanders in Hawai‘i: Generational Comparisons

Lauren Okamoto MD; Sheldon Riklon MD; Kamal Masaki MD; Christina Bell MD, PhD; Anna Tamai MD; and Gregory G. Maskarinec PhD

Abstract

Little is known about Marshallese palliative care practices. We explored traditional and contemporary Marshallese palliative care practices and examined generational differences. We performed three focus groups in 2011-2012 among Marshall Islanders in Hawai‘i. A native speaking interpreter assisted group facilitators. Data were analyzed using classical thematic triangulation methods to identify specific Marshallese palliative care practices, the effect of economic and social challenges in Hawai‘i, and generational differences comparing young and old. Nineteen persons (10 men and 9 women, youth aged 17-27 years, and elders as defined in Marshallese culture, aged 46-79) participated. A "good death" was defined as "peaceful and pain free," occurring from natural causes. Factors associated with a "good death" included gathering of family to absolve conflicts, and proper and timely cultural practices. Factors associated with "bad deaths" included young age, active suffering, accidents, suicides, "black magic/curses," or lack of timely or proper burial. Comparing generational differences, older Marshallese had differing opinions regarding preferred place of death, burial site, cultural practice preservation, artificial prolongation of life, and cremation. Barriers included mortuary fees, cost of transporting bodies, United States (US) government policies, and wait times for death certificates. Many cultural factors contribute to "good" or "bad" deaths. Attitudes toward palliative care practices differ by generation. Having previously documented different approaches by Yapese, a generalized "one size fits all" approach to Micronesians is inappropriate. Overcoming identified barriers may facilitate practices necessary for a good death in Micronesian populations in their home nations and as they migrate to communities throughout the US.

Keywords

Palliative Care, Marshall Islanders, Generational Comparison

Introduction

Death, for Micronesians, is one of the most important events in the life of the entire community. Traditionally, death not only unites the family, it initiates a complex series of reaffirmed interpersonal ties, rituals, and exchanges that refocus the entire community and create new social identities for everyone. In small island communities, traditional palliative care practices release the immediate family from daily chores to allow them to tend full time to the dying. Efforts are made to resolve all family disputes and inheritance issues while the dying person can still participate in the discussions. Our study examines ways that these practices are being reshaped due to new economic challenges and new social pressures faced by citizens of the Marshall Islands.[1]

The Republic of the Marshall Islands (RMI) is an island nation of two parallel archipelagic chains of 29 coral atolls comprising 1,225 islets, located in the Central Pacific, about halfway between Hawai‘i and Australia (Figure 1).[2] In 2018, the population of the RMI was estimated at 75,684.[3] About 53% of the population is younger than 24 years and only about 10% are 55 or older.[3] In 2009, nearly half of the population lived in the capital, Majuro. Another 9,345 citizens resided on tiny (0.23 square miles) Ebeye Island—one of the most densely populated locations in the Pacific.[4]

The RMI became a sovereign, independent country in October 1986, ending over 125 years of foreign control. In 1986, a Compact of Free Association was signed between the RMI and the United States (US), granting the RMI sovereignty in domestic, foreign, and economic affairs, but granting the US defense rights. The Compact allows Micronesians to migrate freely between the nations without visas or time limits.[5]

Bikini and Enewetak atolls are former US nuclear test sites, where, between 1946 and 1958, the US detonated 67 nuclear devices equivalent to over 7,000 Hiroshima bombs. Radioactivity contaminated food and water.[4] Increases in leukemia, breast cancer, and thyroid cancer after radiation exposure have been clearly documented, especially in individuals exposed during childhood.[6] Many RMI citizens continue to suffer from medical conditions that can be traced to the adverse impact of the nuclear testing programs.[4]

Although traditional Marshallese diet consisted of fish and edible plants such as breadfruit, taro, and pandanus, at present, in urban areas, a large percentage of calories consumed are from imported foods.[7] Fresh food is limited and costly. As a result, non-communicable diseases are emerging as the leading cause of mortality. Diabetes-related diseases and cancer (all types) are the leading causes of death. Marshallese also have high rates of infectious diseases such as tuberculosis and leprosy.[4]

Many Marshallese suffer disproportionately from healthcare disparities and seek healthcare services in Hawai‘i.[8] In one decade, the Micronesian population has more than doubled in the US, with the Marshallese population itself increasing from around 7,000 in year 2000 to more than 22,000 in 2010. In 2010, the largest percentage of Marshallese in the US lived in the State of Hawai‘i.[9]

Little is known about Marshallese palliative care practices; there are no studies in the literature. This project is part of a greater

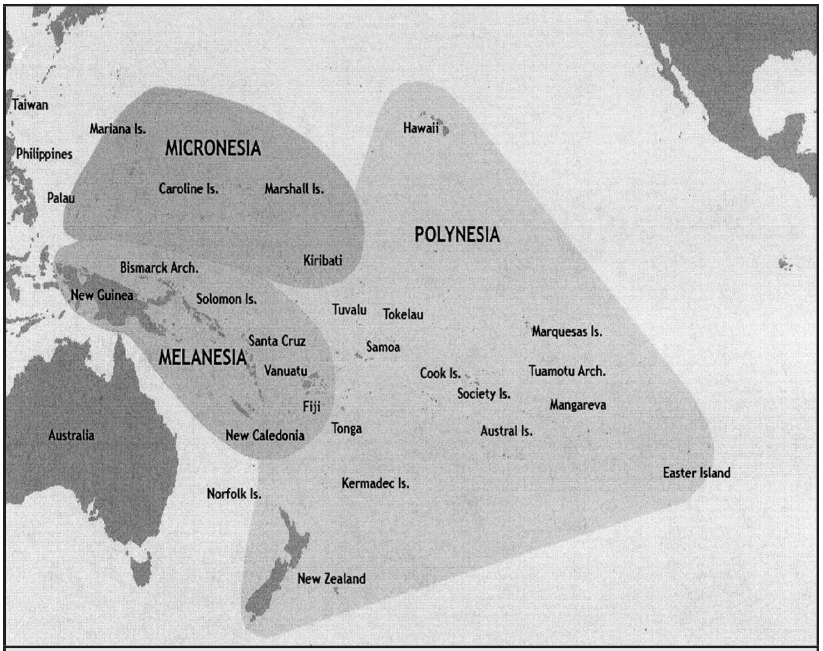

Figure 1. Map of Micronesia[2]

effort to improve end-of-life care for Micronesians, to learn more of traditional and contemporary Marshallese palliative care practices, to examine changes occurring as these migrants adapt to new social and cultural challenges, and to examine generational differences between young and old Marshallese.

Methods

We performed 3 focus groups in 2011-2012 among Marshallese living in or visiting the island of O‘ahu, Hawai‘i. Some were born and raised in the US, while others originated from Ebeye of Kwajalein Atoll and other outer islands including Likiep, Wotho, Ebon, and Jaluit (Figure 2).[10]

This study was declared exempt by the University of Hawai‘i Institutional Review Board, certificate CHS#18261. Subject recruitment was conducted by our interpreter. All participants provided written informed consent. No compensation was provided for participants; however, light refreshments were provided. Group facilitators were uniformly trained to conduct focus groups using a prepared script and a native speaking interpreter. Participants were asked the following open-ended questions:

1) What is a good death?
2) What examples can you give of a bad death?
3) How could the health care system improve its services to help make bad deaths better ones?
4) What traditional aspects of death and dying in your community are most important to preserve as the society and its healthcare system changes?

These questions were adapted from a prior study conducted by Maskarinec, et al, in the islands of Yap, Federated States of Micronesia.[11] All focus groups lasted 90-120 minutes. Participants were encouraged to speak either English or Marshallese. Sessions were audio-recorded with permission, transcribed, and analyzed by the facilitators. Data were analyzed using classical thematic triangulation methods to identify specific Marshallese palliative care practices, the effect of economic and social challenges in Hawai‘i, and generational differences comparing the young (17-27 years, n=6) and the old (as defined in Marshallese culture, 46-79 years, n=13).

Results

Demographic characteristics of participants in the focus groups are presented in Table 1. Four of six participants in the “young” group were born in the US, and only one had lived in the US for less than 5 years.

Six themes emerged as key concepts:

1) Pain Free Death
Both young and old Marshallese wanted a pain free death, both endorsing use of allopathic pain medications:

- “Just as Americans give pain medicine it is the same as giving herbal medicine in the Marshall Islands.”
- “Anything that can be done to take care of pain and suffering should be done by doctors and other medical personnel.”

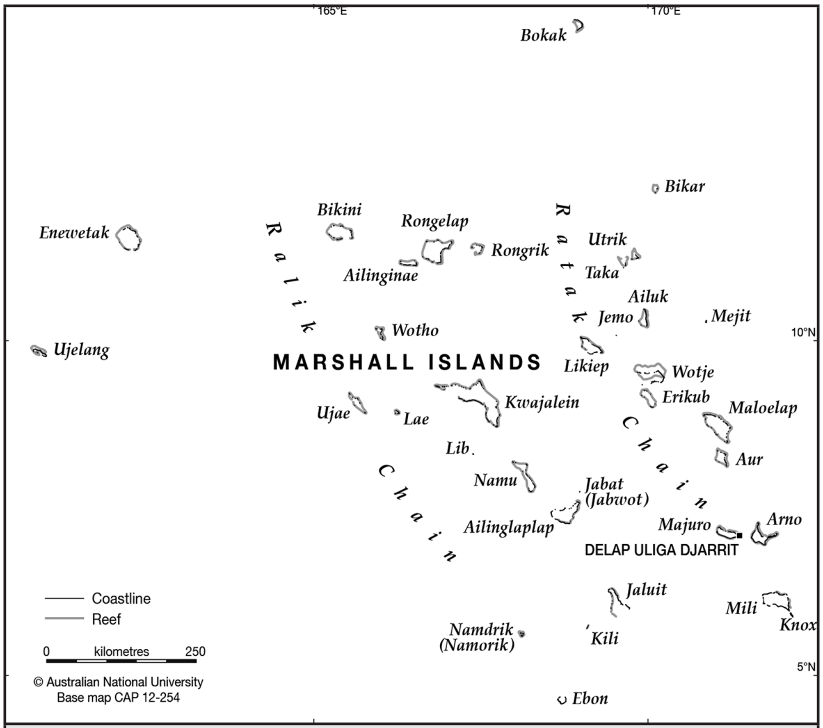

Figure 2. Map of the Republic of the Marshall Islands[10]

Table 1. Demographic Characteristics of Focus Group Participants

Characteristics	Group 1 n=6	Group 2 n=7	Group 3 n=6	All n=19
Age	**54.4 (46-63)**	**65.3 (54-79)**	**20.3 (17-27)**	**47.6 (17-79)**
Gender				
Male	4	3	3	10
Female	2	4	3	9
Time in US				
Since birth	0	0	4	4
< 5 years	0	2	1	3
5-10 years	2	0	0	2
11-20 years	2	1	1	4
> 20 years	2	4	0	6
Marital Status				
Married	4	2	1	7
Divorced/widowed	0	1	0	1
Single	0	0	5	5
Unknown	2	4	0	6

2) Life-Sustaining Interventions

Young and old had different views on the use of life-sustaining interventions in terminal illness. Elders equated a good death as one that is "peaceful and pain free," occurring naturally without artificial life prolongation. The young endorsed aggressive life-sustaining medical interventions.

Younger Marshallese stated:

- Hospitals "should do everything to keep [someone] alive…they have the expertise that the family does not."
- "If there is a way to live longer, they can go to the hospital, but if somebody wants to stay at home and die, it is the person's choice."

3) Place of Death

Preferred place of death differed depending on being in the RMI or in Hawai'i. Most respondents preferred to die in institutions while in Hawai'i. Young and old cited different reasons for this preference. According to elders, having people present that were "connected to" oneself was more important than the actual locale of death.

- "I would like to die at home if I were in Marshall Islands; If here, I [would] rather die…inpatient, hospice, or in some institution. While away [from Marshall Islands], hospice becomes like your home."
- "In the hospital, there's all these people really connected to you…a nurse or a doctor comes in…I [would] rather die in the hospital; if I were back home, I would choose to die with my family, but…here in Hawai'i…I would rather die in the hospital."

Younger Marshallese preferred to die in a hospital so that aggressive medical intervention can be provided.

- "Better [to die] in the hospital. They can help things until they can say they cannot help you anymore."

4) Cultural Practices/Family

Elders emphasized cultural practices surrounding death, while younger Marshallese discussed these practices in less detail.

Elders equated "good deaths" with family gatherings to absolve conflicts and with proper and timely performance of certain cultural practices such as the *ilomej (wake)* and *eorak* (post burial services). These cultural practices were important for understanding genealogic relations and for gathering extended family and friends. A death in the RMI is announced over public radio. In fact, a death that occurs in Hawai'i is still announced over public radio in the RMI. During the *ilomej (wake)*, the body may remain with the family for up to seven days, during which time extended family, friends, and community members pay their respects and bring condolence money and gifts.

The burial occurs after the *ilomej* and takes place on land owned by chiefs, free of charge after permission is granted. Clothing worn at the time of death and the mats used in the *ilomej* are buried with the deceased. Prior to conversion to Christianity, bodies were wrapped in mats and buried. Today, bodies, mats, and personal belongings are placed in coffins and entombed in cement.

Three days after the burial, a memorial service, known as *eorak*, is conducted at the burial site. Family members, dressed in white, place white stones on the grave, symbolizing resolution of conflict and forgiveness of sins. Graves are not touched or tended to until another death takes place to avoid "bwijerro," misfortune.

- "Everyone is welcomed to stay at the person's house day and night during this period, and people travel from the outer islands to pay respect."
- "The day of death, the day you see everybody, the day you understand your genes and relations."
- "In relation to death, the day of death, you will see everybody…you will get to meet everybody, regardless if you are related or not."
- "…after they're buried and after everything is said and done. You can't touch the grave or clean it until someone else dies and is buried in the cemetery. Otherwise, this will be bad luck."

Elders expressed belief in resurrection when speaking about practices that are important in preparation for this.

- "We put their clothing and belongings along with gifts in the coffin so they can come back."
- "Other people put magic, because they think that that person will come back to you to do whatever you want."

Elder participants also expressed concern about loss of their culture as the young become more and more acculturated in Hawai'i.

- "Younger generations do not know much about the culture. We are losing our custom, what we have."

The young focused on other details of the *ilomej* that had impressed them as children, such as having certain food items like ship biscuits available. Young participants said:

- "Every time we used to have a ilomej, we brought biscuits and everybody…would eat the biscuits. It is something you relate with death. It's always been biscuits."
- "I think the whole process is important. If the health care system changes, I don't think [the] culture would be able to keep things… It changes slightly to accommodate the change in the system, but ilomej and the whole process should be preserved."

5) The Body

Elders expressed clear opposition to cremation and wished to be buried on their island of origin. They preferred the body to stay intact for burial, preferring to ship the corpse back to the RMI as soon as possible if death occurred elsewhere.

One elder stated:

- "There was no such thing as cremation back home. People did not believe in cremation."

Younger participants were more accepting of cremation and felt that it was acceptable to hold cultural practices without the body present, stating:

- "Some [younger generation] might just want to be cremated and buried here [in Hawai'i]"
- "I think it is okay to have the wake and the process without the body present."

6) Bad Deaths/Barriers
Both young and old identified similar factors associated with "bad deaths," those from unnatural, abrupt, and unexpected causes, including suicides, stillbirths, accidents, shark attacks, or getting lost at sea. A "bad death" could also result from "black magic, curses, or witchcraft." Death at a young age from a non-communicable disease is viewed as bad.

- "Nowadays, most people die early from some disease [like] diabetes, cancer, or kidney disease. In the past, they [died] from old age."

Both groups identified lack of a timely burial or burial site as a bad death. They identified government policies, laws and regulations, and financial limitations as obstacles to a good death.

- "One of my family members died in Hawai'i. She was free from pain in the end. Bad thing was she spent months and months in the morgue because she didn't [have] enough money to go home right away."
- "Bad death is when you leave somebody unburied. For months, or until the government just cremates the person because there's no space."
- "When people die at home, all the family goes to the house and sleeps over. They stay in the person's house for whole 7 days. We cannot do it here, t hey will kick you out. Too much noise, too crowded. Here we cannot do that."
- "It is very different from our usual customs, we cannot even practice the wake, the white pebbles all that. Even coming to the house to do *ilomej*. In the Marshalls, your house is the morgue, so you can do whatever you want, when you want. It's 24 hours open. At home [in Marshall Islands], if they want, they can just bury right in front of their house. Free of charge. You don't have to pay for a grave."

Discussion and Conclusion

Many underlying cultural factors contribute to "good or bad" deaths. Although a well-developed traditional system of palliative care existed in the RMI, with traditional forms of respite care, bereavement care, estate planning, and even family counseling, all of these structures are threatened by modern social forces. Our study uncovered significant generational differences in attitudes and opinions, as discussed below. The health systems and providers who interface with Marshallese and other Micronesians in their home nations or as they migrate to other parts of the US, may be better able to provide appropriate and culturally relevant end of life care.

Pain Free Death

Participants desired a peaceful pain free death and were open to allopathic pain medications during the dying process. This differs drastically with another Micronesian culture, the Yapese, who indicated that pain while dying is desired and who refrain from using either allopathic or traditional medications to alleviate pain.[11]

Life-Sustaining Interventions

There were clear differences between young and old Marshallese regarding life-sustaining interventions in the setting of terminal illness. The young had conflicting views on palliative care, indicating a desire for a peaceful and pain free death yet still wanting aggressive medical care in terminal illness. Reasons for this difference may include limited exposure to traditional Marshallese practices, the availability of life prolonging medical technology, or the perception that people are dying from what are seen as unnatural causes: diabetes or kidney failure.

Place of Death

The ideal place of death differed depending on whether death occurred in Hawai'i or back home. Similar to Chuukese and Yapese customary practices, dying at home is the norm among people in the RMI where traditional Marshallese end of life practices involve extended family and community.[11] To our surprise, most participants preferred institutional deaths while living in Hawai'i. Elders appeared to value relationships with people surrounding them more than the actual locale of death, stating that in Hawai'i, doctors and nurses "become like your family." Since there are fewer family members in Hawai'i, medical personnel may serve as fictive family members. The young favored institutional deaths for a different reason, as a means for obtaining more aggressive medical care. Understanding these preferences may be especially helpful for palliative care providers who are assisting Marshallese at the end of life.

Cultural Practices/Family

Much like the Chuukese and Yapese, timely and proper performances of cultural practices emerged as an important component of a good death. Marshallese view death as a time to learn their genealogy.[11,12] Important cultural practices like *ilomej* and *eorak* are vital to a good death.

The Body

Our findings show clear generational differences regarding cremation. Marshallese traditionally bury their dead intact. Elders expressed desires for a traditional burial and wished their bodies to be shipped back intact to the RMI for burial. This practice is so important that the US Embassy published a memorandum regarding shipment and disposition of remains.[13] Belief in resurrection could explain this desire to keep the body intact. In contrast, many younger participants felt cremation was acceptable. As Marshallese are dying abroad, shipment of the body back to the RMI is difficult and costly, and cremation may be a suitable alternative for the young.

Bad Deaths/Barriers

Both young and old participants shared similar perceptions of what are bad deaths and on barriers to a good death. Abrupt and unexpected deaths such as from shark attacks or getting lost at sea were considered bad.

