

Disparities in outcomes for pediatric cancer patients treated in Hawai'i: comparing Hawai'i residents to children referred from the Pacific Islands

Abstract: This article examines whether pediatric cancer patients referred to Hawai'i from the Pacific Islands had poorer outcomes than Hawai'i residents treated at the same hospital. For children admitted from 1981 to 2002, we obtained data on patient demographics and outcomes from a review of medical charts and physician case reviews. We found that pediatric cancer patients referred from the Pacific Islands for treatment in Hawai'i had a higher relative risk of death, of not receiving treatment in a timely manner, of not completing treatment, and of being lost to follow-up than pediatric cancer patients that were residents of Hawai'i. The higher risk of poor outcomes for pediatric cancer patients referred from the Pacific Islands can be addressed by improving the health care systems in both the Pacific Islands and in Hawai'i. *Key Words:* Pacific Islands, timely referral, completion of treatment, outcomes

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in their home islands may be referred out of their countries for medical care, particularly to Hawai'i. Specifically, referral systems for the treatment of pediatric cancers have been established in almost all of the U.S.-associated Pacific Island jurisdictions and have been in place for years, some for decades. In most cases, pediatric cancer cases are referred from the Pacific Islands for diagnosis and treatment in Hawai'i. This population of children has never been systematically defined, tracked, or studied.

Introduction

The history of the United States' role in the Pacific has led to official relationships between the U.S. Government and the U.S.-associated Pacific Island jurisdictions of Guam, American Samoa, the Commonwealth of the Northern Mariana Islands (CNMI), the Federated States of Micronesia (FSM), the Republic of the Marshall Islands (RMI), and the Republic of Palau (ROP). Residents of the U.S.-associated Pacific Island jurisdictions—whether territory, commonwealth, or freely-associated state—can travel freely to and from the United States. Residents in need of medical care that cannot be provided

There have been very few studies of cancer among the peoples of the Pacific Islands. In an article reviewing cancer research among Native Hawaiians and Pacific Islanders, Hughes and colleagues found little data on cancers among citizens of American Samoa, Guam, Palau, CNMI, RMI, and FSM¹. The lack of systematic data on the cancer burden and

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The little research that has been conducted on cancer in the Pacific Islands suggests that a number of factors, including poor access to care, have contributed to poorer outcomes among jurisdic-

tional residents compared to U.S. residents. For example, the RMI, a jurisdiction in which nuclear testing has been correlated with higher rates of thyroid cancer, still lacks the primary care infrastructure to screen or treat these cancer patients². A study comparing median years of survival and 5-year survival rates after diagnosis of cervical cancer between Pacific Islanders and non-Pacific Islanders treated at Tripler Army Medical Center in Hawai'i, found that patients from the Pacific Islands tended to present: at a later stage (most likely due to lack of or delayed screening), with relatively large average tumor diameter, with a greater likelihood of metastasis, and with poorer survival³. Furthermore, even after statistically controlling for stage at diagnosis, ethnicity still remained a significant predictor of sur-

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vival. A study conducted in New Zealand found a higher incidence of cancer among those of Pacific Islander ethnicities compared to non-Pacific Islander ethnicities (both Maori and non-Maori)⁴. A study of thyroid cancer in New Caledonia, an island in the South Pacific region of Melanesia, found higher rates of thyroid cancer among residents of Melanesian ethnicity, compared to those of European descent⁵.

The dearth of information about cancer in the Pacific Islands includes a lack of information about pediatric cancer. Through the relationship established between the U.S.-associated Pacific Islands and the U.S., Kapi'olani Medical Center for Women and Children (KMC), located in Hawai'i, diagnoses and treats pediatric cancer patients referred from these islands. Over the years, physicians from the Pediatric Oncology Group at KMC have observed a dismaying disparity in prognoses and outcomes between patients referred from the Pacific Islands and patients who are Hawai'i residents. Patients referred from the Pacific Islands are, in their observations, more likely to die from their illnesses than patients from Hawai'i.