Suicide is another bad death. In 2003, suicide was noted to be the leading cause of death among Marshallese aged 15-44 years. A reported increase in suicide is attributed to the breakdown of family structures and the lack of education and employment opportunities. Rapid urbanization and strong identification with American culture may contribute to a confused sense of identity.[14] Our groups included as bad deaths those from non-communicable disease, like cancer, diabetes, and kidney failure, regarding these deaths premature.

Both groups identified government policies, laws, regulations, and financial limitations as obstacles to a good death. The gathering of family and friends for the *ilomej* is important for a good death, however, visiting hours and rules at hospitals and noise-limits in residential areas limit these important cultural practices. Department of health regulations allow only licensed funeral directors/embalmers to prepare, house, and transport dead bodies, while traditional practice allows Marshallese to prepare the dead and bury them free of charge. Financial constraints along with high mortuary and burial fees are obstacles to proper and timely burials. Participants shared painful stories of bodies of loved ones left in the morgue for months while cultural practices and funerals were either postponed or held without the body present. Cost and regulations governing the shipment of bodies back to the RMI are also barriers.

Study Limitations

As originally conceived, this study was one component of a larger project with initial plans to repeat this exercise in Majuro and Ebeye in the Republic of the Marshall Islands, with Chuukese in Honolulu and in their home islands, including Weno, Fefen, Faichuuk, and the Mortlocks, as well as in Pohnpei and Kosrae, for a more complete understanding of the differences in Micronesian attitudes toward death and dying. Unexpected financial barriers made the aforementioned impossible to complete. Additionally, more attention could have been paid to differences among Catholic, Protestant, Evangelical, Latter-day Saints (Mormon), and Baha'i faith groups, as religious orientation could have a major influence on beliefs and practices. Attitudes among the growing expatriate communities of Micronesians in Guam, Oregon, and Arkansas would have also enriched the findings presented here. In this study, elders were defined in Marshallese culture as aged 46-79, differing from the traditional western definition of 65 and above. Study participants were recruited by word of mouth primarily by Marshallese medical professionals on O'ahu. Due to the utilization of focus groups rather than a population-based sample, there may have been selection bias in those who agreed to participate.

Conclusions

Many underlying cultural factors contribute to "good" or "bad" deaths. Attitudes toward palliative care practices differ by generation. Having previously documented different approaches by Yapese, a generalized "one size fits all" approach to Micronesians is inappropriate. Characterization of a good/bad death is dynamic: death can be good, peaceful, and pain free but turn bad if certain cultural practices cannot be performed. Overcoming identified barriers may facilitate cultural practices necessary for a good death.

Conflict of Interest

None of the authors identify any conflicts of interest.

Presentation at Meetings

This study was presented as a poster at the Annual Meeting of the American Geriatrics Society in May 2014, and as an oral presentation at the 3rd Cross Cultural Health Care Conference in Honolulu, Hawai'i in August 2013.

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Authors' Affiliations:
- The John A. Hartford Foundation Center of Excellence in Geriatrics, Department of Geriatric Medicine, John A. Burns School of Medicine, University of Hawai'i, Honolulu, HI (LO, KM, CB)
- University of Arkansas for Medical Sciences, Northwest Arkansas Campus, Fayetteville, AR (SK)
- Japan Association for Development of Community Medicine, Taito Hospital, Taito-Ku, Tokyo, Japan (AT)
- Office of Global Health and International Medicine, John A. Burns School of Medicine, University of Hawai'i, Honolulu, HI (GGM)

Correspondence to:
Lauren Okamoto MD; 347 N. Kuakini St, HPM-9, Honolulu, HI, 96817;
Email: lokamoto@gmail.com

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Costs and Resources Used by Population-based Cancer Registries in the US-Affiliated Pacific Islands

Patrick Edwards MSc; Lee E. Buenconsejo-Lum MD, FAAFP; Florence K.L. Tangka PhD; Youngju Jeong MS; Janos Baksa MIM; Paran Pordell MPH; Mona Saraiya MD, MPH; and Sujha Subramanian PhD

Abstract

Background: *The costs of cancer registration have previously been estimated for registries in the continental United States and many international registries; however, to date, there has been no economic assessment of population-based registries in the US-Affiliated Pacific Islands. This study estimates the costs and factors affecting the operations of US-Affiliated Pacific Island population-based cancer registries.*

Methods: *The web-based International Registry Costing Tool[1] was used to collect costs, resources used, cancer cases processed, and other registry characteristics from the Pacific Regional Central Cancer Registry (PRCCR), Federated States of Micronesia National Cancer Registry, and nine satellite jurisdictional registries within the US Pacific Islands. The registries provided data on costs for June 30, 2016–June 29, 2017, and cases processed during 2014.*

Results: *Local host institutions provided a vital source of support for US-Affiliated Pacific Islands registries, covering substantial fixed costs, such as management and overhead. The cost per cancer case processed had an almost tenfold variation across registries, with the average total cost per case of about $1,413. The average cost per inhabitant in the US-Affiliated Pacific Islands was about $1.77 per person.*

Discussion: *The challenges of collecting data from dispersed populations spread across multiple islands of the US-Affiliated Pacific Islands are likely leading factors driving the magnitude of the registries' cost per case. The economic information from this study provides a valuable source of activity-based cost data that can both help guide cancer control initiatives and help registries improve operations and efficiency.*

Keywords

Cancer registries, costing, economic evaluation, cancer control, Pacific Islands

Introduction

The US-Affiliated Pacific Islands (USAPI), which comprises three Flag Territories (ie, the Territory of American Samoa, the Territory of Guam, and the Commonwealth of the Northern Mariana Islands) and three Freely Associated States (ie, the Federated States of Micronesia, the Republic of the Marshall Islands, and the Republic of Palau), are facing a rising burden of noncommunicable diseases (NCDs), such as cancer, as a consequence of improved prevention and treatment of infectious diseases leading to improved life expectancy and an aging population.[2] Furthermore, westernization of culture in the USAPI has driven engagement in unhealthy habits. Tobacco and alcohol consumption, diminishing physical activity, and altered dietary patterns, including sugar-sweetened beverages, imported cereals, and imported fatty meat, are all heightened risk factors that have affected the Pacific region's growing NCD burden.[3]

Cancer surveillance provides critical information on cancer incidence and trends that decision makers can use to monitor the burden of disease, as well as develop and evaluate targeted cancer prevention and control interventions at local and national levels. The US government's commitment to collecting timely, complete, and high-quality cancer data was affirmed through the 1992 Cancer Registries Amendment Act, which authorized the US Centers for Disease Control and Prevention (CDC) to establish and administer the National Program of Cancer Registries (NPCR).[4] The CDC financially supports and provides technical assistance and guidance to central population-based cancer registries established in 46 states, the District of Columbia, Puerto Rico, the US Virgin Islands, and the USAPI. The registries provide information on new cancer cases, including type, stage, and location, along with treatment and outcomes.[5]

The Cancer Council of the Pacific Islands (CCPI), which includes regional physician leaders, public health administrators, and comprehensive cancer control program coordinators, established the Pacific Regional Central Cancer Registry (PRCCR) in 2007 in response to the lack of high-quality data collection in the USAPI region, and to improve efforts to combat the rising rates of NCDs.[6] The CCPI serves as the advisory board to the registry and guides efforts to customize specific data fields and reports that can be used towards the needs of the USAPI region.[6] The PRCCR is the central administrative hub for multiple population-based cancer registries across jurisdictions within the USAPI. Although cancer registries that produce high-quality cancer data cover most of the US population, the USAPI faces many unique challenges in monitoring the Pacific region's burden of cancer. With a diverse population of around 460,000, the region covers fewer people than the smallest US state, but twice the geographic area of the continent.[6] The USAPI region faces limited resources,[7] and the health care infrastructure, capacity, and resource availability vary widely throughout the jurisdictions and represent major structural barriers to diagnosing cancer cases early, providing in-jurisdiction treatment, and implementing cancer control efforts.[8] Individuals living on remote islands face further barriers to accessing high-quality care because many must travel long distances by boat to reach primary care or treatment centers.[8] Although no analysis has been done, the CCPI has presumed that rates of cancer in the USAPI may be underreported in light of inconsistent screening and other barriers.[8]

Previous studies have estimated the costs incurred by NPCR registries along with the internal and external factors that affect registry operations and costs.[9-11] Further studies improved the costing methodology from the NPCR study to estimate the costs of international population-based cancer registries of various designs and locations, including island regions and low-income settings.[12,13] No study has been conducted on the specific economic costs incurred by central and jurisdictional cancer registries located in the USAPI, which has larger geographic disparities compared to previously studied island regions. One needs to know the true cost of cancer registration in the USAPI region to assess efficiencies in the data collection approach and the overall registry structure. We estimate the cost per cancer case of individual population-based cancer registries and overall PRCCR, and identify potential factors that can affect the cost per case and variation between registries.

Methods

Participating Registries and Reporting Structure

The 11 registries located within the USAPI were selected to participate in the costing study to help guide registry leaders and decision makers on the overall and individual factors facing cancer surveillance in the USAPI region. The PRCCR, as the central administrator of cancer registries in the USAPI, oversees and receives data on cancer cases collected by the jurisdictional registries. Although the University of Hawai‘i serves as the host institution for the central registry and is responsible for overall administration, each registry is located within the jurisdiction's Ministry or Department of Health, Division of Public Health, Non-Communicable Disease Bureau, or Branch. The largest registry, Guam Cancer Registry, is based at the University of Guam with support from the Cancer Research Center of Guam. The registries cover a range of populations, from 6,616 inhabitants under the Kosrae State Registry in Federated States of Micronesia (FSM) to 159,358 inhabitants covered by the Guam Cancer Registry. The registries cover a large geographic area throughout the Pacific Ocean, as shown in Figure 1. Individually, the registries cover areas as small as 110 square kilometers in Kosrae to more than 7,000 square kilometers under the FSM National Cancer Registry. Both the PRCCR-Central Cancer Registry and the FSM National Cancer Registry do not collect or process cancer cases, and the remainder of the registries each processed less than 90 cancer cases during the reporting year, with the exception of Guam, which processed 289 cancer cases.

The reporting structure of cancer surveillance operations in the USAPI is presented in Figure 2. Each jurisdictional registry is population-based and functions as a small central registry by consolidating data from a variety of data reporting sources, including out-of-country hospitals, before sending the case to the PRCCR. Each individual jurisdiction manages and performs their own cancer case data collection and entry to localize the process and to support local monitoring and program initiatives in both the public health and curative or hospital sectors. Each

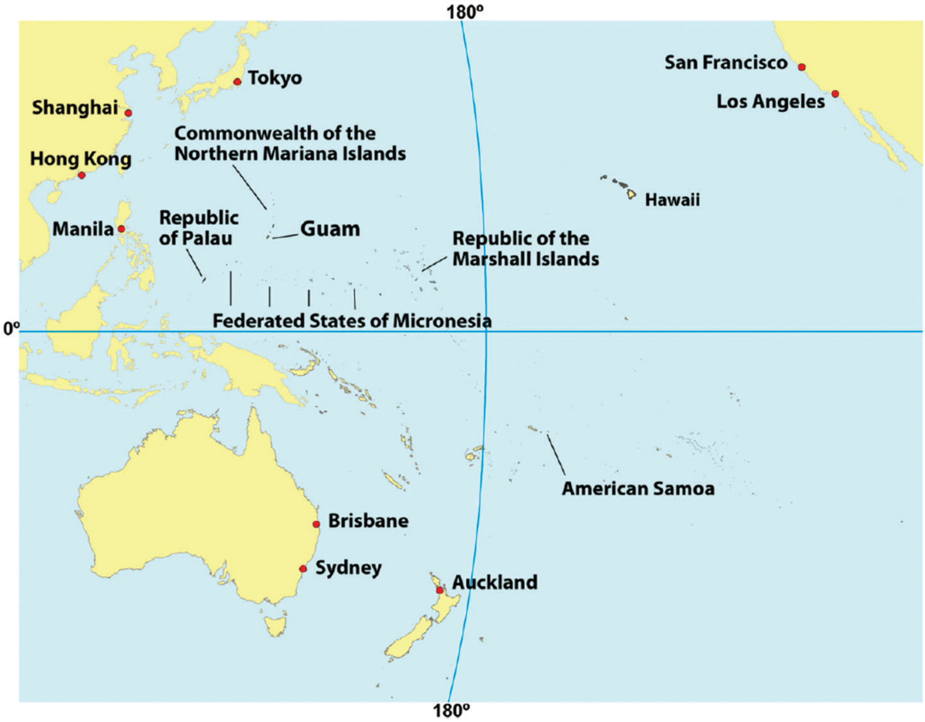

Figure 1. Map of the US-Affiliated Pacific Islands Registries' Coverage Area

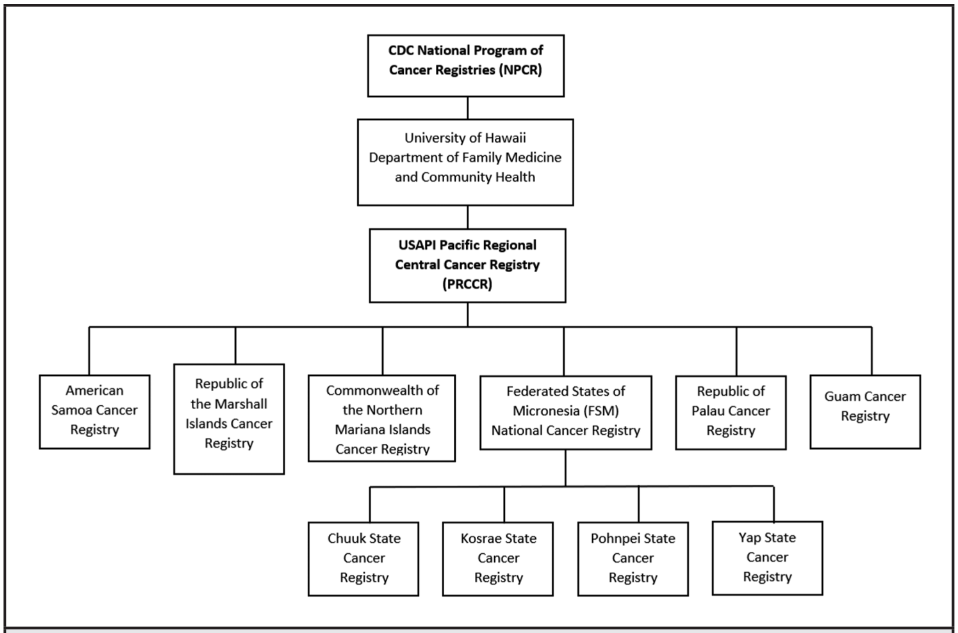

Figure 2. Structure of the US-Affiliated Pacific Islands' Central and Jurisdictional Registries

Notes: PRCCR and FSM National Cancer Registry do not perform data collection directly from original sources; FSM collects cancer cases from 4 state registries within the FSM region, and PRCCR collects cancer cases from all jurisdictional registries.

jurisdictional registry performs their own case ascertainment, data abstraction, editing, death clearance, and follow-up. Jurisdictional registries use CDC-customized reports in Abstract Plus to support efforts to tailor the reporting to individual registry needs.[14] Cases collected by each of the jurisdictional registries are reported to the PRCCR through WebPlus[15] software (CDC-developed software provided at no cost). For the FSM, the National Cancer Registry serves as the intermediary, which performs additional data checks for the state registries of Chuuk, Kosrae, Pohnpei, and Yap within the FSM. FSM has a unique structure compared to the other jurisdictional registries in that the state registries do not submit cases directly to the PRCCR. After the additional data checks, including visual editing and consolidation, FSM transmits cases from the 4 states to the PRCCR. Additional roles of the jurisdictional registries include communication with vital statistics, hospitals, off-island referral offices, and other data sources. Registrars participate in local meetings for comprehensive cancer control (CCC) and NCD working groups and in regional cancer control planning, regional training for software usage, report writing, and cancer staging. The registries work with the University of Hawai'i and CDC to implement new software and to receive ongoing technical assistance and guidance.

Main activities performed by PRCCR include staff trainings, implementing new processes at jurisdictional registries, oversight of local data processes, implementing systems for case identification and cancer reporting in USAPI, building capacity, developing cancer registration systems, and linking individual jurisdictional registries to cancer and NCD control efforts to support public health initiatives. PRCCR monitors overall trends and cancer burden and guides the USAPI health officials on the appropriate use of cancer data. The PRCCR compiles the cancer data collected by jurisdictional registries and develops reports that are submitted to CDC, jurisdictions, USAPI regional leadership, other US Health and Human Services funding agencies, and other stakeholders and partners, including international partners, such as the World Health Organization (WHO) and the Pacific Community.

Cost Data Collection Approach

The PRCCR used the CDC's web-based International Registry Costing Tool[1] to assess individual island and overall registry costs and resources used. The *IntRegCosting Tool*[1] is web-based data collection and analytic tool where registry staff can directly input information into various modules relating to registry characteristics, resource use and costs and will receive instant summary reports showing outputs of interest to the registry, such as the cost per case results. The tool was initially developed for US cancer registries in the NPCR and was pilot tested among US states and international registries by using an Excel-based version.[9,13] The PRCCR is the first US-affiliated registry to use the web-based tool since improvements were implemented to streamline the cost collection process. The web tool consists of 10 data collection modules that collect registry characteristics by using an activity-based costing approach. The data collection modules included registry background information, funding sources, data collection approach, registry personnel, personnel activities, other personnel (eg, consultants), computers, travel, training, and other materials, software licensing, overhead or indirect costs, and narrative feedback. Drop-down boxes allowed registries to allocate specific expenses and labor hours across a wide range of cancer registry activities. All resources were allocated to specific cancer registry activities, which included over 30 registry functions, such as management, training, data collection, data entry, validation, database management, quality control, IT support, and other advanced activities, such as production of materials to support public health functions, research studies funded by the National Cancer Institute, or publications. Registry staff entered the percentage of their overall time that was spent performing the activities, which was used to determine the distribution of their salary allocated across the registry functions. Both actual costs through funds and donations were considered in the calculation of the overall registry cost.

After a series of training webinars and an in-person meeting with the jurisdictional cancer registrars, the PRCCR used a worksheet to collect information from each jurisdictional registry. To simplify the data collection, the worksheet used by the jurisdictional registries was an Excel-based replica of the *IntRegCosting Tool* modules. Each jurisdiction entered details into the worksheet for their registry and then submitted to the PRCCR for review and confirmation. The PRCCR staff then entered each registry's detailed information from the worksheets into the web-based costing tool across budget categories related to both labor and nonlabor costs and resources used, including donations or in-kind contributions. A user's guide and ongoing technical assistance were provided to the registry to support their data inputs. Because the USAPI's structure includes multiple islands and jurisdictional registries, we collected and entered cost data separately for each location to isolate the cost per jurisdiction before assessing the cost of the full registry. Costs were collected for a 1-year time frame: June 30, 2016 through June 29, 2017. The registries provided the number of cancer cases that were reported during 2014. Costs were reported for all 11 registries, although only the registries that performed data collection (all except PRCCR and FSM) reported cancer cases.

After the PRCCR registry completed the data inputs, the web tool ensured that all quality checks had been satisfied through a series of quality validations. The validations helped confirm that all required information was entered into the data modules, and that the registries' data passed quality checkpoints, such as percentages adding to 100 percent. Following the registries' confirmation of data, researchers also reviewed the data to ensure completeness.

The *IntRegCosting Tool*[1] contains a built-in data analytic tool that calculated the registry's cost results. Using the cost and resource use data provided by the USAPI registries, the analytic tool produced summary reports that estimated the registry's high- and low-cost activities, resources per budget category, resources by source, and cost per cancer case and inhabitant. Resources allocated to the overhead data module, such as for rent or utilities, were prorated across the distribution of the other cancer registry activities, as these indirect costs were in support of overall registry operations. We present the results based on data entered into the web-based tool.

Results

Registry Characteristics and Incidence Rates

Characteristics of the 11 USAPI registries are presented in Table 1. In 2016–2017, the registries each had at least 1 full-time equivalent, with PRCCR-Central having fewer than 3 full-time equivalents, including the staff based in Honolulu at the University of Hawai‘i. Cancer is a reportable disease, by law, in all USAPI registries, which aligns with US policy; and all actively enforce cancer reporting to the jurisdictional registry, in which the registry is able to use the legislation to mandate access to cancer cases. Registries that collect and process data have at least 3 total data sources, with Yap having 7 total sources. None of the registries perform regular active follow-up on all cases as they are staffed by one person to accomplish all activities. However, all registries perform death clearance, along with the collection of *in situ* cancers of the breast, cervix, vagina, and anus, as well as melanoma and nonmelanoma skin cancers. Because the smaller jurisdictional registries are housed within a hospital's medical records department or have an excellent reporting relationship, the registrars receive new information, update their database, and provide updates to the PRCCR.

The age-standardized incidence rates for the top 5 cancers across all USAPI registries are reported by sex in Figure 3. Among females, breast cancer had the highest annual, age-standardized incidence rate from 2007 to 2014, with almost 52 new cases per 100,000 population. This is followed by lung and bronchus cancer with about 22 new cases per 100,000 per year, then uterus, cervical, and colon and rectum cancers. Among males, prostate cancer has the highest age-standardized annual incidence rate, with 57 new cases per 100,000 population, followed by lung and bronchus cancers with 53 new cases per 100,000 population. Colon and rectum cancers have about half the incidence rate of lung and bronchus, followed by liver cancer and leukemia.

Registry Cost Results

Figure 4 presents the sources of support for registry operations, including through actual funds that support registry costs and donated resources, such as office space. Registries receive their main source of financial support via sub-awards by the University of Hawai‘i through funding from the NPCR. The sub-awards go towards the central registries, along with each of the jurisdictional registries for the financing of personnel, and is often used for the financing of computers, travel, training, and other materials. PRCCR-Central is entirely supported by the University of Hawai‘i, which serves as its host institution,

Table 1. Characteristics of the US-Affiliated Pacific Islands Population-based Cancer Registries

	American Samoa	Republic of the Marshall Islands	Common-wealth of the Northern Mariana Islands	PRCCR - Central	Republic of Palau	FSM National	Pohnpei State, FSM	Chuuk State, FSM	Kosrae State, FSM	Yap State, FSM	Guam
Date established	2007	2007	2007	2007	2007	2007	2007	2007	2007	2007	2007
Host institution type	Health Dept.	Health Dept.	Health Dept.	University	Health Dept.	Health Dept.	Health Dept.	Health Dept.	Health Dept.	Health Dept.	University
Population covered	55,519	53,158	53,883	0	20,518	0	35,981	48,651	6,616	11,376	159,358
Area covered (sq KM)	199	181	464	2,550	465	7,006	346	701	110	118	540
Cancer cases processed (2014)	7	67	82	0	27	0	46	7	5	29	289
Full-time equivalents	1	1	1	2.84	1.6	1	1	1	1	1	2.52
Reportable disease	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
If yes, actively enforced?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Total sources	3	5	3	11	3	1	6	3	3	7	6
Performs active follow-up	N	N	N	N	N	N	N	N	N	N	N
Performs death clearance	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Collects *in situ* cancers	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Collects melanoma skin cancers	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Collects nonmelanoma skin cancers	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Notes: Cancer cases correspond to the number of cases collected and processed during 2014. Information on other factors and characteristics were reported by cancer registry representatives and correspond to the year of cost data reported, June 30, 2016–June 29, 2017. PRCCR Central Registry and FSM National Cancer Registry do not directly perform data collection; thus, cancer cases processed is 0 for both registries. All registries collect *in situ* uterine cervix, vagina, and anal cancers to monitor long-term impacts of the human papillomavirus vaccination programs. FSM, Federated States of Micronesia; PRCCR, Pacific Regional Central Cancer Registry.

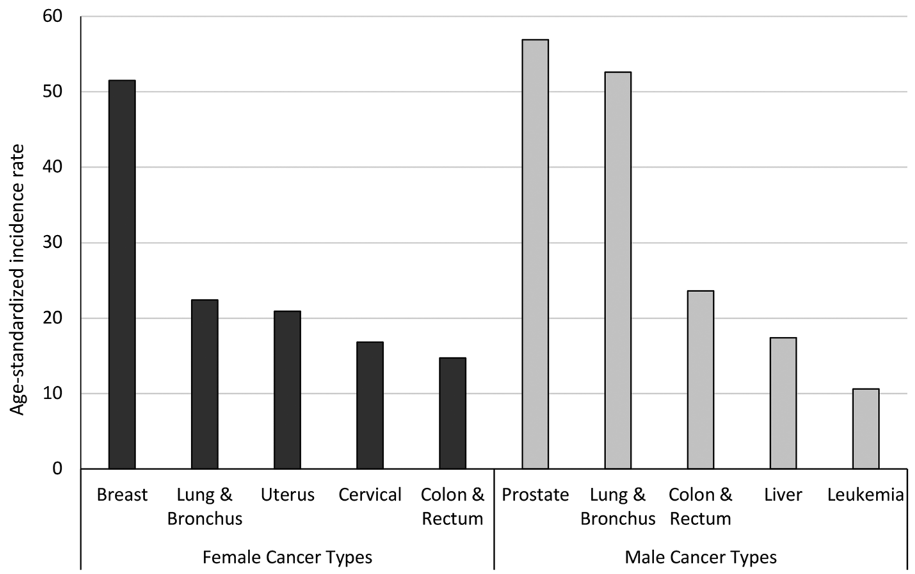

Figure 3. Age-standardized Incidence (per 100,000) for the Five Major Cancers of Each Sex in the US-Affiliated Pacific Islands, 2007–2014

Source: Pacific Regional Central Cancer Registry (PRCCR), 2007–2014.

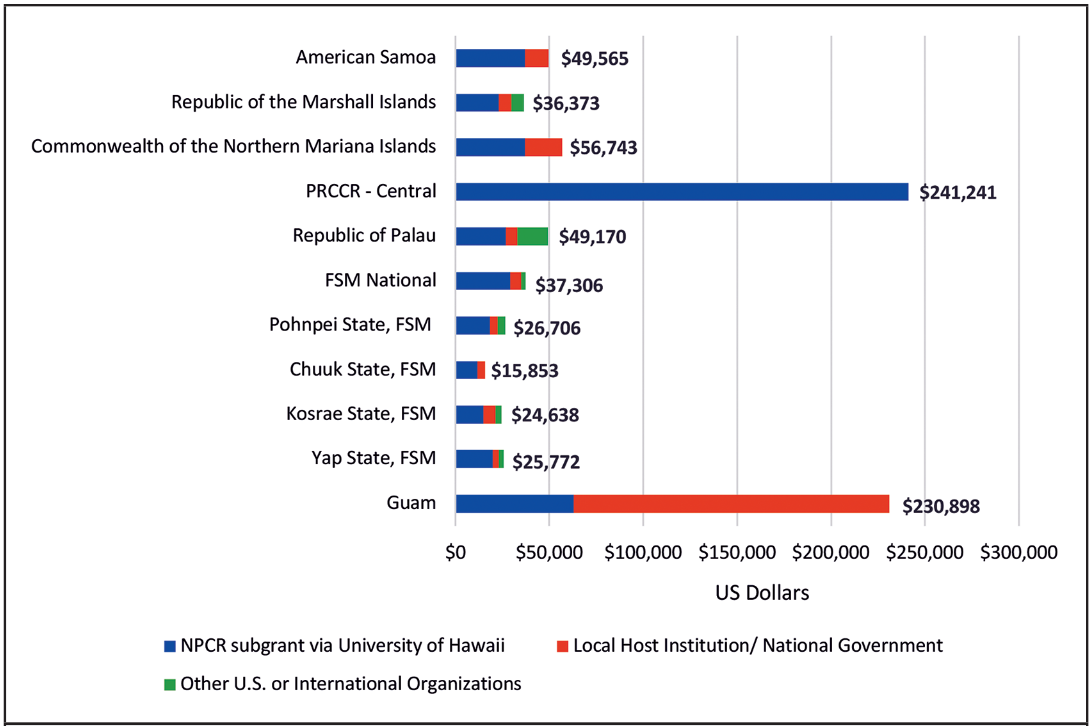

Figure 4. US-Affiliated Pacific Islands Registries' Resources by Source

Notes: Costs were reported by cancer registry representatives for the reporting year June 30, 2016–June 29, 2017; PRCCR-Central and FSM National do not directly perform data collection but received funding to perform administrative duties, training, and other essential central registry functions. PRCCR-Central is entirely funded via grant support from the University of Hawai'i. FSM, Federated States of Micronesia; PRCCR, Pacific Regional Central Cancer Registry; RMI, Republic of the Marshall Islands.

as well as its *bona fide* agent for the region's NPCR funding. Support from the registries' local host institutions largely supports registries' space, utilities, minimal IT support, and other administrative resources. The University of Guam provided the majority of support for the cancer registry in Guam, which also received a portion of their funding from the University of Hawai'i, through a sub-award of the NPCR funding. In contrast to the other registries, the registry in Palau received significant funding through international organizations, such as the New Zealand Agency for International Development, Japan International Cooperation Agency, and WHO.

Figure 5 presents the distribution of total USAPI registries' resources by budget category. About 55% of all the resources went towards registry personnel, through employee salaries. Registrar salaries ranged from $20,000 to $35,000 in most of the jurisdictions, and as low as $11,000 in the FSM States. The second largest portion of resources went toward overhead, representing about 22% of the overall registries' resources. Other personnel, such as consultants, represented about 14% of the registries' resources, whereas computers, travel, training, and other materials represented 9% and software less than 1%.

The distribution of total registries' resources by cancer registry activity, including donations, are presented in Figure 6. Management had the highest level of resources incurred, (around $166,000). Public health, contributing data to research projects, and other activities had around $160,000 incurred, which largely included manually linking records to other databases. The third largest activity was data collection and abstraction (around $141,000). With the exception of Guam, which has a cancer research center partially supported by NCI funding, all jurisdictional registry data products and outputs were used primarily to improve public health outreach, education, screening services, and to guide prioritization of other local programs and health services to support cancer patients and their families.

Table 2 presents each of the registries' cost per cancer case processed and cost per inhabitant, with the exception of the PRCCR and FSM National Registry. The largest registry, located in Guam, had a cost per case of nearly $800 and cost about $1.45 per inhabitant in its coverage area. The registry with the highest cost per case was the American Samoa Cancer Registry, at about $7,080 per cancer case processed, whereas the registry with the lowest cost per case was the Cancer Registry of RMI, which cost about $476 per case. Altogether, the registries processed 559 cancer cases during 2014 and had a cost per case of $1,413 and a cost per inhabitant of about $1.77.

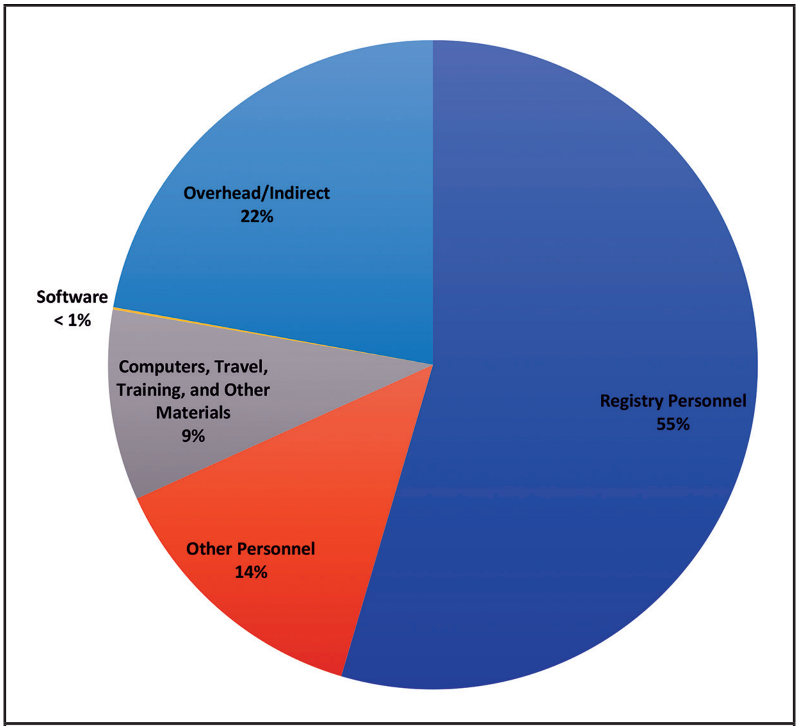

Figure 5. US-Affiliated Pacific Islands Registries' Resources by Budget Category

Notes: Costs were reported by cancer registry representatives for the reporting year June 30, 2016–June 29, 2017. FSM, Federated States of Micronesia; PRCCR, Pacific Regional Central Cancer Registry; RMI, Republic of the Marshall Islands.

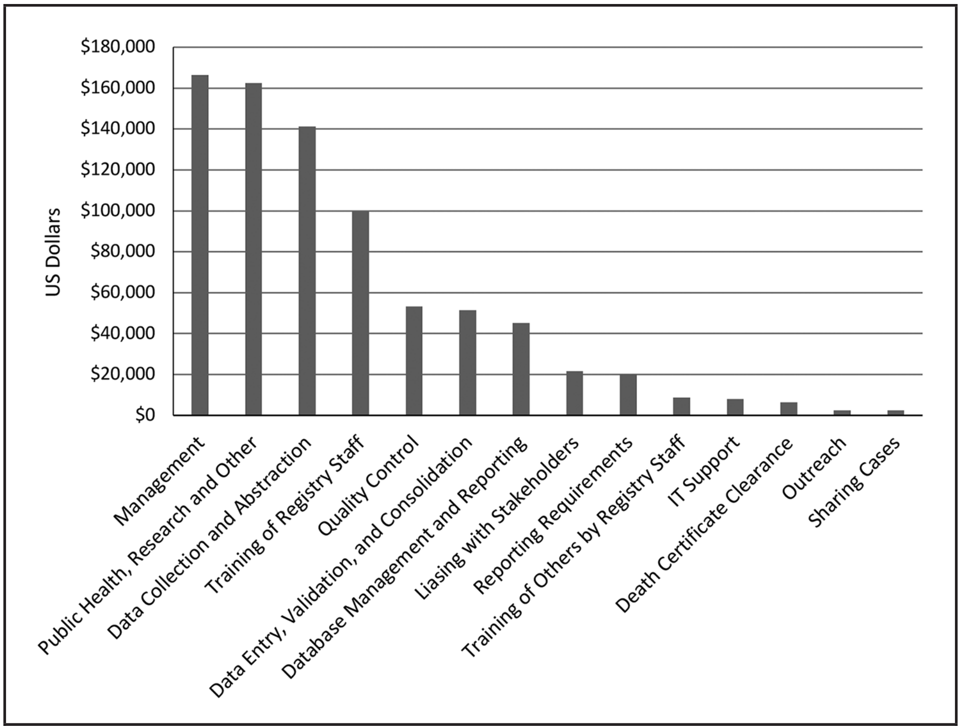

Figure 6. Distribution of Total US-Affiliated Pacific Islands Registries' Resources by Activity

Notes: Costs were reported by cancer registry representatives for the reporting year June 30, 2016–June 29, 2017. The activity "Public Health, Research and Other" is inclusive of traditionally non-core registry operations and largely includes record linkages to other databases, including contributing data to NCI-funded research studies and advanced analysis, publications, and other public health-related efforts.

Table 2. US-Affiliated Pacific Islands Registries' Cost Per Case and Cost Per Inhabitant

	American Samoa	Republic of the Marshall Islands	Commonwealth of the Northern Mariana Islands	Republic of Palau	FSM					Guam	USAPI Total
					Total	Pohnpei State	Chuuk State	Kosrae State	Yap State		
Cancer Cases	7	67	82	27	87	46	7	5	29	289	559
Inhabitants	55,519	53,158	53,883	20,518	102,624	35,981	48,651	6,616	11,376	159,358	445,060
Cost per Case	$7,080	$476	$692	$1,713	$1,497	$581	$2,265	$4,927	$889	$799	$1,413
Cost per Inhabitant	$0.89	$0.68	$1.00	$2.25	$1.27	$0.74	$0.33	$3.72	$2.27	$1.45	$1.77

Notes: Cancer cases corresponds to the number of cases collected and processed during 2014. Costs were reported by cancer registry representatives for the reporting year June 30, 2016–June 29, 2017. FSM Total includes the costs for FSM National along with the individual states; USAPI Total includes the costs for PRCCR, FSM National, and each of the jurisdictional registries within the USAPI. FSM, Federated States of Micronesia; PRCCR, Pacific Regional Central Cancer Registry; RMI, Republic of the Marshall Islands; USAPI, US-Affiliated Pacific Islands.

Table 3. Narrative Feedback on Potential Factors Affecting US-Affiliated Pacific Islands Registries' Operations

Factor	Description
Internal Barriers and Facilitators	
Volume of cases	Low case volume makes it more difficult to achieve economies of scale.
Data abstraction methods	Widely paper-based methods because of a lack of implementing electronic methods.
Quality of data	Lack of complete case reporting in some jurisdictions.
Staff expertise	Technical expertise needed to improve or begin use of more electronic reporting.
Organizational structure	Resources spread across many satellite registries with large administrative resource needs.
External Barriers and Facilitators	
Geographic coverage	Travel and data collection are costly across large geographic area.
Funding	Funding supports improvements in registry capacity and training programs.
IT support and technical assistance	Further technical assistance can improve capabilities in electronic reporting.
Partnerships	Partnerships are crucial for helping synergize efforts and seeking additional resources.

Notes: Narrative feedback received by registries through costing tool or correspondence via email.

Table 3 includes the qualitative data that was collected from the registries through narrative feedback in the costing tool. Registries and the directors noted important factors that they perceived to be barriers or facilitators to their operations and achievement of registry objectives. All registries within the USAPI note their need to improve case completeness, and to achieve more complete staging or treatment information on cancer cases because many are treated abroad. The lack of electronic health records in some jurisdictions means that poorly organized paper records are widely used, which creates inefficiencies and leads to a higher chance of lost records. USAPI registry directors reported that given limited capacity and resources, the USAPI does not plan to prioritize e-reporting until jurisdictions substantially improve their health IT capacity. Consequently, many providers and hospitals in the USAPI are not able to meaningfully use electronic health records or participate in the Promoting Interoperability Program.[16-17] Along with information and communication technology challenges, the lack of sufficient on-island expertise to work on e-reporting was cited as an area for improvement in registry operations. However, registry directors did not anticipate that this would change anytime soon, given the need to apply current resources and capacity to other pressing health priorities. Many registries also noted the need for additional training and support for registry operations.

Discussion

This is the first study to report detailed costs of cancer registration in the context of the US-Affiliated Pacific Island Region. The results of this web-based cost data collection showed that the total cost per case across all registries was about $1,413. This cost per case is substantially higher than the average cost per case of US registries that participated in the NPCR evaluation, which was about $61 per case.[10] The total cost per inhabitant of about $1.77 was also much higher than the cost per inhabitant of international cancer registries, in which most had a cost per inhabitant of less than $0.50.[12] The USAPI likely faces higher costs per case than other registries because of their unique circumstances as island territories.