The objective of this study was to establish whether pediatric cancer patients referred from the Pacific Islands and treated at KMC were more likely to die of their cancer and its complications than those residing in Hawai'i (at the time of their diagnoses). This study further explored factors that may contribute to this disparity, including whether patients from the Pacific Islands with pediatric cancers were diagnosed and treated in a less timely manner, whether they were less likely to complete their treatment, and whether they were more likely to be lost to follow-up.

Methods

The Pediatric Oncology Clinic at KMC maintains information on every child seen or treated at the clinic since the mid-1970s. This study focused on the pediatric cancer cases referred from the U.S.-associated Pacific Islands who were treated at KMC between 1981 and 2002.

This study was approved by the Institutional Review Board of the Hawaii Pacific Health Research Institute. A total of 100 cases were identified, and all were included in the medical charts review. A comparison group was constructed through a simple random sample of 100 pediatric cancer cases from O'ahu, Hawai'i, treated during this same time period. Because data were originally collected to examine the role of relocation in pediatric cancer outcomes, the comparison group was limited to children from the Hawaiian island of O'ahu, where KMC is located. Five of the cases selected were

dropped because further examination revealed that they did not meet the criteria of residence, thus reducing the sample for Hawai'i to 95 cases. All the cases in this study were treated at KMC's Pediatric Oncology Clinic.

A form was created for the medical chart review to collect data on patient demographics (including gender, age, birth date, ethnicity, birthplace, zip code, and island of residence), diagnosis (including type of cancer, age at diagnosis, date of diagnosis), the referral (referral source, payment type, timeliness of referral, treatment, treatment location, and treatment completion), outcome, and social factors (family members accompanying the child, sources of housing and transportation, problems identified by the family, and other sources of support provided to the family). The data collection form also allowed for the documentation of additional information deemed pertinent by the reviewer. Information was not complete for all cases in the

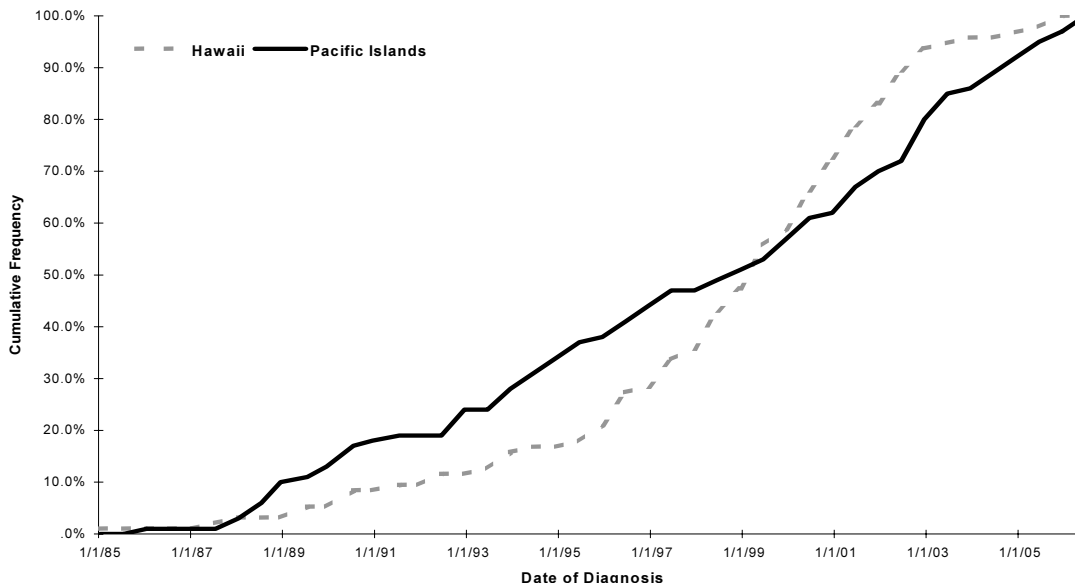
medical charts. Missing data were provided by interviews with attending physicians and the Pacific Island's medical referral services staff familiar with the cases. Cancer diagnoses were categorized based on the International Childhood Cancer Coalition Classification system⁶.