The burden of surveilling a geographic area almost twice the size of the continental United States requires substantial resources to support a large number of satellite registries. Each registry faces significant fixed costs, including rent for office space and equipment. Furthermore, all registries perform active data abstraction, including Guam's routine communication with hospitals and free-standing clinics to acquire information. Data abstraction is almost entirely paper-based in most jurisdictions, which contributes to inefficiencies. Records from out-of-country cancer care are actively sought and can take up to 6 months in some locales. Travel throughout jurisdictions covering a large geographic area makes data collection resource-intensive, and leads to significant expenses for annual meetings or training on other islands. The geography of the Pacific islands presents many unique challenges; most previously studied registries were single entities that spread resources across large volumes of cancer cases.

Another primary factor driving the higher cost per case among the USAPI registries is likely the small number of cancer cases processed within the USAPI. A previous study showed case volume to be significantly associated with a cancer registry's cost per case.[10] In the US NPCR study, in which the majority of registries processed at least 10,000 cases annually, registries that processed a larger volume of cases were able to achieve economies of scale by spreading fixed and semivariable costs across a set number of cases. As the USAPI registries altogether cover a smaller population than NPCR registries, and processed less than 600 cancer cases annually across 11 individual registries, the high cost per cancer case processed in the USAPI is aligned with expectations. This factor is further evident in the high cost per case of the American Samoa registry, which like Chuuk, processed a small number of cancer cases because of personnel challenges noted by the PRCCR staff.

The quality of the data collected has also been shown to be an important factor in the cost per case of cancer registries, with NPCR registries that produce higher quality data experiencing a significantly lower cost per case.[10] Per the internal report from CDC to PRCCR of a routine NPCR data quality audit of 2013 cases, coding was correctly supported by text fields with 96% concordance. However, cancer registries in the USAPI do not meet some of the other quality thresholds needed for inclusion in the *Cancer Incidence in Five Continents* publication,[18] and face many limitations in their processes for collecting cancer data.[8] Cancer cases are likely underreported in the USAPI, as there is lack of complete case reporting in some jurisdictions because of individuals on remote islands who are unable to or avoid seeking care, or patients with high personal wealth choosing to travel elsewhere for diagnosis and treatment.[8]

Local capacity building, more intensive training, and increased technical assistance are areas that registry directors and other stakeholders may consider when seeking to improve efficiency in registry operations and reduce structural barriers to cancer registration.[13] The registries noted that through the efforts of the Pacific Island Health Officers Association, CDC, the Association of State and Territorial Health Officers, and other funders, resources have been allocated in the USAPI in the past 4 years to strengthen their overall capacity for surveillance of both chronic and infectious disease. The registries also indicated that on-site technical assistance and training for strengthening the civil registration and vital status functions were perceived as viable solutions to improve the quality of data and improvement of registry operations. Furthermore, the USAPI registries have already formed partnerships with the International Agency for Research on Cancer and the International Association of Cancer Registries in the development of the WHO Pacific Hub and will continue to explore opportunities to collaborate and synergize efforts to improve efficiencies in the USAPI Cancer Registries.

A limitation of this study is the estimation of indirect costs. As many costs relating to overhead or equipment used were provided by a host institution without a direct transfer of cash from the registry, many web-tool users estimated the market value of their office space and administrative costs. These costs were important to collect as part of evaluating the overall economic costs of cancer registration, which include both donations and expenses. Potential errors were minimized through the use of market value or exact amounts provided directly by the local host institutions. In addition, all values were reviewed by researchers for their plausibility. Another limitation of this study is the retrospective nature of the cost data collection. Retrospective data collection can lead to recall error; the reliability of exact costs and factors provided may depend on the registries' recordkeeping practices, or in instances of donations, recall of exactly what was provided during the reporting year.

Strengths of this study include the use of a validated web-based costing tool that collects detailed activity-based costs on all aspects of cancer registry operations. As the costing tool included details of important indirect costs and in-kind contributions, the results in this study represent the true economic costs of running the registries. This study sought information on costs and factors directly from registry representatives and allowed each staff member to report the allocation of their time across specific registry activities. Therefore, this study provides a realistic account of what the registries are facing. The cost per case varied significantly across registries in this study; thus, future assessments could review causes of this variation to identify lessons learned and potential options for improving efficiency and reducing registries' cost per case.

Conclusions

This study provides needed information for decision makers to understand sources of financial support for registries in the USAPI, proportions of resources allocated to various registry activities, and factors that may be influencing the high cost per case experienced by USAPI registries. Registry leaders and other decision makers can use the cost per case and cost per inhabitant figures from this study to identify areas for potential operational improvement and to inform efforts to align cost-drivers and quality of registration activities for USAPI registries with those of other NPCR registries.

Conflict of Interest Disclosure Statement

Dr. Buenconsejo-Lum (University of Hawai‘i) received CDC cooperative agreements for the USAPI Pacific Regional Central Cancer Registry program. Otherwise, all authors declare that this work was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Authors' Affiliations:
- RTI International, Research Triangle Park, NC (PE, SS)
- Pacific Regional Central Cancer Registry (PRCCR), University of Hawai‘i at Manoa, Honolulu, HI (LEB-L, YJ, JB)
- Division of Cancer Prevention and Control, Centers for Disease Control and Prevention, Atlanta, GA (FKLT, PP, MS)

Correspondence to:
Sujha Subramanian PhD; RTI International, 1440 Main St., Ste. 310,
Waltham, MA 02451-1623; E-mail: ssubramanian@rti.org

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Cancer Mortality in the US-Affiliated Pacific Islands, 2008–2013

Elizabeth A. Van Dyne MD, MPH; Mona Saraiya MD, MPH; Arica White PhD, MPH;
Daniel Novinson MD, MPH; Virginia Senkomago PhD, MPH;
and Lee Buenconsejo-Lum MD, FAAFP

Abstract

*Cancer-related mortality in the US-Affiliated Pacific Island (USAPI) jurisdictions is unknown. This is the first ever reporting of cancer-related mortality in the USAPI using cancer registry data. The individual USAPI jurisdictions collected incident cancer data and submitted it to the Pacific Regional Central Cancer Registry (PRCCR). All cases reported to PRCCR (n = 3,118) with vital status of dead (n = 1,323) during 2008–2013 were examined. Cause of death was coded based on clinical information provided in the cancer registry. Incidence-based mortality (IBM) rates were calculated using SEER*Stat software and age adjusted to the US standard population. Total cancer IBM rates among males were highest in Palau (151.5 per 100,000), Republic of the Marshall Islands (RMI, 142.0), and Guam (133.2); rates were lowest in American Samoa (21.7), the Commonwealth of the Northern Mariana Islands (CNMI, 22.7), and the Federated States of Micronesia (FSM, 28.9). Total cancer IBM rates among females were highest in RMI (120.3 per 100,000), Palau (107.7), and Guam (72.2); rates were lowest in CNMI (19.0), FSM (23.2), and American Samoa (42.8). The median time from cancer diagnosis to death was 8–28 days in the Freely Associated States and 102–128 days in the Flag Territories. IBM rates were higher among individuals in USAPI jurisdictions than among Asian/Pacific Islanders in Hawai'i for many cancers preventable through vaccination, smoking cessation, overweight and obesity prevention, and cancer screening. Geographic remoteness, underreporting, delay in reporting, and challenges with accurate death registration and certification led to lower IBM rates for some jurisdictions. These mortality data can help prioritize evidence-based interventions to reduce cancer-related deaths through risk factor reduction, early detection, and improved quality of life after a cancer diagnosis through palliative care.*

Background

In 2010, a state of health emergency due to an epidemic of non-communicable diseases (NCD) was declared in the six US-Affiliated Pacific Island (USAPI) jurisdictions.[1,2] The USAPI are politically linked to the US as "Flag Territories" (Guam, American Samoa and the Commonwealth of the Northern Mariana Islands [CNMI]) or as "Freely Associated States" (Federated States of Micronesia [FSM, grouped into four states: Chuuk, Kosrae, Pohnpei, and Yap], Republic of the Marshall Islands [RMI], and Republic of Palau, Figure 1) through the Compacts of Free Association.[3] USAPI jurisdictions have among the highest prevalence of obesity and tobacco use in the world and insufficient resources to prevent and control cancers.[4-9] Despite substantial under-diagnosis and under-reporting for many areas of the USAPI, the age-adjusted incidence of some cancers are still high.[10] High cancer incidence rates in the USAPI are due to lack of preventive health services and high prevalence of cancer risk factors, such as alcohol, tobacco, betel nut use, and chronic hepatitis B.[6,7,11,12] Cancer is now the second most common cause of death in nearly all USAPI jurisdictions.[5] The USAPI healthcare systems have numerous challenges that influence cancer registration and cancer mortality reporting. Per capita health care expenditures, including health prevention (vaccines), public health, and medical care, range from $500–$1,310, in comparison to $10,348 spent in the US (Table 1). The populations in most jurisdictions are scattered among multiple islands and atolls across thousands of square miles of ocean. Geographic isolation creates limitations not only for preventive health care, but also for cancer diagnosis and treatment, which requires a subspecialized and multidisciplinary team not available in most jurisdictions. Most jurisdictions do not have computerized tomography (CT) or other advanced radiology service, endoscopy, or on-island pathology, causing delays in tissue diagnosis (Table 2).[13,14] Patients are often sent off-island for staging and treatment, but in the FSM, patients with a less than 50% five-year survival are not referred due to severe financial limitations.[15]

Due to limited health information systems, difficulty obtaining reports from off-island medical treatment referrals, and incomplete reporting of cause of death certifications, there is a paucity of cancer mortality data.[16-19] To address these issues systematically, all jurisdictions participate in the Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR) as the Pacific Regional Central Cancer Registry (PRCCR). The University of Hawai'i, John A. Burns School of Medicine's Department of Family Medicine and Community Health (UH) is the bona fide agent for the PRCCR, providing salary and training support for registry personnel in each jurisdiction and for the regional cancer registrar.

Like other US cancer registries, the USAPI cancer registries obtain mortality information from medical records, off-island referrals, insurance offices, and in some jurisdictions, death certificates from local vital statistics offices. All cancer registries compare their database with local vital statistics records and update vital status in the cancer registry. However, not all jurisdictions require death certifications. For those that do, many death certificates are improperly or not coded, or there are significant delays in receiving the coded death certificates to vital statistics offices.[20] Despite lacking the cause of death codes from death certificates, in most jurisdictions, the cancer registry contains sufficient text information recorded directly from medical records to determine if cancer was an attributable cause of death.[21] In order to identify high-need health

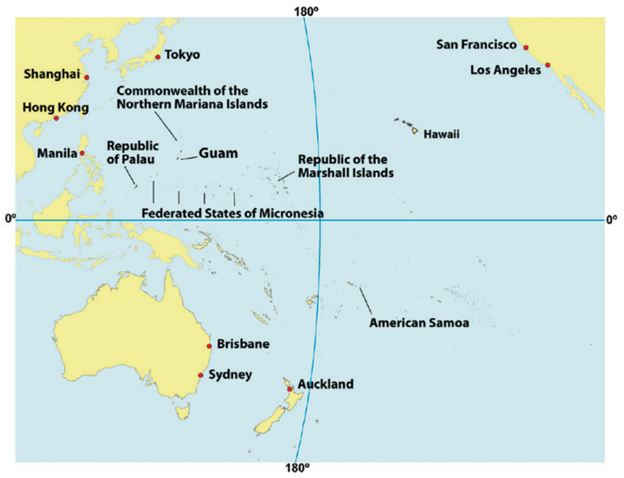

Figure 1. Map of the US-Affiliated Pacific Island Jurisdictions

Table 1. US-Affiliated Pacific Islands Demographics and Selected Indicators

	American Samoa	Commonwealth of the Northern Mariana Islands	Guam	Federated States of Micronesia	Palau	Republic of the Marshall Islands	United States
Population (midyear estimates, 2014)[a,b]	53,426	53,021	165,864	105,681	21,186	70,983	318,857,056
Number of Islands[c]	7	14 (most residents live on 3 islands)	1	4 major island groups; 607 islands total	340 (9 inhabited)	1,225 remote islands (29 atolls and 5 major islands)	—
Land surface area (sq. km)	199	464	544	702	459	181	9,826,675
Political status with US	Territory	Commonwealth	Territory	Freely Associated	Freely Associated	Freely Associated	—
Median age (years)[d]	25.5	33.6	29.0	25.1	33.4	22.9	38.1
Birth rate (births/1,000 population, 2017 est.)[d]	19.6	15.0	19.7	20.0	11.3	24.4	12.5
Death rate (deaths/1,000 population)[d]	5.9	4.8	6.0	4.2	8.1	4.2	8.2
Life expectancy (years)[d]	73.4	75.4	76.0	73.1	73.4	73.4	80.0
Health expenditures per capita (US$)[e,f,g,h,i]	$500	$723	$1,032	$447	$1,310	$651	$10,348
Hospitals	1	1	2	5	1	2	5,534[j]

[a] US Census Bureau, International Programs, International Data Base [internet], Revised:December 22, 2017; [cited 2018 April 2]. Available from: https://www.census.gov/data-tools/demo/idb/informationGateway.php.

[b] US Census Bureau, Population Division, Annual Estimates of the Resident Population for Selected Age Groups by Sex for the United States, States, Counties, and Puerto Rico Commonwealth and Municipios: April 1, 2010 to July 1, 2014 [internet], Released: June 2015; [cited 2018 April 2]. Available from: https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk.

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[d] Central Intelligence Agency. The World Factbook. Washington, DC: Central Intelligence Agency, 2012; [cited 2018 April 3]. Available at: https://www.cia.gov/library/publications/the-world-factbook/.

[e] World Health Statistics 2015 (Federated States of Micronesia, Palau (unadjusted), and the Marshall Islands)

[f] World Health Organization Country Profiles, 2011 (American Samoa, Guam, health expenditures in year 2000)

[g] For CNMI 39 million 2009 FY budget/53,883 population in 2010 (unadjusted)

[h] Centers for Medicare & Medicaid Services. [internet], 2016; [cited 2018 June 1]. Available from: https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/NationalHealthAccountsHistorical.html.

[i] Includes all vaccines, public health and medical.

[j] American Hospital Association (AHA) [internet], 2018; [cited 2018 April 3], Available from: https://www.aha.org/statistics/fast-facts-us-hospitals. Registered hospitals are those hospitals that meet AHA's criteria for registration as a hospital facility. Registered hospitals include AHA member hospitals as well as nonmember hospitals.

Table 2. US-Affiliated Pacific Islands Cancer Screening, Diagnosis, and Treatment Availability[a,b]

	American Samoa	Commonwealth of the Northern Mariana Islands	Guam	Federated States of Micronesia	Palau	Republic of the Marshall Islands	Number of territories/ freely associated states where available	Percent of territories/ freely associated states where available (%)	United States
Cancer screening or diagnosis									
Mammography	X	X	X		X	X	5	83	X
Ultrasound	X	X	X	X	X	X	6	100	X
Cervical screening	X	X	X	X	X	X	6	100	X
Cytology specimens collected (smear/ liquid-based)	X	X	X	X	X	X	6	100	X
On-island processing of cytology	X						1	17	X
Human papillomavirus DNA co-testing	X	X					2	33	X
Visual inspection with acetic acid				X		X	2	33	
Colonoscopy	X	X	X	X (Pohnpei only)		X	4	67	X
Fecal occult blood test	X	X	X	X (Yap only)	X	X	6	100	X
National Breast and Cervical Cancer Early Detection Program	X	X	X		X		4	67	X
On-island cancer diagnosis and treatment									
Pathologist	X		X				2	33	X
Histopathology	X		X				2	33	X
Oncologist			X				1	17	X
Obstetrician-Gynecologist	X	X	X	X	X	X	6	100	X
Radiologist	X	X	X				3	50	X
General surgeon	X	X	X	X	X	X	6	100	X
Dental	X	X	X	X	X	X	6	100	X
Chemotherapy		X[c]	X	X (Pohnpei only)			3	50	X
Radiation therapy			X				1	17	X
Palliative care	X	X	X	X	X	X	6	100	X
Off-island treatment when on-island treatment or diagnosis unavailable									
Off-island treatment restricted based on expected cost of treatment	X	X	X	X	X	X	6	100	N/A
Referred to Hawai'i	X	X	X	X			4	67	N/A
Referred to New Zealand	X						1	17	N/A
Referred to Philippines		X	X	X	X	X	5	83	N/A

[a] Pacific Regional Central Cancer Registry Cancer Council of the Pacific Islands. Cancer in the US Affiliated Pacific Islands 2007–2012 [Internet]. May 2015 [cited 2018 April 2]. Available from: http://www.pacificcancer.org/site-media/docpdfonwebpage/2015/PIJ%20Cancer%20Facts&%20Figures%202007-2012%20060115.pdf.

[b] X = available screening, diagnosis, or treatment. In many cases, these are only available at the main island hospital and not available on other islands.

[c] Maintenance chemotherapy only

system strengthening efforts to reduce the burden of cancer, UH requested CDC's assistance in determining USAPI cancer mortality statistics.

Methods

The individual USAPI jurisdictions collect incident cancer data starting with the cancer diagnosis date of January 1, 2007. After abstracting information from multiple data sources, the registrars send the completed abstracts to the PRCCR registrar for quality control and preparation for data submission to CDC. UH staff performs detailed analyses and provides technical assistance. Per the CDC NPCR standards, cases are classified by anatomic site and cell type using the *International Classification of Diseases for Oncology, 3rd Edition.*[22] Based on a data quality evaluation re-abstracting audit done by the CDC NPCR, the 2013 registry data were 96% concordant. The protocol was reviewed by human subjects' research advisors at the CDC and was deemed to be public health practice, not research. As such, IRB review was not required.

During the study period of January 1, 2008–December 31, 2013, all 3,118 cases reported a vital status (alive/deceased). All cases reported as deceased during the study period were included in the analysis. Two study clinicians (EAV, oncologist and LB, family medicine) and a fourth-year medical student (DN) conducted a review of cases using available information in the database's text fields (text from clinical progress notes, pathology reports, imaging results, and discharge and death summaries). Cases were coded for cause of death using the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) version[23] and also coded with Surveillance, Epidemiology, and End Results (SEER) cause-specific death classification (of death attributable to cancer diagnosis). Date of cancer diagnosis was previously coded by the registrar. Date of death was obtained from the date on the death certificate or death summary; if not available, the last clinical date entered in the cancer registry was used for the data of death. Coding disagreements were resolved by a review by the second clinician.

Incidence-based mortality (IBM) rates were obtained by dividing the number of deaths among incident cases (primary site diagnosis code) by the population. IBM rates were calculated by primary cancer site.[24] Only cases that were malignant and had cause-specific death classification of death attributable to cancer diagnosis were included in IBM rates. Cases in which cause of death was unknown or not cancer-related were excluded. IBM rates were chosen due to the limited mortality information and the availability of incident data. As IBM is likely underestimated in the early years of registry operations, deaths in 2007 were excluded. IBM rates were calculated using year of death 2008–2013; rates were adjusted to the 2000 US standard population. The analysis was performed using Microsoft Excel and software from the National Cancer Institute's SEER cancer registry program: SEER*Prep and SEER*Stat. SEER registry data (year of death 2008–2013) for Asian/Pacific Islanders in Hawai'i (malignant, cause-specific death classification of death attributable to cancer diagnosis) are presented for contrast.

All-cause one-year case fatality ratios were the proportion of people diagnosed with cancer with vital status of deceased within 365 days from the date of diagnosis (January 1, 2008–December 31, 2013, including all deaths even if cancer was not the attributable cause of death). All-cause one-year case fatality ratios were used to determine condition severity when the cause of death information was not available in the text fields. All other cancer-related outcomes were among persons who died of cancer. Cancer-related case fatality ratios were the proportion of people diagnosed with cancer during the study period who had vital status deceased and cause-specific death classification of death attributable to cancer diagnosis. Also analyzed were other cancer and care usage outcomes among those who were diagnosed during the study period and died of cancer: (1) median time from diagnosis to death (days), (2) median age of death (years), (3) access to palliative care (%), and (4) documented off-island treatment. Documented off-island treatment was based on cancer registry information that indicated cancer treatment took place outside the island jurisdiction.

Results

During the six-year period of 2008–2013, 1,323 out of 3,118 people (42.4%) diagnosed with cancer in the USAPI died. Of the 1,323 deaths, 79.3% (n = 1,045) of deaths were cancer-related. Total cancer IBM rates among males were highest in Palau (151.5 per 100,000), RMI (142.0), and Guam (133.2, Table 3). Rates were lower in American Samoa (21.7), CNMI (22.7), and FSM (28.9). For comparison, the IBM rate of cancer among Asian/Pacific Islanders in Hawai'i was 136.9. Lung cancer and liver cancer were among the most common causes of mortality among men in the USAPI. IBM rates for liver cancer among men were 28.0 in Palau, 24.5 in the RMI, and 20.7 in Guam; among Asian/Pacific Islanders in Hawai'i IBM rates of liver cancer was less than half that (9.9). IBM rates for lung cancer among men were 50.0 in Guam, 35.6 in Palau, and 35.0 in RMI; the rate was 37.3 among Asian/Pacific Islanders in Hawai'i. Prostate cancer was the third most common cause of death in half of the jurisdictions (RMI, Palau, and American Samoa); in Palau the rate was 26.9 compared to the rate of 9.7 among Asian/Pacific Islanders in Hawai'i. IBM rates for cancer of the oral cavity and pharynx among men were 16.8 in Palau, 9.3 in RMI, 5.0 in FSM, and 4.6 in Guam; among Asian/Pacific Islanders in Hawai'i, the IBM rate was 4.3.

Total cancer IBM rates among women were highest in RMI (120.3 per 100,000), Palau (107.7), and Guam (72.2). Rates were lower in CNMI (19.0), FSM (23.2), and American Samoa (42.8). The IBM rate of total cancer among female Asian/Pacific Islanders in Hawai'i was 88.6. The most common cause of mortality varied among women by jurisdiction and included

Table 3. Cancer Age-adjusted Incidence Based-mortality (IBM) by Site and Sex — US-Affiliated Pacific Islands, 2008–2013[a,b]

	American Samoa		Guam		Commonwealth of the Northern Mariana Islands		Federated States of Micronesia		Marshall Islands		Palau		Hawai'i Asian/Pacific Islander[c]	
	Rank	Rate	Rank	Rate	Rank	Rate	Rank	Rate	Rank	Rate	Rank	Rate	Rank	Rate
Males														
Total		21.7 (11.9–35.6)		133.2 (119.2–148.3)		22.7 (9.7–42.4)		28.9 (20.4–39.7)		142.0 (101.5–191)		151.5 (108.7–203.4)		136.9 (132.7–141.2)
Colon & rectum	4	2.4 (0.5–7.8)	3	12.3 (8.2–17.5)		0[d]	4	3.6 (0.6–10.1)	5	2.7 (0.5–11.9)	6	11.4 (1.7–32.7)	2	15.8 (14.4–17.3)
Esophagus		0[d]	8	3.4 (1.4–6.5)		0[d]		0[d]		0[d]	8	5.8 (1.1–17.9)	9	3.7 (3–4.4)
Leukemia	7	0.7 (0.1–5.0)	9	1.7 (0.5–3.9)	3	2.1 (0.1–10.0)	6	1.0 (0.1–4.1)	8	1.0 (0–10.1)	7	6.1 (1.2–18.4)	8	4.9 (4.1–5.7)
Liver	5	2.0 (0.2–7.6)	2	20.7 (15.9–26.5)	1	5.7 (0.3–20.8)	2	5.1 (2–10.4)	2	24.5 (8.5–50.8)	2	28.0 (13–51.1)	4	9.9 (8.8–11.1)
Lung & bronchus	1	4.4 (1.1–11.4)	1	50.0 (41.3–59.6)	2	4.8 (1.7–11.8)	1	6.0 (2.8–11.4)	1	35.0 (17.1–61.5)	1	35.6 (17.9–61.7)	1	37.3 (35.2–39.6)
Oral cavity & pharynx		0[d]	6	4.6 (2.5–7.5)		0[d]	3	5.0 (2–10.2)	4	9.3 (4.4–19.8)	4	16.8 (4.6–39.4)	7	4.3 (3.6–5.1)
Pancreas	6	1.2 (0–6.4)	5	5.6 (3.1–9.2)	5	0.7 (0–6.4)	8	0.5 (0–3.4)	6	1.5 (0.2–10.5)		0[d]	3	11 (9.8–12.2)
Prostate	3	3.7 (0.1–14.8)	4	8.5 (5.2–13.0)		0[d]	6	1.0 (0.1–4.2)	3	9.4 (1.6–26.8)	3	26.9 (8.8–57.3)	5	9.7 (8.6–10.8)
Stomach	2	4.1 (0.7–11.6)	7	4.5 (2.2–7.9)	4	1.0 (0.1–6.5)	5	1.4 (0.3–4.6)	7	1.1 (0–10.3)	5	11.6 (2.1–31.7)	6	7.8 (6.8–8.8)
Thyroid		0[d]	10	1.2 (0.1–3.7)		0[d]		0[d]		0[d]	9	2.6 (0.1–13.7)	10	0.6 (0.3–0.9)
Females														
Total		42.8 (28.1–61.4)		72.2 (62.7–82.7)		19.0 (7.4–37.5)		23.2 (15.7–32.7)		120.3 (87.2–160.2)		107.7 (77.5–145.0)		88.6 (85.6–91.7)
Breast	1	11.2 (5.3–20.3)	2	7.6 (4.8–11.3)	4	0.6 (0–6.0)	1	4.1 (1.6–8.6)	3	12.9 (5.9–24.9)	7	5.8 (0.6–19.3)	2	10.8 (9.7–11.9)
Cervix	5	4.2 (0.6–12.6)	9	1.9 (0.8–3.7)		0[d]	3	3.2 (1.3–6.8)	1	34.0 (18.4–56)	3	11.7 (4.7–24.8)	10	1.7 (1.2–2.2)
Colon & Rectum		0[d]	3	5.2 (2.9–8.5)		0[d]	6	1.9 (0.2–6.1)		0[d]	9	4.7 (0.5–16.6)	3	9.8 (8.9–10.9)
Esophagus		0[d]	13	0.3 (0–1.5)		0[d]		0[d]		0[d]	10	3.1 (0.1–14.6)	13	0.3 (0.2–0.6)
Leukemia	7	0.3 (0–4.0)	9	1.9 (0.7–4.0)		0[d]	7	0.5 (0–2.8)	10	3.9 (1.3–11.7)	12	2.0 (0.1–11.3)	8	3.1 (2.6–3.8)
Liver		0[d]	5	3.9 (1.9–6.8)		0[d]	5	2.2 (0.3–6.6)	4	6.9 (2–17.6)	2	15.2 (5.6–31.9)	8	3.1 (2.6–3.7)

Table 3. Cancer Age-adjusted Incidence Based-mortality (IBM) by Site and Sex — US-Affiliated Pacific Islands, 2008–2013[a,b] (Continued)

Lung & bronchus		0[d]	1	22.5 (17.2–28.7)		0[d]	3	3.2 (0.8–8.1)	2	23 (7.7–48.2)	1	19.4 (7.8–38.6)	1	19.8 (18.4–21.3)
Oral cavity & pharynx	6	2.7 (0.1–10.9)	9	1.9 (0.6–4.2)	3	3.2 (0.5–10.7)	7	0.5 (0–2.9)	7	5.0 (0.2–19.2)	8	5.2 (1.0–15.8)	11	1.2 (0.9–1.6)
Ovary	4	4.7 (0.8–13.0)	8	2.7 (1.2–5.2)		0[d]	7	0.5 (0–2.8)	7	5.0 (1.7–13.4)	5	7.3 (1.3–21.2)	6	3.7 (3.1–4.4)
Pancreas		0[d]	7	3.2 (1.5–5.8)		0[d]	7	0.5 (0–2.9)	5	6.8 (0.4–24.1)	6	6.3 (0.7–20.4)	4	8.1 (7.3–9.1)
Stomach	3	4.9 (1.2–12.4)	4	4.0 (1.9–7.1)	1	8.9 (1.1–26.0)	7	0.5 (0–2.9)	6	5.6 (0.4–19.8)	12	2.0 (0.1–11.3)	7	3.4 (2.9–4.1)
Thyroid	8	0.9 (0–5.3)	12	1.0 (0.2–2.8)		0[d]		0[d]	9	4.5 (0.1–18.8)	10	3.1 (0.1–14.6)	12	0.7 (0.5–1)
Uterus	2	8.8 (2.9–19.0)	6	3.4 (1.7–5.8)	2	4.8 (0.7–14.5)	2	3.6 (0.9–8.8)	11	3.5 (0.7–12.1)	4	8.9 (1.7–24.4)	5	4.8 (4.1–5.5)

[a] Data from Pacific Regional Central Cancer Registry Cancer Council of the Pacific Islands, based on vital status deceased was reported with a cause-specific death classification attributable to cancer diagnosis, year of death January 1, 2008–December 30, 2013. IBM rates are per 100,000 persons and age-adjusted to 2000 US Standard population.

[b] Based on chart review using available clinical information from clinical notes, death summaries, pathology notes, and imaging results in cancer registry, cases were coded with cause of death using the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) 2016 version. World Health Organization. International Classification of Diseases for Oncology, Third Edition, First Revision. [Internet]. Geneva: World Health Organization, 2013 [cited 2018 April 2]. Available from: http://codes.iarc.fr/.

[c] Surveillance, Epidemiology, and End Results (SEER) registry data (2000–2015), with a cause-specific death classification attributable to cancer diagnosis, among Asian or Pacific Islander, diagnosed in Hawai'i 2008–2013.

[d] Rate was not calculated as case count was zero.

breast, cervical, lung, and stomach cancer. IBM rates for cervical cancer among women were 34.0 in RMI and 11.7 in Palau; the IBM rate of cervical cancer among Asian/Pacific Islanders in Hawai‘i (1.7) was 20 times lower than in RMI. IBM rates for liver cancer among women were 15.2 in Palau and 6.9 in RMI; the IBM rate of liver cancer among Asian/Pacific Islanders in Hawai‘i (3.1) was less than half of the rates in Palau and RMI. Stomach cancer IBM rates were 8.9 in CNMI, 5.6 in RMI, and 4.9 in American Samoa; among Asian/Pacific Islanders in Hawai‘i the rate was 3.4. Oral cavity and pharynx cancer were approximately four times higher in Palau (5.2) and RMI (5.0) than among Hawai‘i Asian/Pacific Islanders (1.2).

In the Freely Associated States (FSM, RMI, and Palau), 58%–67% of those diagnosed with cancer died within a year of diagnosis, compared to 27%–28% in the Flag Territories (Table 4). In the Freely Associated States, 24%–64% of those diagnosed with cancer died of cancer, compared to 20%–31% in the Flag Territories. In the Freely Associated States, the median time from cancer diagnosis to death was 8–28 days; in the Flag Territories, the median time was 102–128 days. Among Asian/Pacific Islanders in Hawai‘i, the median time from diagnosis to death was 270 days, over 8 months greater than in the Freely Associated States. The median age of death was 54–62 years in the Freely Associated States and 58–64 years in the Flag Territories. Palliative care was documented in the cancer registry in 9%–16% of cases. Off-island treatment was reported in 27%–48% among persons who were unable to initiate chemotherapy or radiation therapy on-island; in Guam, where most cancer treatment modalities are available, only 10% were referred off-island for treatment.

Discussion

This is the first cancer mortality study done across USAPI jurisdictions. This study found that IBM rates in USAPI jurisdictions were higher than rates among Asian/Pacific Islanders in Hawai‘i for many cancers that could be prevented through vaccination, smoking cessation, overweight and obesity prevention, and cancer screening. Resource-limited or geographically dispersed populations throughout the South Pacific also face similar high mortality in cervical and liver cancers where vaccination and/or screening are routinely recommended.[25-30]

Cancer outcome data can be used to inform outreach, vaccination programs (human papillomavirus and hepatitis B), and education to clinical providers. Implementing recommended clinical preventive services for prevention and early detection may improve cancer outcomes. USAPI jurisdictions have breast cancer screening by mammography in five of six jurisdictions and cervical cancer screening by cytology in all jurisdictions (Table 2). Limited mammography is available only on the main islands. In all jurisdictions, cytology tests may only be performed in central locations on the main island and are not available at rural sites, especially in the outer islands. In addition, cytology

Table 4. Cancer-related Outcomes Among Persons Who Died of Cancer[a] — US-Affiliated Pacific Islands, 2008–2013

	All-cause case fatality within 1-year[b] (%)	Cancer-related case fatality[c] (%)	Median time diagnosis to death[d] (days)	Median age of death (years)	Access to palliative care[e] (%)	Documented off-island treatment[e] (%)
Flag Territories						
American Samoa	27	29	110 (0–1,054)	60 (3–82)	10	27
Guam	27	31	128 (0–2,002)	64 (11–97)	16	10
Commonwealth of the Northern Mariana Islands	28	20	102 (0–1,299)	58 (31–84)	13	48
Freely Associated States						
Federated States of Micronesia	67	24	8 (0–844)	54 (4–81)	9	36
Marshall Islands	58	54	28 (0–1,215)	53 (1–100)	13	35
Palau	67	64	18.5 (0–452)	62 (10–90)	14	32
Asian/Pacific Islander, Hawai‘i	—	—	270[f]	—	—	—

[a] Data from Pacific Regional Central Cancer Registry Cancer Council of the Pacific Islands, based on vital status deceased was reported, year of diagnosis January 1, 2008–December 30, 2013. Based on chart review using available clinical information from clinical notes, death summaries, pathology notes, and imaging results in cancer registry, cases were coded with cause of death using the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) 2016 version. World Health Organization. International Classification of Diseases for Oncology, Third Edition, First Revision. [Internet]. Geneva: World Health Organization, 2013 [cited 2018 April 2]. Available from: http://codes.iarc.fr/.

[b] Number of persons diagnosed with cancer that had vital status deceased in cancer registry and date of death ≤365 days from date of diagnosis (even when cancer may not have been the coded cause of death) divided by the incident cases.

[c] Number of persons diagnosed with cancer that had vital status deceased and coded with cause-specific death classification of death attributable to cancer diagnosis divided by the incident cases.

[d] Date of cancer diagnosis based on date recorded in cancer registry, many times based on date of pathology review of cancer tissue. Date of death based on date on death certificate or last clinical date entered in the cancer registry if date of death not recorded.

[e] Based on clinical information included in cancer registry.

[f] Median number of days calculated using Surveillance, Epidemiology, and End Results (SEER) registry data (2000–2015), Kaplan-Meier survival analysis with a cause-specific death classification attributable to cancer diagnosis, among Asian or Pacific Islander, diagnosed in Hawai‘i 2008–2013.

testing is processed off-island in five of six jurisdictions.[21] This can delay diagnosis of pre-cancers and cancers, leading to loss to follow-up and later stage presentation, consistent with IBM rates in the USAPI.[31]

Women in the RMI have eight times the US incidence of invasive cervical cancer (70.0 per 100,000),[16] making this the highest incidence of cervical cancer in the world.[10] Mortality due to cervical cancer is over 20 times higher in RMI than in Hawai‘i among Asian/Pacific Islanders. This may be due to differences in screening access, follow-up, later stage presentation, and inadequate on-island treatment.

In FSM, RMI, and Palau, travel from the outer islands to the only hospital can take several hours to days by small motor boats. In the most remote areas, large government cargo ships travel a few times a year with health teams and supplies and are subject to frequent delays and cancellation. In most jurisdictions, when cancer is a suspected diagnosis, clinicians have only basic x-ray and ultrasound to supplement their clinical skills. Due to the remoteness and limited clinical on-island resources, cancer may be diagnosed at later stages, demonstrated by higher all-cause case fatality ratios and shorter times from diagnosis to death in the Freely Associated States. Women in Pohnpei State, FSM are often diagnosed with late-stage cervical cancer, and the median survival from diagnosis to death for all types of cancer diagnosed in FSM is eight days. Because of the high numbers of cancers diagnosed at late stage and lack of on-island treatment for advanced cancers, all USAPI jurisdictions have also been focused on improving access to palliative care.[32]

Palliative care is an approach that improves the quality of life of patients and their families facing a life-threatening illness through the prevention and relief of suffering by means of early identification and treatment of pain, and supportive services for physical, psychosocial and spiritual problems.[33] Well-integrated palliative care not only reduces unnecessary hospital admissions but improves quality of life in geographically remote places where there are barriers to screening, diagnosis, and curative treatment.[34,35] Palliative care was documented in only 9%–16% of cancer-related deaths. As part of the requirements for CDC's National Comprehensive Cancer Control (CCC) Program, all USAPI jurisdictions have coalitions that have developed objectives to increase access to palliative care for patients with cancer through provider education and expanding some existing home-based care programs.

This study has some limitations. Not all cases were reported from Chuuk State in FSM and American Samoa due to lack of staff capacity. Guam and CNMI are working on backlogged cases that have not yet been reported to the PRCCR. This may be the reason why IBM rates are lower for these jurisdictions. Geographic remoteness and challenges with accurate death registration and certification may have resulted in under-reporting of mortality. Due to limitations on data available in the cancer registry text field or to poor documentation in the original medical record, it was sometimes difficult to determine cancer-related mortality based on the information provided. The proportion of deaths that could not be coded due to limited text field information varied by jurisdiction: 2% in American Samoa, 4% in Guam, 45% in CNMI, 67% in FSM, 8% in RMI, and 7% in Palau. Those diagnosed with cancer during the study period and who died after 2013 (due to longer survival times or diagnosis near the end of the study period) were excluded; this could lead to an underestimation of IBM rates and an underreporting of case fatality. Lastly, since the combined population of USAPI islands is relatively small (450,000 people total, with populations ranging from 7,000–20,000 in some FSM states and in Palau), the sample size for this study was small and made it challenging to calculate detailed stratified estimates for cancer mortality.

A key strength of this study is that the available PRCCR data are accurate and of high quality for the initial diagnostic information. Based on available information from multiple data sources, the cancer registrars are abstracting the information with 96% concordance on re-abstraction by CDC contractors. There are many active partnerships working to ensure all cancers in the jurisdictions are reported. Widespread health system strengthening efforts spearheaded by the Pacific Island Health Officers' Association started in 2015 in the areas of health information systems (medical records) and in civil registration, vital statistics, and death certifications. Over time, these larger efforts will positively influence the quality and quantity of accurate mortality data reported to cancer registries.