Timeliness and Completion of Treatment. Timeliness of diagnosis and treatment was determined by a pediatric oncologist based on three factors:

- 1) How advanced the disease was at the time of referral. Diagnosis and treatment were determined to be not timely under the following conditions:
 - a. A cancer has metastasized when, in general pediatric oncology practice, this type of cancer is usually detected before metastasis.
 - b. The cancer that is treatable in general practice is found at such an advanced stage that the only treatment option available is palliative care.
- 2) How long symptoms had been present. Diagnosis and treatment were determined to be not timely under the following conditions:
 - a. The symptoms were present and recognized by the family, but medical attention was not sought immediately (due to lack of access to care or ignorance of the significance of symptoms).
 - b. The family sought medical care for the child's symptoms, but a delay occurred before referral or work-up for the symptoms, and this delay was longer than the generally accepted lag time between initial presentation and diagnosis for the particular cancer.
- 3) The presence of complicating factors. Diagnosis and treatment were determined to be not timely if the child had any of the complications that are rarely seen in

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Figure 1. Cumulative frequencies of dates of diagnosis, comparing Pacific Islands and Hawaii cohorts



general practice. Many malignancies, in their advanced stages, can cause one or a number of complications, such as organ failure. In some cases, advances made in pediatric oncology have allowed these malignancies to be detected early enough that their complications are now very rarely seen.

Treatment completion was verified by documentation in the medical chart of the administration of prescribed drugs at each time point required. Treatment was considered complete if the prescribed treatment plan had been carried out to its scheduled end point. The treatment was considered incomplete if the patient’s family terminated contact with KMC before the treatment plan had been completed.

Data were collected on standardized forms and subsequently entered and managed in EPI INFO 6.04b. Most fields were set up with real-time edits to forestall gross entry errors. Data were verified after entry by inspection. Relative risk and 95% confidence intervals, as well as Fisher’s exact test for difference from 1.00, were calculated using the StatXact-4 statistical program.

Results

Characteristics of the study and control populations. To confirm that both cohorts of patients were distributed similarly over the study period, the dates of diagnosis were plotted together (Figure 1). The two

cohorts show a similar pattern of distribution across the 20-year span; however, patients from the Hawai’i cohort were somewhat more concentrated in the later years than patients from the Pacific Islands. A possible explanation for this observation might be that during the 1990s, Pacific Island jurisdictions began to refer children to other communities, including other parts of the U.S. and foreign countries such as the Philippines.

Demographic characteristics of the Pacific Islands’ referrals and the Hawai’i residents are shown in Table 1. Both the

Table 1. Demographic characteristics of pediatric cancer patient samples, KMC 1981-2002

Characteristics	Pacific Islands cohort (n=100)	Hawai’i cohort (n=95)
Gender		
Male	64% (64)	55% (52)
Female	36% (36)	45% (43)
Age		
0-4	45% (45)	45% (43)
5-9	29% (29)	38% (36)
10-14	18% (18)	15% (14)
15-19	8% (8)	2% (2)
Ethnicity		
Pacific Islander (does not include Hawaiian)	85% (85)	11% (10)
Hawaiian or Part-Hawaiian	0	24% (23)
Non-Pacific Islander	15% (15)	65% (62)
Place of birth		
Pacific Islands	95% (95)	2% (2)
Hawai’i	0	86% (82)
Other	5% (5)	12% (11)

Table 2. Distribution of cancer diagnoses treated at KMC

ICCC Classification*	Pacific Islands cohort (n=100)	Hawai'i cohort (n=95)	p-value**
Leukemia (I)	47.0% (47)	40.0% (38)	0.0710
Lymphoma (II)	5.0% (5)	7.4% (7)	0.1862
Central Nervous System (III)	10.0% (10)	18.9% (18)	0.0340
Sympathetic Nervous System (Neuroblastoma) (IV)	7.0% (7)	7.4% (7)	0.2163
Retinoblastoma (V)	3.0% (3)	3.2% (3)	0.3168
Renal Tumor (VI)	4.0% (4)	4.2% (4)	0.2785
Hepatic Tumor (VII)	0.0% (0)	2.1% (2)	0.2361
Malignant Bone (VIII)	1.0% (1)	8.4% (8)	0.0130
Soft Tissue Tumor (IX)	9.0% (9)	3.2% (3)	0.0589
Germ Cell Tumor (X)	3.0% (3)	1.0% (1)	0.2630
Other	1.0% (1)	0.0% (0)	0.5128
Blood Dyscrasia	10.0% (10)	4.2% (4)	0.0672