Some of the highest IBM rates in the USAPI were for cancers (lung, liver, cervical, oral cavity, and pharynx) where there are opportunities for prevention through a reduction in risk factors or early detection when treatment is more effective. The CCC coalitions in all jurisdictions place public education, outreach, and health provider education among the highest priorities. The CCC coalitions work closely with their local cervical cancer screening teams and other primary care providers, with technical assistance and health provider education done by partners at UH. Four of the six USAPI jurisdictions participate in the CDC's National Breast and Cervical Cancer Early Detection Program and all have limited cervical cancer screening through other US federally funded programs. Even with these programs the financial and human resource capacity are presently inadequate to achieve high cancer screening uptake. A population-wide colorectal cancer screening program does not exist due to lack of financial and staff resources. USAPI focus has been on risk-factor reduction, early detection of cervical and breast cancers, and increasing access to palliative care for the numerous patients diagnosed at late stage. This cancer mortality analysis supports ongoing multi-pronged approaches to prioritize, implement, and evaluate evidence-based interventions that could reduce cancer-related deaths through health promotion, early detection, and adoption of policies aimed at protecting youth from uptake of risk factors. The Affordable Care Act and certain aspects of Medicare and Medicaid are relevant only to those insured in the Flag Territories. With the scheduled cessation of US Compact sector grant funding in 2023 and transition to uncertain income from compact trust funds, the Freely Associated States may need substantial assistance and other sources of income that increase cancer screening capacity in order to decrease premature deaths from cervical, breast and colorectal cancers.[36]

Disclaimer

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Conflict of Interest Disclosure Statement

Dr. Buenconsejo-Lum (University of Hawai'i) received CDC cooperative agreements for the USAPI cancer registry program. Otherwise, all authors declare that this work was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Authors' Affiliations:
- Epidemic Intelligence Service, CDC, Sells, AZ (EAVD)
- Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, CDC, Atlanta, GA (EAVD, MS, AW, VS)
- University of California, San Francisco School of Medicine, San Francisco, CA (DN)
- Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawai‘i, Honolulu, HI (LB-L)

Correspondence to:
- Mona Saraiya MD, MPH; Division of Cancer Prevention and Control, Centers for Disease Control and Prevention, 4770 Buford Hwy NE; Mailstop F-76,
Atlanta, GA 30341; Email: msaraiya@cdc.gov
- Elizabeth A. Van Dyne MD, MPH; Email: Elizabeth.VanDyne@ihs.gov

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Building Capacity for Logic Models and Evaluation Planning Using Canoe-building Concepts

Nicole M. Kuiper MPH; Haley L. Cash PhD, MPH; MaryBeth T. Welton BS; and Celeste Chung MSW, MPH

Abstract

Non-communicable diseases (NCDs) are the leading causes of death in the United States Affiliated Pacific Islands (USAPIs); US Centers for Disease Control and Prevention funds programs for prevention and control of diabetes, tobacco use, and related chronic disease conditions. To build USAPI programs' capacity in evaluation and surveillance, we held in-person and virtual trainings on evaluation planning and logic models that were tailored with traditional canoe-building themes to be relatable and memorable. Evaluation results suggest the efforts were effective at translating concepts. Additional tools and technical assistance reinforced concepts and resulted in quality evaluation plans. Culturally tailored evaluation tools can be useful and should be developed with population representatives.

Issue

The United States Affiliated Pacific Islands (USAPIs) consist of six island jurisdictions: American Samoa, Commonwealth of the Northern Mariana Islands, Federated States of Micronesia, Guam, Republic of the Marshall Islands, and Republic of Palau. These 6 jurisdictions are part of a myriad of more than 2,100 coral atolls and volcanic islands spread out over millions of square miles of ocean and crossing 5 time zones, and with varying governing structures.[1] The USAPIs have some of the highest burden of obesity and diabetes in the world, with prevalence of obesity and diabetes as high as 93% and 47% respectively in some island jurisdictions.[2] Average adult smoking prevalence is also high.[1,2] In 2010, the Pacific Island Health Officers Association Board declared a state of emergency for a non-communicable disease epidemic.[3]

The US Centers for Disease Control and Prevention (CDC) funds a cooperative agreement to support prevention and control of diabetes, tobacco use, and related modifiable chronic disease risk factors in Pacific and Caribbean jurisdictions.[1] Public health efforts in diabetes and tobacco prevention and control are critical to promoting overarching national goals to (1) increase the length and quality of life, and (2) eliminate health disparities by addressing social determinants of health.[4]

Similar to the gap in surveillance data and epidemiological capacity,[5] USAPI programs have indicated needing program evaluation training, according to CDC program consultants. In past cooperative agreements, evaluation efforts generally entailed monitoring activities such as submitting meeting agendas and minutes, counting numbers of attendees at coalition meetings, trainings held, or health materials distributed, instead of more robust process and outcome evaluation. Logic models were introduced but not successfully linked to outcome evaluation. Minimal access to advanced evaluation training and infrastructure barriers that result in difficulties accessing Internet- or technology-based training have made the need for learning basic evaluation concepts more salient. Moreover, culturally tailored resources for USAPIs can build capacity to conduct important programmatic functions in chronic disease prevention programs.[6]

Description

The purpose was to develop culturally relevant brief training/tools on logic models and evaluation planning for a week-long kick-off meeting in Honolulu, Hawai‘i in May 2015. This meeting brought together program representatives from all USAPIs, Puerto Rico, US Virgin Islands, regional partners, and CDC staff, and integrated CDC and grantee presentations with training sessions. Program evaluation was one training topic among a wealth of content, and our evaluation of this session shaped evaluation technical assistance efforts after the kick-off meeting.

CDC's Framework for Evaluation in Public Health emphasizes logic models in evaluation planning.[7] Logic models are visual depictions that summarize relationships among program inputs, activities and outcomes; this clarity can help with both strategic planning and program evaluation. Training objectives were to:

- Demonstrate the utility of developing logic models with a stakeholder group as part of program planning;
- Provide in-person technical assistance on logic models, with input from CDC staff;
- Describe steps of evaluation planning and components of a written plan; and
- Provide culturally relevant tools to assist in developing an evaluation plan that aligns with the CDC Evaluation Framework.

Methods

Development of Canoe-building Concepts for Logic Models and Evaluation Planning

Monitoring and Evaluation Subcommittee members (representing 2 funded programs, 6 representatives from 4 CDC programs, and the regional epidemiologist funded by CDC) planning the evaluation content of the meeting discussed the importance of beginning with fundamental concepts of evaluation planning and logic models. Iconic events (eg, wedding planning) are often used to illustrate the linkages between inputs, activities, and outcomes in US introductory logic model trainings. Island representatives planning the meeting suggested that such concepts would not resonate with USAPI populations; the Regional Epidemiologist (HLC) suggested a canoe building metaphor because of perceived past success in a Palau workshop conducted by a sister federal agency (ie, Substance Abuse and Mental Health Services Agency).

A search for canoe building or other culturally specific metaphors in the Pacific found little in peer reviewed literature.[8] To develop these concepts, the lead trainer (NMK) studied the historical culture and importance of canoe building to Pacific island cultures.[9,10] The goal was to weave concepts throughout both presentations and tools. The lead trainer drafted a logic model and shared it with Evaluation Subcommittee members, revising based on feedback (See Figure 1).

Training Delivery

The first half hour-long training session on Day 4 discussed the utility of logic models as program development and evaluation tools. The presentation compared canoe design (eg, hull type, sail, and outrigger) to a public health program, in that design varies based on what one hopes to accomplish (eg, voyaging, fishing, or warring). We used a scenario of the community being funded for one canoe, and participants had to decide on a design and then evaluate the canoe building "program." Discussing critical factors in traditional canoe building, the presenter asked for input for each logic model element before displaying that portion of the logic model. For example, inputs were described as the human, natural, financial, and relationship/partner resources. Participants described examples of each element prior to being shown the examples the presenter had developed. At the end, the full logic model was displayed and we discussed the utility of the example and how these concepts could be used with stakeholders to develop or adapt their own program logic models. Following the session, a 45 minute breakout session was held so participants could work on their program plan or their logic model, with CDC staff available for input.

The second hour-long training on evaluation planning on Day 4 incorporated canoe building concepts into the six step-CDC Evaluation Framework, which are; engaging stakeholders; describing the program; focusing the evaluation design; gathering credible evidence; justifying conclusions; and disseminating and sharing lessons learned.[7] For the 1.5 hour breakout session following the presentation, we disseminated a planning sketchpad from *Developing an Effective Evaluation Plan*, (which provides information and tools for evaluation planning using the CDC framework), the descriptions of which were tailored using canoe-building concepts (Please contact the authors for a copy of the Evaluation Sketchpad at nik4@cdc.gov).[11] For instance, example stakeholders were elders, fishermen, gatherers, builders, travelers and funders. Groups discussed how their interest in or use of evaluation findings may vary. Participants were sent home with these presentation and sketchpad resources so they could refer back to them and use them in planning exercises if they wished.

Several months after in-person training, brief virtual training sessions during quarterly group calls reinforced basic evaluation concepts and requirements of the cooperative agreement. The team developed and disseminated an evaluation plan template, including example process and outcome evaluation questions relevant to their work (rather than the illustrative canoe-building concepts). Evaluation plans developed by the programs were reviewed for as many iterations as necessary to ensure a high quality, feasible plan; this process ranged from 2 months to about 8 months. Plans were reviewed by two evaluators to standardize guidance.

Evaluation of the In-person Trainings

All in-person training sessions were evaluated using paper forms and using five-point Likert scale items to assess whether objectives were met; presenter knowledge; helpfulness and utility of material covered. Open-ended questions asked about improvements for training and opinions on the best part of each session. Results were entered into Survey Monkey by the evaluation team for ease of analysis. Descriptive statistics (percentages) and arithmetic means of responses on Likert-type scales (out of 5) were used to summarize quantitative data. Qualitative responses were recorded verbatim, though corrected for obvious grammatical or spelling errors. Response rates were around 50%, though an exact rate cannot be calculated because participants were free to come and go during the sessions and exact numbers of attendees for each were not counted.

Results

There were 47 awardees from all 6 funded USAPI programs in attendance at the May 2015 training. Evaluation results of the logic model training and breakout are shown in Table 1. The session was highly rated with 96% of respondents agreeing that the material would be useful in their work. Qualitative findings suggest respondents appreciated the canoe-based example. There were no suggestions for improvement, and 6 of 8 respondents expressed the best part of the session was the canoe, island-based example logic model.

Evaluation results of the evaluation planning training and breakout are shown in Table 2. The session was highly rated, with 90% of respondents agreeing that materials would be useful in their work. Qualitative findings suggest the discussion and planning tools (ie, sketchpad with canoe based tips) facilitated learning and were easy to understand and use. Suggestions for improvement primarily related to breakout facilitation. Anecdotally, comments during the breakouts included, "Now I finally understand what an evaluation question is," and "I can see how involving different stakeholders can change what the evaluation will focus on."

All jurisdictions had representation on the webinar training on evaluation planning held several months following the in-person training that reinforced these concepts and explained the evaluation plan template and requirements. Evaluation plans were received from all jurisdictions, 6 of 8 using the provided template, while 2 used their own structure but still included all the required elements from the template. After providing systematic feedback to suggest improvements to the structure and content of plans, including specific evaluation questions, revised plans were submitted that demonstrated increased understanding of evaluation concepts. All plans now include process and outcome evaluation rather than surface level process evaluation counting outputs.

Conclusions

Building capacity in evaluation planning can benefit from training tools integrating concepts that resonate or "stick," which include being simple, unexpected, and using concrete images.[12] Building on local culture and existing knowledge can facilitate understanding and using culturally appropriate frameworks makes concepts more "sticky." While indigenous knowledge is not always meant to be accessible to all,[8] using metaphors that resonate with communities to teach new and interrelated concepts can be very useful.[13] Though our response rate is unknown, those USAPI participants that completed the evaluation forms for the sessions expressed gratitude for tools they could relate to, and that helped them understand logic models and evaluation questions. These efforts were a good starting point to engage awardees without formal evaluation training. More training, tools, evaluation planning templates, and technical assistance were needed to reinforce these concepts, which resulted in submission of evaluation plans that covered all steps of the CDC evaluation framework.[7] Good quality plans and implementation of those plans, aided by continual technical assistance and good surveillance will help improve the programs working to prevent and control high rates of chronic diseases in USAPIs.[5,14] So while it's unknown whether the culturally tailored tools, the intensive technical assistance, or the combination was most useful, lessons can be learned from the experience of tailoring the tools.

Lessons Learned

Particularly as outsiders to the USAPI culture, it was important for the trainers to get feedback early and often with tools and models, from both those working with these populations and USAPI representatives. It was important not to appropriate indigenous cultural knowledge, but rather, learn and adapt tools in ways that reflected it.[15] To some, that line may be too fine; in fact, there was one individual (who was an expert canoe builder from a Pacific Island jurisdiction) who, when told canoe-building concepts would be discussed in the training, expressed disfavor because this person thought we would be trying to teach them about their culture. However, during informal discussions, representatives of various islands who were aware of the content reassured the trainers that the tools would be helpful to the attendees. Additionally, during the presentation, the trainer stressed that historical traditions were used to develop relatable concepts, and the metaphor may not necessarily be applicable in their present day setting. It may also be important to recognize the gendered aspects of canoe-building, and that in some Pacific cultures, genders may even have different metaphorical uses of canoes.[16] Moreover while males were the primary canoe builders, women were involved in building the sails and supporting communities during voyages.[10] Overall, according to evaluation qualitative responses, participants appreciated the efforts put forth to tailor concepts to Pacific culture, and found the material highly useful and relevant (Tables 1 and 2).

Another lesson learned when developing tools based on cultural traditions is to not leave out important cultural components. For example, during the training, participants informed the trainer that the ceremonial canoe blessing was missing. Though that part of the process come up when studying canoe-building traditions, it had not been deemed relevant for our logic model. Future efforts to engage communities in culturally appropriate models as training tools should include all cultural aspects, regardless of perceived relevance to trainers. Actively engaging with a variety of stakeholders during development can ensure the appropriateness of these elements.

Conflict of Interest

None of the authors identify a conflict of interest.

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Authors' Affiliations:
- Office on Smoking and Health, Centers for Disease Control and Prevention, Atlanta, GA (NMK)
- Pacific Island Health Officers Association, Honolulu, HI (HLC)
- Centers for Disease Control and Prevention, Atlanta, GA (MTW, CC)

Correspondence to:
Nicole M. Kuiper MPH; Office on Smoking and Health, Centers for Disease Control and Prevention, 4770 Buford Highway, MS F79, Atlanta, GA 30341;
Email: NKuiper@cdc.gov

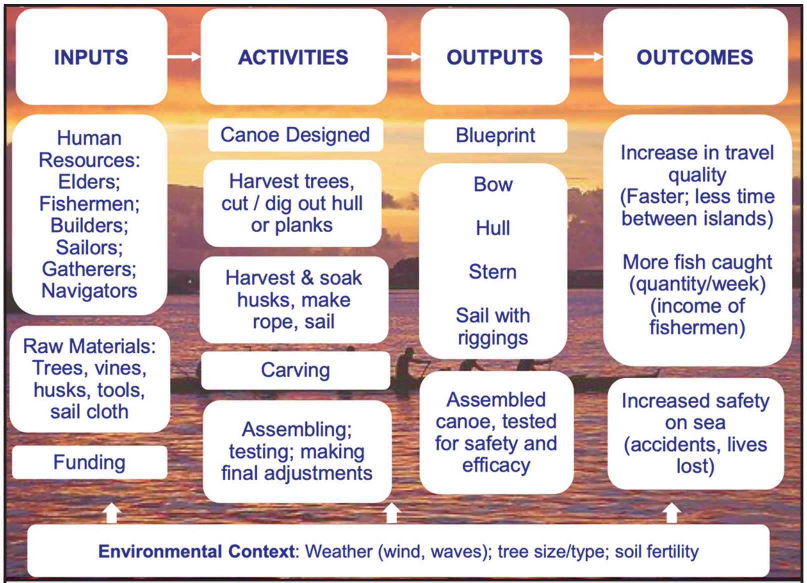

Figure 1. Final Draft of the Canoe Logic Model Used in the Training

Table 1. Quantitative Ratings and Qualitative Responses of the Session, "What is a Logic Model and How is it Related to Your Program Plan?"

Quantitative Ratings

Description	Strongly Disagree % (n)	Disagree % (n)	Undecided % (n)	Agree % (n)	Strongly Agree % (n)	Total N	Average (out of 5)
The objective for this session was met.	0% (0)	0% (0)	0% (0)	38% (10)	62% (16)	26	4.6
Session content was organized and easy to follow.	0% (0)	0% (0)	0% (0)	35% (9)	65% (17)	26	4.7
The presenters were knowledgeable about the topic.	0% (0)	0% (0)	0% (0)	35% (9)	65% (17)	26	4.7
The time allotted for the session was sufficient, including time for questions.	0% (0)	0% (0)	4% (1)	40% (10)	56% (14)	25	4.5
The breakout session was helpful in providing an opportunity to apply principles and reinforce ideas.	0% (0)	0% (0)	0% (0)	38% (9)	63% (15)	24	4.6
Material covered in this session will be useful in my work.	0% (0)	0% (0)	4% (1)	40% (10)	56% (14)	25	4.5

Qualitative Responses

Question: What aspects of the session could be improved? Please include comments on material not covered that you hoped would be, if applicable.

Responses: n=5

- All responses were themed "Not applicable" or "none"

Question: What did you find to be most valuable in this session?

Verbatim Responses: n=8

- Thank you Nicole for your "Island" example
- Well-presented canoe example
- Canoe building sample on logic model
- Canoe building model for was helpful for the model
- Presentation was easily understood because of using a simple building a canoe to prepare a logic model. Most of us know the building a canoe process which made it easier for us to connect.
- All are valuable
- Increase and encourage use of logic models and ties objectives to activities
- Most useful

Table 2. Quantitative Ratings and Qualitative Responses of the Session, “Developing an Evaluation Plan: Resources and Tools in Action with Breakout Session”

Quantitative Ratings

Description	Strongly Disagree % (n)	Disagree % (n)	Undecided % (n)	Agree % (n)	Strongly Agree % (n)	Total N	Average (out of 5)
The objective for this session was met.	0% (0)	0% (0)	0% (0)	37% (8)	64% (14)	22	4.6
Session content was organized and easy to follow.	0% (0)	5% (1)	0% (0)	32% (7)	64% (14)	22	4.6
The presenters were knowledgeable about the topic.	0% (0)	5% (1)	0% (0)	23% (5)	73% (16)	22	4.6
The time allotted for the session was sufficient, including time for questions.	0% (0)	10% (2)	5% (1)	38% (8)	48% (10)	21	4.2
The breakout session was helpful in providing an opportunity to apply principles and reinforce ideas.	0% (0)	0% (0)	20% (4)	40% (8)	40% (8)	20	4.2
Material covered in this session will be useful in my work.	0% (0)	0% (0)	10% (2)	33% (7)	57% (12)	21	4.5

Qualitative Responses

Question: What aspects of the session could be improved? Please include comments on material not covered that you hoped would be, if applicable.

Verbatim Responses: n=7 (1 response was “none”)

- Breakout was a bit confusing and the guidance an example from Puerto Rico or Guam
- Smaller room to promote more interaction and needed more time for the breakout
- The presentation was good but the presenter should put more life into it
- We had more than one facilitator spoke at once and with different guides [in the breakout], thus I could not follow and end up confused
- Having work plan in hand would have been helpful
- Work group discussion is more structured and jurisdiction need driven

Question: What did you find to be most valuable in this session?

Verbatim Responses: n=13

- Evaluation content was excellent
- The types of evaluation, what’s in an evaluation plan, and the development of it
- Presentation
- Breakout discussion with work plan document was very helpful
- Materials are very user friendly, easy for us to understand and work with. Breakout facilitator was very helpful and guided us.
- Breakout helped understand the formation of evaluation taskforce/stakeholders of how to fill in the table
- Evaluation discussion
- Excellent walk through evaluation planning tool
- The [canoe] tips on the evaluation template. If only we could have the same facilitator during this breakout session
- Template sheets useful
- The introduction of the evaluation planning tool
- All good excellent sessions

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Hemodialysis in the Compact Nations of the US Affiliated Pacific: History and Health Care Implications

Margaret S. Min BA; Arnold W. Siemsen MD; Emi Chutaro MSc; James E. Musgrave MD; Ramona L. Wong MD; and Neal A. Palafox MD, MPH

Abstract

Background: *The epidemic of non-communicable disease in the Compact nations of the US Affiliated Pacific Islands and the associated renal complications drive the demand for hemodialysis. Limited healthcare budgets and a lack of trained human health resources in these areas make hemodialysis a challenging undertaking that may require significant sacrifices in competing health care priorities.*

Methods: *Two nephrologists who developed hemodialysis in the US Affiliated Pacific Islands provide its history. Cost estimates of hemodialysis for the Compact nations are collected from a 2014 hemodialysis feasibility report. The experiences and outcomes of current hemodialysis centers in the United States and other island nations provide a framework by which to assess the potential benefit and impact of hemodialysis in the Compact nations.*

Discussion: *A consideration of how and why different stakeholders value hemodialysis will be crucial because they will drive the public's response to the institutionalization of any new intervention or the cessation of any existing intervention like hemodialysis.*

Conclusion: *Updated cost estimates for dialysis clinics and data on renal disease rates in the Compact nations will be necessary to make informed decisions about hemodialysis in the current health systems. In the meantime, it is essential to enhance current medical interventions and public health strategies to prevent kidney disease and decrease the risks for kidney failure. Such preventive interventions must be culturally appropriate, effective, cost-efficient, and sustainable in the unique context of the Pacific.*

Introduction

The Story of a Marshallese Dialysis Patient and Dr. Arnold Siemsen's Inspiration (A. Siemsen, personal communication, June 2019)

On April 25, 1972, Dr. Arnold Siemsen received a call from the United States Pacific Trust Territory Liaison Officer that a girl from the Marshall Islands would arrive in 3 hours on Air Micronesia. Dr. Siemsen, as the director of the Hemodialysis Center of St Francis Medical Center in Honolulu, Hawai‘i, admitted her for treatment.

The 13 year old girl, named Amjur, arrived with her family. She was treated for more than 2 years until July 4, 1974, at which point she and her family wished to go back to their island home in the Marshall Islands. Furthermore, the hospital administration at St Francis noted that the payments for Amjur's hemodialysis, to be covered by the Marshallese government, were delayed.

Dr. Siemsen discussed alternatives with Dr. Masao Kumangai, who at the time was the Trust Territory Director of Health Services. After months of correspondence, it was jointly decided that Dr. Siemsen would go to Majuro, the capital of the Marshall Islands, to make recommendations to set up a self-care hemodialysis unit at Majuro Hospital. Upon arrival, Dr. Siemsen drew up a plan, including the placement of electrical outlets, water outlets, and drains, a list of supplies to purchase, and the recruitment of a seasoned Marshallese nurse, Hemiko, who would be trained to administer hemodialysis.

Dr. Siemsen oversaw the training of both Hemiko, the Marshall Islands graduate nurse, and Amjur, the patient. Within months, self-care hemodialysis was started in Majuro. Whenever complications arose, Amjur and other dialysis patients were transferred back to Honolulu for treatment via Air Micronesia. Dr. Siemsen continued to visit the Majuro dialysis unit approximately every 4 months. Over the next decade, Dr. Siemsen and his staff were able to train several more dialysis nurse technicians, Jordan, Christina, and Caleb; 3 dialysis machines were operational and 17 new hemodialysis patients were undergoing treatment in the Marshall Islands.

The Marshall Islands dialysis clinic, although technically robust with trained staff, struggled to maintain supplies, medications, and regular staffing. The finances of the Marshall Islands health services were stretched between many health priorities and heavy disease burdens. Dialysis patients began missing their dialysis treatments which resulted in preventable complications. Equipment fell into disrepair and the dialysis machines could not be maintained to appropriate standards. In 1986, the Primary Health Care Act was instituted in the Marshall Islands, closing the dialysis clinic.

What is COFA?

The Republic of the Marshall Islands (RMI) is one of six United States Affiliated Pacific Islands (USAPI) in the Western Pacific. Three of the USAPI, including the RMI, are freely associated with the United States (US) under a Compact of Free Association (COFA) and are referred to as "COFA nations" or "Compact nations" in this paper. The other two COFA nations are the Republic of Palau (Palau) and the Federated States of Micronesia (FSM).

The COFA nations are geographically dispersed and isolated countries. The FSM and the RMI are considered low-middle income countries while Palau is now considered a high-income country due in part to its eco-tourism, proximity to Asia, natural ocean environment, and its world-class diving and fishing industry. Under COFA, the COFA nations allow the US government to have military oversight and strategic denial of access to land, air, and ocean in these countries. In exchange, the COFA nations receive federal assistance and political benefits from the US government. The citizens of the COFA nations are allowed to migrate to and work in the US without visas or time restrictions. Many travel to the US to seek greater educational opportunities, work, and medical treatment such as hemodialysis.[1,2]

Background on Hemodialysis and End-stage Renal Disease

Hemodialysis is a renal replacement therapy often used at the last stage of chronic renal disease, known as end-stage renal disease (ESRD) or kidney failure. Hemodialysis replaces defunct kidney function by filtering blood externally via a dialysis machine; the blood exits the body and passes through a dialyzer, which filters out waste products and excess fluids, and then the blood returns to the body. Treatment is usually done in an outpatient setting 2-3 times a week for several hours at a time and is required for the rest of a patient's life or until a kidney transplant is available.

Vascular access is necessary for hemodialysis. The preferred access type is an arteriovenous (AV) fistula because it is the least likely to become infected, lasts the longest, and provides high blood flow. An AV fistula is placed by a vascular surgeon and takes 2-3 months to mature before it can be used for hemodialysis. Therefore, chronic renal disease patients must be monitored for renal function leading up to kidney failure and prepared before hemodialysis is needed.

There are two common alternative renal replacement therapies used to treat ESRD, but neither is being pursued in the COFA nations or the US Pacific Territories. One is kidney transplant surgery, which, when successful, restores renal filtration and eliminates the need for regular dialysis treatments. Though kidney transplant surgery has these benefits and even has lower costs than hemodialysis in the US, it is not feasible in the COFA nations because of the robust hospital infrastructure, resources, and personnel that is required for such a complex procedure.[1,3] Additionally, the potential complications of a transplant, including infection and kidney rejection, would require support from a highly developed medical system. For now, it would be difficult for the hospitals in the COFA nations to support such demands.[1] Furthermore, there is a shortage of donor kidneys in the United States with a median waiting time of 3.6 years as of 2011, and therefore would likely not be a solution for all ESRD patients in the COFA nations.[3]

An alternative is peritoneal dialysis, which makes use of the patient's abdominal lining (peritoneum) to filter body fluids internally. Peritoneal dialysis has the benefit of home use without either a hemodialysis machine or placement of vascular access. However, there is a high risk of infection if replacement of the exchange fluid is not done in a sterile environment by meticulous patients. A ready supply of medications to treat infections promptly is a necessity.[4] In some Micronesian cultures, an extended family may share a small living area with limited running water and bathroom facilities, and household members may have minimal health literacy regarding peritoneal dialysis, making the risk of infection significant and peritoneal dialysis inappropriate for use.[2] Furthermore, the geographic isolation and limited medical inventories of the COFA nations preclude a reliable and accessible local supply of medications, including the required dialysate solution which must be changed 4-6 times daily.[1]

Hemodialysis in COFA Nations

After Dr. Siemsen established self-care hemodialysis machines in the Marshall Islands, he subsequently developed dialysis units in the other COFA nations, including Pohnpei State of the FSM and Palau. Both of these clinics have been operating intermittently since and are currently in use. The dialysis facility in the RMI has not reopened since its closure by the 1986 Primary Health Care Act.

Hemodialysis is a contentious topic in the COFA nations in part because the Compact of Free Association will expire in 2023 for the FSM and the RMI. Financial assistance from the US federal government will be replaced with trust funds, and the state of healthcare funding will likely change dramatically, making the discussion of hemodialysis time-sensitive and crucial.

The need for hemodialysis is intensified by the crisis of non-communicable diseases (NCD) that has led the region to declare a state of emergency.[5] The health profiles of the USAPI, particularly the COFA nations, have been associated with the introduction of Western processed foods and a rapid transition to more sedentary lifestyles over the last 70 years. Environmental degradation and inadequate nutrition has been further complicated in the RMI due to 12 years of US nuclear weapons testing, which destroyed ancestral lands and displaced residents, leading many to rely on processed foods after the growing of traditional foods became unfeasible.[1,2,6] In Pohnpei State of the FSM, 73.1% of adults are overweight or obese.[7] Rates of hypertension and diabetes are also high; in Yap State of the FSM, 35% of the adult population have hypertension; in Palau, diabetes is estimated at 17.9% of the adult population; in the RMI, diabetes is estimated at 32.9% of the adult population.[8,9] Obesity, hypertension, and diabetes are risk factors for many chronic diseases including ESRD, the focus of this study.[10]

In the US the prognosis for dialysis patients depends on many factors but is significantly worse than the general US population. In the general population, a 60-year-old will on average live 20 more years while a dialysis patient aged 60 years can expect to live for less than 6 years. Five-year survival rate specifically for hemodialysis patients in the US was 42% in 2011.[3] While dialysis services can prolong life for some years, it is also important to recognize that it does not restore the same quality of life or life expectancy as a healthy individual.

Dialysis patients with comorbidities have worse prognoses. For example, diabetes can both cause ESRD and significantly impact the survival rate of ESRD patients once they start dialysis. A study of more than 7000 patients in northwest Italy demonstrated that dialysis patients with type 2 diabetes had a significantly higher 5-year mortality rate than non-diabetic dialysis patients (71% versus 53%).[11] In the US, the 5-year mortality rate for dialysis patients is 65%, but 75% for dialysis patients who also have diabetes.[12] The limited benefit of dialysis for patients with comorbidities such as diabetes is important to consider especially in the Pacific region where such comorbidities are highly prevalent.[5]

The object of this study is to analyze the cost-effectiveness of sustaining existing hemodialysis services in Palau and Pohnpei State and commencing hemodialysis services in other parts of the COFA states. The benefits of dialysis are considered in terms of survival and quality of life.

Methods

Some cost data were collected from an unpublished feasibility study that was completed in 2014 under the direction of the Pacific Island Health Officers Association (PIHOA). This data include cost estimates and predictions of dialysis services in the COFA nations.

Other more recent information was obtained through correspondence with healthcare providers and public officials from the US and the COFA nations.

Much of the collected information was aggregated in the context of COFA histories and the current NCD crisis.

Results

As specified by health officials in the COFA nations, there are only two clinics offering dialysis services as of 2019, one at Pohnpei State Hospital of the FSM and another at Belau National Hospital in Palau. There are 6 dialysis machines in Pohnpei, though only one is in operation at present. There are 7 dialysis machines in Palau serving ESRD patients and one machine serving hepatitis B patients. Chuuk State, Kosrae State, and Yap State of the FSM do not have any dialysis machines.

According to the feasibility study by PIHOA, in 2013, the numbers of patients undergoing dialysis treatment were as follows: 32 in Koror, Palau and 12 in Pohnpei, FSM. There were expected increases in 2014 to 35 patients in Palau and 13 in Pohnpei, which would constitute 0.17% and 0.04% of the populations, respectively.

In the sites that do not provide dialysis services, the estimated number of patients in need of dialysis by 2014 were as follows: 41 in Chuuk, FSM; 8 in Kosrae, FSM; and 61 in Majuro, RMI. They would constitute 0.08%, 0.10%, and 0.11% of the population, respectively. Estimates for Yap State, FSM were unavailable in the feasibility study. However, according to health officials, as of 2019, Yap State does not provide dialysis services but approximately 6 dialysis patients from Yap are cared for in Palau.

In Palau, the total annual cost to serve an expected 35 patients in 2014 was $1,483,055, which would have accounted for 9.89% of the national healthcare budget. In Pohnpei, FSM, the total annual cost to serve an expected 13 patients in 2014 was $360,968, which would have accounted for 4.51% of the healthcare budget. In the other sites without running dialysis units, startup costs would be high. To meet expected need in 2014, Chuuk State of the FSM, Kosrae State of the FSM, and Majuro of the RMI would have had to spend 14.40%, 15.45%, and 7.95% of their respective healthcare budgets in the first year to establish dialysis services.

Discussion

Capacity to Support ESRD-related Incidental and Unexpected Care for Patients on Dialysis

The typical ESRD dialysis patient requires extensive medical care beyond hemodialysis for the rest of their life. In Kosrae of the FSM for example, the projected cost to serve its hemodialysis patients (0.10% of the population) would be 15.45% of their healthcare budget. This figure excludes any incidental costs like hospitalizations for complications, but it is likely that many patients would need unexpected interventions. In the US for example, inpatient care accounts for 33% of Medicare spending for patients with ESRD, and dialysis patients averaged 1.7 hospital admissions in 2016 with a 30-day readmission rate of 35.4%.[3] If such unexpected costs were included in the expense calculations for the COFA states, the costs to treat ESRD patients relative to the total healthcare budget would likely exceed that what has been cited in this paper (ie, greater than the 15.45% referenced in this paper for Kosrae).

Because of the lack of data in the Pacific, it is difficult to quantify precisely the costs associated with both hemodialysis and ESRD in general. However, the cost estimates stated in this paper are a starting point.

Capacity to Address the Complications of Common Comorbidities in COFA: NCDs and Infectious Diseases

Comorbidities negatively affect longevity for ESRD dialysis patients. The rapid rise of NCDs in the USAPI has moved to a critical juncture and in 2010, a Regional State of Health Emergency was declared due to an epidemic of NCDs.[5] As obesity, hypertension, and diabetes are risk factors for ESRD and are all highly prevalent in the COFA nations, it is likely that many ESRD patients in the COFA nations have such comorbidities, none of which are treated directly through hemodialysis.[7-10] Conditions like diabetes complicate dialysis treatment and may require costly interventions to mitigate, with an overall worse prognosis.[11,13,14]

The COFA nations are concurrently battling infectious diseases like tuberculosis (TB). Dialysis patients are at a higher risk of contracting TB in part due to their immunocompromised state.[15-17] In the RMI, the incidence rate of TB was reported at 480 cases per 100,000 people in 2017 (compared to 2.7 cases per 100,000 people in the US in 2019), which means dialysis patients would be at an increased risk of contracting TB than they would be elsewhere with fewer TB cases.[18,19] Dialysis patients who do contract TB may suffer adverse effects from anti-TB treatment. In one study, only 53.1% of dialysis patients with TB completed TB treatment and recovered.[20] Another study cited a 36.8% mortality rate within 6 months of TB treatment initiation.[21]

A Consideration of the Cost Efficiency of Hemodialysis

The principal cost of providing dialysis is high (eg, 9.89% of the healthcare budget in Palau) and thus unfeasible in some COFA nations without sacrifices in other branches of healthcare or the government in general. Furthermore, in light of other complications like the estimated incidental costs of treating ESRD (eg, hospitalizations), the current NCD epidemic in the region, and the current struggle with communicable diseases like TB, the cost of providing dialysis is likely even higher than the approximations provided in this paper. Even more importantly, given the ongoing health disparities in the COFA nations, the poorer prognoses for COFA patients who are on dialysis might tip the scale such that providing dialysis is not a cost-effective measure for promoting health and longevity in the COFA nations.

How Do Other Countries Do It? Three Case Studies of Treating ESRD in Different Contexts

1. United States (large healthcare budget)

A high-income country like the United States provides dialysis services but still at a high cost. In the US in 2015, ESRD afflicted less than 1% of the Medicare population yet accounted for 7.2% of Medicare paid claims in 2015.[3] (Though this figure includes kidney transplants, peritoneal dialysis, and other costs like hospitalizations and emergency visits.) However, with the highest gross domestic product (GDP) in the world and national health expenditures at $10,739 per person, the US is able to provide a costly service like dialysis at lesser sacrifice to other medical care.[22] In contrast, Palau, the wealthiest of the COFA nations with the highest GDP per capita, spent $1,429 on health per capita in 2014.[23-25] However, it should be noted that in Palau, the government subsidizes the dialysis unit $500,000 annually to sustain this effort. In the FSM, which is more resource-limited than Palau, the health expenditure per capita in 2014 was $473.[24] In the COFA states, dialysis services require (or would require) a very large proportion of a very limited health care budget.

2. US Territories (financial support from a larger country)

Dr. James Musgrave, a Hawai‘i-based nephrologist, partnered with Dr. Siemsen to open a dialysis clinic in American Samoa in August of 1980. Because American Samoa is a US territory, this clinic is supported by Medicare. Dr. Siemsen retired in 1985 and Dr. Musgrave continued running the American Samoa clinic with other colleagues. While there is no vascular surgeon onsite, a surgeon from the Philippines was taught to do simple fistulas by a visiting vascular surgeon and so almost 90% of dialysis patients have AV fistulas. Similar to the COFA nations, most patients have either diabetes or hypertension or both, which complicates treatment with an estimated yearly mortality rate of 12%. Nevertheless, the clinic is continually expanding with an adjusted annual growth of 5.5% and currently has 32 dialysis machines for 170 patients. Without Medicare support, this clinic would not be sustainable in meeting current or future demand (J. Musgrave, personal communication, March 2019).

The other US territories of Guam and the Commonwealth of the Northern Mariana Islands also provide dialysis services to their residents, but similarly do so only through Medicare funding. Because the COFA nations are only freely associated with the US and are not territories, they do not receive Medicare support. Therefore, any dialysis intervention in a COFA nation would need to be self-sustaining.

3. Two South Pacific Nations (treatment provided within a larger, affiliated country)

In comparison, in small island nations of the South Pacific, such as the Cook Islands and Tokelau, there are no dialysis services offered. Instead, these nations rely on their affiliations with New Zealand to access renal care. As dialysis is a life-prolonging measure, this arrangement is less than ideal because it requires a patient to move permanently to New Zealand. Similarly, residents of COFA states are able to access dialysis services in the US, though understandably, many would prefer to access dialysis in their home countries.

A Prevention-based Approach for the COFA Nations

With these complexities of providing dialysis in mind, it would be essential to consider alternative approaches to ESRD in the COFA nations, such as strengthened NCD prevention programs and more robust glomerular filtration rate (GFR) tracking of individuals at high risk of ESRD. A small quality improvement study on the impact of Aloha Kidney, a comprehensive series of classes educating patients on kidney health and self-management of chronic kidney disease, was conducted in Hawai'i. Dr. Ramona Wong retired from her nephrology practice to provide the classes in person and via telehealth to neighboring islands. The results of this study suggest that education can slow kidney function decline and improve preparedness for the transition to ESRD (R. Wong, email communication, March 2020). Looking forward, enhancing preventive healthcare measures may reduce the occurrence of ESRD and more importantly, improve the general health of COFA populations. Such a prevention-based approach is moving forward but has not yet been emphasized among public health officials and community members as a needed and evidence-based strategy to prevent and slow renal failure.