*Classification system published by the International Agency for Research of Cancer (8)
 **Fisher's exact test

Pacific cohort and the Hawai'i cohort contained greater proportions of male than female patients, although the difference was greater for Pacific Islands patients. The age distributions were similar between the two cohorts, with most patients under 10 years of age at time of diagnosis. Ethnic distribution was markedly different between the two cohorts, as would be expected. The vast majority of the Pacific Islands cohort was of Pacific Islander ethnicity and only 15% were of other ethnicities, including Filipino, Chinese, Japanese, Caucasian, and Puerto Rican. In contrast, only 11% of the Hawai'i cohort was of Pacific Islander ethnicity; 24% were Hawaiian or Part-Hawaiian, and 65% were of other ethnicities, including Filipino, Chinese, Japanese, Caucasian, Puerto Rican, and Vietnamese.

Distribution of cancer diagnoses. The distribution of diagnoses among the Pacific Islands and Hawai'i cohorts are shown in Table 2. In both cohorts, leukemia made up almost half of the cancer diagnoses. A significantly higher proportion of the Hawai'i cohort was diagnosed with tumors of the central nervous system ($p < 0.01$) and malignant bone tumors ($p < 0.05$). A higher proportion of the Pacific Islands cohort

was diagnosed with soft tissue tumors and blood dyscrasia, although the differences were not statistically significant.

Outcomes. The data in Table 3 show that among children treated for cancer at KMC, a greater percentage of children referred from the Pacific Islands died during the study period (46%) than did children from Hawai'i (31%), and that the difference was statistically significant. The relative risk of dying for Pacific Islands children compared to children from Hawai'i was 1.51.

Data from the medical chart reviews, and information provided by those familiar with the cases, were used to determine whether diagnosis and treatment were delivered in a timely manner (see Methods section for definition). Pacific Islands children were significantly less likely to be referred for treatment of cancer in a timely manner; 36% of referrals were not timely, while only 3% of referrals of Hawai'i children were considered not timely ($p < 0.01$). The relative risk of non-timely referral was 11.40 times higher for Pacific Islands children than for Hawai'i children.

Table 3. Comparison of outcomes* and timeliness between Pacific Islands and Hawai'i cohorts

Outcome***	Percent (n) in Pacific Islands cohort (n=100)	Percent (n) in Hawai'i cohort (n=95)	Relative Risk (95% Confidence Interval)	p-value**
Death	46% (46)	31% (29)	1.51 (1.04, 2.18)	<0.0001
Treatment not timely	36% (36)	3% (3)	11.40 (3.63, 35.78)	<0.0001
Did not complete treatment as recommended	30% (30)	4% (4)	7.13 (2.61, 19.46)	<0.0001
Lost to follow-up	20% (20)	3% (3)	6.33 (1.95, 20.62)	0.0002

* Death, loss to follow-up, and non-completion of treatment measured during the study period only

** Fisher's exact test. *** Not exclusive categories

Almost one-third (30%) of Pacific Islands children did not complete their treatment as recommended, compared to only 4% of the children from Hawai'i ($p < 0.01$). The relative risk of not completing treatment was 7.13 times higher for Pacific Islands children than for Hawai'i children.

Pacific Islands children were also more likely to be lost to follow-up than Hawai'i children (20% and 3% respectively), usually after returning to their home islands ($p < 0.01$). The relative risk of loss to follow-up was 6.33 times higher for Pacific Islands children than Hawai'i children.

Discussion

The findings in this study reveal significant differences in the outcomes between children from the Pacific Islands and children residing in Hawai'i treated for cancer at KMC's Pediatric Oncology Clinic. Pacific Islands children were more likely to have delays in diagnosis and treatment, more likely to not complete treatment, more likely to be lost to follow-up, and more likely to die from their condition than children from Hawai'i.