Perspectives of Public Officials and Community Members

1. US Congress

In a letter to the US Secretary of State and Secretary of the Interior, members of the US Congress expressed concern with the rising costs of the Compact Impact. The Compact Impact describes the effects of the Compact of Free Association, which in part allows COFA residents to migrate, live, and work in the US without a visa or time limits. In this letter, COFA migrants' increasing reliance on social services in the US is cited as a major factor for the financial burden in question. It was recommended that an allocation of a portion of the Compact grant assistance, specifically, the Infrastructure Sector and Health Sector grant, be used to establish and operate dialysis facilities in the FSM and the RMI. This recommendation was made with the explicit intention of mitigating migration of COFA residents seeking ESRD healthcare in the US (L. Murkowski, et al, written communication, May 12, 2011). However, this Congressional idea ultimately could not be carried out because local health officials recognized that this intervention would not be sustainable and would utilize health funds from other areas of higher priority such as diabetes, heart disease, and cancer prevention and control.

2. Community Members: A Consideration of Human Values

At least anecdotally, community members support the provision of dialysis services in the COFA nations, which could be explained in several ways. One possibility is skepticism over how resources will be redirected upon closure of dialysis services. It is difficult to discern whether the funds saved would be used toward NCD prevention or toward financing other interests in the public sector. Such ambiguity might make community members less comfortable with forgoing dialysis as it is unclear what the return would be, if any at all.[26]

A second explanation regards the symbolic value of dialysis as a life-prolonging intervention. While many people might regard life as priceless, there are many governmental policies that are ultimately detrimental to the public's health. That said, the provision of hemodialysis is symbolic in the public's eyes as a unique demonstration that everything will be done to prevent death, even if early prevention measures would be ultimately more effective. In this way, hemodialysis services provide a false sense of security.[26]

Third, while the lack of NCD prevention programs will lead to premature death, so will the lack of hemodialysis. The latter is more clearly the direct cause of death. For example, if an ESRD patient dies, "kidney failure" will likely be deemed as the cause of death rather than "lack of access to hypertension or diabetes prevention programs". The former can thus be perceived as of grave concern while the latter is more of an unfortunate detail.[26] In order to begin prioritizing prevention programs, there needs to be some reconciliation of this tendency to undervalue the potential benefits of early intervention.

Fourth, in Palau and Pohnpei, dialysis services are currently available, and patients who have been receiving treatment for years may have a reasonable expectation that these services will continue. For those current patients, the closing of clinics may be viewed as an especial betrayal by the health system.[26] Therefore, it would be worthwhile to discuss how to continue treatment for current patients amidst phasing out dialysis more broadly.

A consideration of how and why people value dialysis will be crucial because they will drive the public's response to the institution of any new intervention and the cessation of any existing intervention (ie, hemodialysis). Despite these complexities, hemodialysis, as a limited resource in the COFA nations, must be at the forefront of current healthcare discussions. COFA communities are approaching (or have already arrived at) the difficult moral situation of deciding who gets access to the limited hemodialysis. There is already a precedent for this in the genesis of hemodialysis in the 1960s. It is imperative that COFA communities proactively engage in strategic planning to address the need and impact of hemodialysis for their nation.

God Panels: A Cautionary Tale

At the advent of dialysis in the US in the 1960s, dialysis treatment was limited and could not meet the existing demand. In response, special hospital committees, "God panels", were instituted to determine which patients would receive dialysis treatment based on a patient's determined social worth.[27] Understandably, such subjective determinations were condemned as discriminatory by bioethicists.[28,29] The ESRD program was instituted in 1972 to mitigate any future need for God panels by providing widespread, federally funded dialysis treatment to all US citizens with ESRD.[27,30]

In the COFA nations, where it is not financially feasible to expand the current dialysis clinics to meet the increasing demand, the God panels of the 1960s serve as a cautionary tale of the difficult decisions that lie ahead. Though such decisions might not be based on patients' social worth, referral decisions based on prognosis are already being made in the Pacific. To ensure the most ethical and effective approach to treating ESRD, a discussion of the future of hemodialysis (or lack thereof) among healthcare providers, public health officials, and the public is essential. Alternatives must be considered.

Conclusion

The utility of hemodialysis, the determination of its value, and its place in a health care system is a function of medical necessity, resource priorities, and the values and perspectives of the stakeholders. As an example, from a US-centric point of view, the establishment of hemodialysis in the COFA nations may be beneficial to the States and Territories as it would mitigate the need for COFA residents to migrate to receive dialysis. However, from a COFA-nation centric point of view, establishing hemodialysis may not have an overall net benefit because resources are generally limited, hemodialysis may detract from other more pressing local health care priorities, and hemodialysis may not be a sustainable health intervention. In the US Pacific Territories, Medicare funding supports hemodialysis treatments which decreases the local financial burden. Nevertheless, the infrastructure needed for hemodialysis in the Territories may still stretch health human resource capacities. Understanding the perspectives and priorities of stakeholders and managing individual biases may be helpful in evaluating the impact of hemodialysis in the COFA populations.

Hemodialysis has increased the life expectancy and quality of life for many. However, the average longevity for a patient on dialysis is still significantly limited and even shorter for patients with comorbidities. Also, medical complications while preparing patients for dialysis and during the course of dialysis treatments are not uncommon and significantly impact quality of life. The local authors of health policy and the public's expectations of hemodialysis may further benefit by reviewing the evidence, outcomes, and experiences of dialysis centers across the globe.

With these variables in mind, cost data indicate that hemodialysis is likely not cost-effective in most of the COFA areas. Therefore, alternatives to treating ESRD must be developed that are both community-specific and resource-appropriate. With the unique disparities of this region, each community will likely require unique solutions. The positive results of the Aloha Kidney program suggest that education is an important tool in managing chronic kidney disease and kidney health is relevant to health educational programs in the COFA nations. If additional support for such programs is needed, telemedicine can be a useful method of providing knowledge to both healthcare professionals and patients while local capacity is developed to sustain educational and outreach efforts independently.

Data on current cost estimates of dialysis clinics and ESRD rates in the COFA communities will be essential to make informed decisions about hemodialysis in the current health systems and as these systems plan for the future. It is essential to enhance current medical interventions and public health strategies to prevent kidney disease and decrease the risks for kidney failure in the COFA nations and all the USAPI. Such preventive interventions must be culturally appropriate, effective, cost-efficient, and sustainable in the unique context of the Pacific.

Conflict of Interest

None of the authors identify any conflict of interest.

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Authors Affiliations:
- Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawai'i, Honolulu, HI (MSM, NAP)
- St. Francis Medical Center, Renal Institute of the Pacific, Honolulu, HI (AWS)
- Department of Medicine, John A. Burns School of Medicine, University of Hawai'i, Honolulu, HI (AWS)
- Pacific Island Health Officers Association, Honolulu, HI (EC)
- Department of Pediatrics, John A. Burns School of Medicine, University of Hawai'i, Honolulu, HI (JEM)
- Aloha Kidney, Honolulu, HI (RLW)

Correspondence to:
Neal Palafox MD, MPH; Department of Family Medicine and Community Health,
John A. Burns School of Medicine, University of Hawai'i, 651 Ilalo Street MEB224,
Honolulu, HI 96813; Email: npalafox@hawaii.edu

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Pacific Voyages - Ships - Pacific Communities: A Framework for COVID-19 Prevention and Control

Neal A. Palafox MD, MPH; Bruce R. Best MS; Allen Hixon MD; and Wilfred C. Alik MD

US National COVID-19 data trends suggest that those living in rural areas, those who are Pacific Islander, Native Hawaiian, Black, Hispanic, and Native Americans suffer a disproportionate share, worse health outcomes, and higher mortality rates from COVID-19.[1,2]

With respect to Oceania, to date May 12, 2020, the US Affiliated Pacific Islands (USAPI) Guam and Commonwealth of the Northern Mariana Islands have reported COVID-19 cases, 152 and 19 respectively, and that their infection curves have flattened.[3,4] American Samoa, the Republic of Palau, the Federated States of Micronesia, and the Republic of the Marshall Islands report no cases to date.[5,6] French Polynesia reports 60, New Caledonia 18, and Tonga and the Cook Islands report no cases.[6,7] Are there Pacific relevant models to better understand how and why SARS-CoV-2 can affect Pacific communities? Two current Pacific voyages may be relevant in predicting the effects, the disparate outcomes, and needed response to the COVID-19 pandemic in Pacific Islander communities.

Voyage 1: USS Theodore Roosevelt

The USS Theodore Roosevelt, a US Navy Aircraft Carrier supporting a crew of about 4985, reported three of its crew COVID-19 positive on March 23, 2020. The carrier pulled into Guam's harbor on March 27, 2020 and was brought pier-side seven days later on April 3, 2020. At that time, 114 of the sailors tested positive for COVID-19, which was about one-third of the total number of the USS Roosevelt sailors who were tested. In anticipation of a medical surge related to the infection, the military built a tent hospital and would provide medical services for the crew who were quarantined in nearby hotels.[8,9]

By April 4, 2020, 4234 crew members had been shuttled ashore into housing on Naval Base Guam and hotels in the Tamuning and Tumon community districts for testing and two weeks of social isolation. Approximately 700 members remained on board to guard and disinfect the USS Roosevelt. These crew members who remained on board were then rotated ashore after three weeks and placed into community hotels for quarantine. A few of the 700 crew members later became COVID-19 positive.[8,9]

Eventually, 1102 of the Roosevelt's near 4985 crew members tested COVID-19 positive, including the Captain, resulting in more than 22 percent of the crew being infected within five weeks. The high rate of infection occurred in spite of attempts of off-the-ship social distancing and quarantine measures. About 40 of those with prior COVID-19, upon retesting, were found positive.[8-12]

Voyage 2: USS Kidd

A second naval vessel, the USS Kidd, a Naval Guided Missile Destroyer with a crew of 350, departed Hawai‘i in late March. The Destroyer was detached from the Theodore Roosevelt Carrier Strike Group while the USS Theodore Roosevelt was pier-side in Guam with the COVID-19 outbreak.[13,14]

During the third week of April, a month later, a COVID-19 outbreak occurred while the ship was working off the Pacific coast of South America. A crew member displayed symptoms of an "influenza-like illness" on April 22, and was subsequently evacuated off the ship to a military hospital in San Antonio, Texas. On April 23, the sailor tested positive for COVID-19. The entire crew had not been ashore since their Hawai‘i visit in mid-March 2020. That positive test began a two-month process to rid the deployed ships of the SARS-CoV-2 virus.[12,13,15,16]

The USS Kidd pulled into San Diego on Tuesday, April 28 to begin disinfecting the ship, as well as isolating, testing, and treating the crew. At least 78 members of the Kidd's crew of about 300 tested positive to COVID-19, according to the last figures released by the Navy on April 30, 2020. At least 25 percent of the crew of the USS Kidd were infected.[14,17]

As of the latest available reports, 26 naval vessels have had COVID-19 outbreaks. There were 1,366 current COVID-19 cases, as of early May 2020.[18]

A Framework for Understanding COVID-19

COVID-19 (the disease) is caused by the SARS-CoV-2 (the virus). It has been found to transmit rapidly between humans. The risk for transmission between humans is enhanced by particular environmental attributes such as crowding which increases the frequency and duration of contact with infected individuals or contaminated environments.[19]

Individual health outcomes from COVID-19 are associated with: (a) personal health (eg, age, immune status, and underlying conditions including hypertension, heart disease, diabetes, asthma and other lung conditions, pregnancy, and smoking); and (b) access to appropriate medical support if required (eg, supportive hospital care and ventilators).[19,20]

Community health outcomes from COVID-19 are associated with: (a) the built environment (eg, density of population and homes); (b) population and demographic factors [age distribution and rates of the co-morbid conditions (listed earlier)]; (c) access to supportive medical care (health infrastructure and the ability to access the health infrastructure); and (d) the ability of the community to prevent and manage the COVID-19 disease through organization, social-cultural attributes, health literacy, and financial assets.[20,21]

A COVID-19 Ship Framework for Pacific Islander Communities

The USS Theodore Roosevelt and USS Kidd provides real time, Pacific relevant examples of the nature of COVID-19 within crowded living conditions, highly interdependent communities, with limited health infrastructure services, limited group capacity to manage their personal situation, and an impossible environment to maintain social distancing.

Many of the Pacific Island communities have similar situations with densely populated communities, highly culturally interdependent communities, limited access to adequate health infrastructure, limited resources for the group to affect disease transmission, and living environments not conducive to social distancing should COVID-19 surge. Several examples are Ebeye Island where 11,000 people live on 66 acres, Majuro atoll with 20,000 people, Tarawa the capitol of Kiribati supports 45,000 citizens, and a high density of Moen, Chuuk.[22-25] Pacific Islander communities within the US or its territories with large extended families in single dwelling homes or in low-income housing settings, poor access to health care, and little possibility for social distancing face the same issue.[2,5] Recognizing, interpreting, and describing the disparate effects of the COVID-19 pandemic on the Pacific Island communities sets the stage for what must be done quickly and precisely in context of the Pacific Island communities.

Perhaps the story of COVID-19 aboard the USS Theodore Roosevelt and the USS Kidd during their recent Pacific tours may help Pacific communities and small Pacific Island nations anticipate what may unfold, and what is needed if COVID-19 enters their communities. The USS Roosevelt and the USS Kidd crews live and work in close proximity, confined by livable space and the structure of the ship.[17] The crew members, like many Pacific Islander communities, must be tightly interdependent to manage the ship. They live in close quarters and are in close and frequent physical contact. As a part of a large Naval ship, the sailors cannot physically exit or meaningfully isolate themselves as they are surrounded by the ocean, by the bulkheads, and clearly bound by the naval culture and rules of the mission.[17] When COVID-19 presented to each of the vessels, the virus spread very quickly. From 0 to 114 to 1102, over 22 percent of the 4985 crew were infected within five weeks, including two dozen hospitalizations, and one death.[8-12] The mission and work of the USS Roosevelt and the USS Kidd came to a grinding halt with the advent of the infection. Would a similar scenario unfold in small Pacific Island nations or in tightly knit Pacific Island communities, which are culturally and environmentally limited in options? Notably, a few cases of COVID-19 may bring a Pacific community to a grinding halt and functionally inoperable.

The USS Roosevelt command and the US Navy recognized the immediate need to address COVID-19 isolation, social distancing, and a potential surge of illness. The 4.5 billion dollar aircraft carrier could not handle these protective and anticipatory COVID-19 measures on its own. The Captain and crew, and indeed the US Navy, sought the support of the Guam community. They sought shelter for over 4234 crew members in Guam hotels and the community to isolate them, protect them and to manage the spread of the illness. Concurrently, the Air Force built a 75 bed medical units on the Naval Base and the Navy and Marines built a 150 bed field hospital on the Department of Defense property to support a potential COVID-surge.[26,27]

COVID-19 transmission was rampant on a 4.5-billion-dollar aircraft carrier. The access to financial and strategic resources was not the problem. The physical structure of the ship, the ships isolation in the middle of the ocean, and the lack of on-site medical support was problematic. Wisely, they did and could move their entire ship's community to Guam. Where would the people of small island nations or communities go to protect their own? How would they gear up for a COVID-19 surge with limited resources, lack of housing infrastructure, health resource shortages, and lack of transportation from their distant outer island communities hundreds of miles away? The islands and Pacific Islander communities cannot move.

There was only one death in the crew of the USS Roosevelt.[8] They were blessed. Of significance, the sailors of the USS Roosevelt and USS Kidd were generally young, healthy sailors. In many of the Pacific communities, the affected would be the elderly and Pacific Islanders with hypertension, diabetes, and heart disease. In the Pacific Island communities, unlike young healthy sailors, the individual health outcomes would be significant from COVID-19.

In theory, the USS Roosevelt and the USS Kidd could replace its sick crew. The island nations and communities do not have the option to replace their crew nor can they sail to safe harbor. Using the Naval ship model, we can visualize how and why Pacific Islander communities, especially those with limited resources, needing health infrastructure, with dense living environments, are at great risk for rapid spread, high mortality, and unmanageable illness. A significant outbreak could lead to closure of function of that community or island nation. The analogous model of the USS Roosevelt and USS Kidd suggest this would be the case. The structural, economic, planning and global support that is required to assist, manage, and prevent the disparate effect on Pacific Island communities by COVID-19 comes into focus.

Ships, like island nations or small Pacific Islander communities within the US, cannot remain isolated forever. They cannot close off from the world due to trade, citizen travel, students, and indeed their economies. There have already been 26 Naval vessels infected,[18] and other entertainment, fishing and commercial vessels. As the world "opens up" again, every community or island nation should take into account how it is unique and how each should determine what is scientifically, culturally, economically appropriate as a COVID-19 response. Opening up for one country may be correct, but a disaster for another. Further, the actions of one country or community opening or closing will impact the global community.

We all need to pay attention - as the COVID-19 pandemic with the Pacific Island nations and peoples will unwind and declare itself in the upcoming weeks to months. What has been learned from the USS Roosevelt, USS Kidd, and a total of 26 Naval ships, cruise ships, fishing vessels, and cargo ships which were not allowed to land in any port is important to internalize and anticipate.

Prevention strategies that do not allow the coronavirus to take hold in remote communities are essential. Culturally appropriate distancing, developing a plan to provide quarantine and isolation, ensuring access to appropriate medical care, and other efforts to protect elders and vulnerable people should be prioritized and shared. Once a vaccine is available, specific campaigns should be stood up to promote herd immunity.

The COVID-19 narrative of the USS Roosevelt and the USS Kidd is not over. It is the beginning. The Pacific should pay attention to the outcomes and processes that affected the USS Theodore Roosevelt and the USS Kidd. Global institutions should be prepared. The Global health community, the US government, the Pacific nations, must together work proactively to prevent and manage disparate COVID-19 outcomes in Pacific communities. There is no other way.

Authors' Affiliations:
- Department of Family Medicine and Community Health, John A. Burns School of Medicine, University of Hawai'i, Honolulu, HI (NAP, AH)
- Pacific Basin Telehealth Resource Center, University of Hawai'i, Honolulu, HI (BRB)
-Kaiser Permanente Hilo, Hilo, HI (WCA)

Correspondence to:
Neal A. Palafox MD, MPH; Email: npalafox@hawaii.edu

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Aim:

The aim of the Hawaiʻi Journal of Health & Social Welfare is to advance knowledge about health and social welfare, with a focus on the diverse peoples and unique environments of Hawaiʻi and the Pacific region.

History:

In 1941, a journal then called The Hawaiʻi Medical Journal was founded by the Hawaiʻi Medical Association (HMA). The HMA had been incorporated in 1856 under the Hawaiian monarchy. In 2008, a separate journal called the Hawaiʻi Journal of Public Health was established by a collaborative effort between the Hawaiʻi State Department of Health and the University of Hawaiʻi at Mānoa Office of Public Health Studies. In 2012, these two journals merged to form the Hawaiʻi Journal of Medicine & Public Health, and this journal continued to be supported by the Hawaiʻi State Department of Health and the John A. Burns School of Medicine.

In 2018, the number of partners providing financial backing for the journal expanded, and to reflect this expansion the name of the journal was changed in 2019 to the Hawaiʻi Journal of Health & Social Welfare. The lead academic partners are now the six units of the UH College of Health Sciences and Social Welfare, including the John A. Burns School of Medicine, UH Public Health, the Myron B. Thompson School of Social Work, the School of Nursing and Dental Hygiene, the UH Cancer Center, and the Daniel K. Inouye College of Pharmacy. Other partners are the Hawaiʻi State Department of Health and the UH Office of the Vice Chancellor for Research. The journal is fiscally managed by University Health Partners of Hawaiʻi.

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Mailing Address: Hawaiʻi Journal of Health & Social Welfare
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Website: http://hawaiijournalhealth.org/
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