One of the factors that may contribute to the Pacific Island children's poorer outcomes is the relative lack of medical expertise and equipment on their home islands. McCuddin and colleagues documented that the health care systems in the Pacific Islands are not on par with those available in the United States⁸. The authors specifically cite shortages of medical personnel, medical supplies, and drugs, and "non-functional medical equipment" in American Samoa and Guam. More broadly, the Pacific Islands lack the resources to fund a health infrastructure that meets the standards of the U. S., despite the U.S. government's partial payment of benefits such as Medicaid in some of the jurisdictions. Palafox and Yamada² state that "...the health systems in many of the U.S.-associated jurisdictions are inappropriate, have been unsuccessful at improving health, and are not sustainable from either a financial or human resource standpoint." The health plans often lack emphasis on public health and preventive services, and instead spend a disproportionate amount of their budgets on out-of-country referrals for tertiary care. This tertiary care usually costs more than the health plan can afford, leaving families to pay for the rest, out of pocket⁷. These descriptions of the Pacific Islands' health care systems suggest that the disparity of pediatric cancers may be due to a lack of qualified providers, lack of testing equipment, and lack of adequate health budgets, all of which work to delay cancer diagnoses and increase the likelihood that the cancer will be diagnosed at such an advanced stage that it will not respond to treatment.

Factors that occur following referral to Hawai'i also may contribute to the disparity in pediatric cancer outcomes. Pacific Island-based parents accompanying their children must leave their homes, jobs, and families thousands of miles away to seek treatment in Hawai'i. They face numerous barriers to completing treatment, including financial difficulties, gaps in communication with providers due to language and cultural differences, and the loss of their customary network of social support⁷. These difficulties may impair Pacific Island families' ability to maintain contact with KMC after treatment is finished and contribute to their greater rates of loss to follow-up and failure to finish treatment protocol.

Additional factors that may contribute to the disparity in outcomes between Pacific Islands and Hawai'i patients occur when the Pacific Islands patients return to their home islands. Many families must interrupt treatment at KMC to return home, for family or financial reasons. Non-adherence to treatment has not been observed among Pacific Islands' pediatric cancer patients who are in Hawai'i and undergoing treatment⁹. However, maintaining treatment on the home island is extremely difficult, and in some cases impossible. First, the prescribed treatment may not be available on the island. Second, the island may lack the medical expertise necessary to provide or maintain the prescribed treatment. Finally, KMC has no protocol for maintaining contact between the oncologists and their patients once the family leaves Hawai'i; it is up to the families and the medical providers on the home islands to maintain contact with KMC. This contact is often severed due to technical problems, costly communication, and/or lack of personnel. This can affect both the adherence to the treatment regimen as well as the continuation of follow-

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up after treatment is completed. The greater loss to follow-up among Pacific Islands children may also mean that the death rate might be even higher among this population than is evidenced from the review of KMC medical records, as we were unable to follow up to see if children died after returning home.

Given all of these factors, improving the outcomes of pediatric oncology patients referred from the Pacific Islands so that they are comparable to those of Hawai'i residents will be a monumental task. The Pacific Islands' health care infrastructures could be improved to include more staff with training in oncology, better equipment for testing, more effective follow-up for cancer patients, and better access to cancer treatments. In the short run, existing programs and services could be strengthened by providing early screening and monitoring of infants and young children, increasing the chances of early detection of pediatric cancers. An

interim system for evaluation and diagnosis of identified cases could be provided by specialty clinics or through computer-assisted technology such as telemedicine. The infrastructure for treatment of referral patients, once they are in Hawai'i could also be improved by providing better non-medical support to overcome cultural and language barriers and to maintain better contact when families return home. All of these improvements will require a greater financial commitment from the U.S. government towards the health of the people of the Pacific Islands, a commitment that is by no means guaranteed.

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A person who betrays a confidence
or spreads words of others
is a basket with a hole in it.

Mortlockese proverb