Cancer in Kosrae State, Federated States of Micronesia

Abstract: Little is known about the impact of cancer and the extent of cancer-related services in Kosrae. The purpose of this study, funded by the National Cancer Institute, was to document the state of cancer awareness and services in Kosrae and to begin to identify cancer-care needs. Findings suggest that cancer is the eighth-leading cause of death in Kosrae, although a number of factors contribute to a possible undercount of cancer cases. Cancer-related services are limited. A number of needs were identified, and an action plan was developed based on three priority areas: 1) establishing a cancer registry; 2) increasing public awareness about cancer risk, prevention, and detection; and 3) expanding cancer screening and detection programs. *Key Words:* Medically underserved area, needs assessment, oncology services, Pacific Islanders, quality of health care, health services research

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Introduction

This paper presents findings from an assessment of cancer awareness and needs in Kosrae, funded by the Center to Reduce Cancer Health Disparities - National Cancer Institute. This work represents the first time that cancer needs were assessed and prioritized for Kosrae.

History, geography, and population of Kosrae State

The State of Kosrae is the only single-island state in the Federated States of Micronesia (FSM). Altogether, the FSM includes approximately 607 islands, grouped into four states—Yap, Chuuk, Kosrae, and Pohnpei—in the Western Pacific, which lie between 1°S and 14°N latitude and between 135°E and 166°E longitude. Although the islands are situated across a large expanse of ocean, the FSM has a combined total land area of only 271 square miles. The nation's 600+ islands vary from large, high mountainous islands of volcanic origin to small coral atolls.

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The relationship between the United States (U.S.) and Kosrae began during World War II. Prior to that, from about 1920, Kosrae and the rest of Micronesia had been under the administration of Japan. After World War II, the United Nations created the Trust Territory of the Pacific Islands (TTPI) and designated the U.S. as the trustee. TTPI included Kosrae, Pohnpei, Chuuk, Belau, Yap, the Marshall Islands, and the Northern Mariana Islands. In 1979 the districts of Kosrae, Chuuk, Yap, and Pohnpei formed a federation under the Constitution of the Federated States of Micronesia (FSM), making the islands a sovereign and independent nation. Despite this, much of the FSM's economics were still closely tied to the United States. The FSM continued to use the U.S. dollar as currency and in 1982, a Compact of Free Association was made between the U.S. and the FSM in order to fulfill the U.S. promise to promote economic development and self-sufficiency in the islands. U.S. financial support to the FSM was recently renewed in late 2003 thus extending the U.S.'s involvement in the region for the next 20 years[1].

The island-state of Kosrae is located in the furthest southeastern point of the FSM. It is the second-largest inhabited island in the FSM after Pohnpei, with a land area of approximately 42.3 square miles. The inner part of the island is characterized by high, steep, rugged mountain peaks, with Mount Finkol being the highest point of Kosrae at 2,064 feet above sea level. Because of the steep, rugged mountain peaks, all of these communities are coastal communities. The island is surrounded by low-lying reefs and mangrove swamps.

Kosrae State is divided into the four municipalities—Lelu, Malem, Utwe, Tafunsak. The capital of Kosrae is Tofol, located in the municipality of Lelu. Tofol is the location of the majority of the government buildings and offices, the sole high school, the Kosrae State Hospital, and the offices of private businesses including Continental Air Micronesia, the Bank of the FSM, and the FSM Development Bank. The community of Walung (population of 200), which is part of Tafunsak municipality, is isolated and only accessible by a half-hour boat ride at high tide. All other communities are connected by paved roads, and it is possible to drive from one end of the island

to the other in approximately two hours.

Based on the 2000 preliminary census counts, the total population of the FSM stands at 107,008 residents. Kosrae has the smallest state population in the FSM, with 7,686 residents that make up 7.2% of the FSM population. About 50.2% of the population is male, and 49.8% are female. Approximately 33% of the residents live in Tafunsak, 33% in Lelu, 20% in Malem, and 14% in Utwe. The median age of the population is 19.2 years, which means that half the population is under 20 years of age. Only 23% of the population is age 40 or older, including 423 (5.5%) residents age 60 or older, 446 (5.8%) age 50 to 59, and 800 (10.4%) age 40-49 years. According to the FSM 2000 census, there were a total of 1,087 households, with a median of 6.9 persons per household. Almost all (97.4%) households reported some cash income, with a median annual household income of approximately $7,528[2].

Health care delivery in Kosrae

The Kosrae State Department of Health Services (DHS) is responsible for operating the Kosrae State Hospital and providing primary care and preventive services. The Kosrae State Hospital has an emergency room, outpatient clinics, inpatient wards, surgical suites, a dental clinic, a pharmacy, laboratory and X-ray services, and health administration and data management offices, but no ventilator or dialysis units. By Kosrae state law, no patient can be denied care, and hence all patients who need hospital-based care are admitted. Only 17% of Kosraeans are insured (predominantly government employees and their dependents), so most Kosraeans must pay for care in cash or labor (e.g., by helping with hospital maintenance). Even if they can afford to pay, they are charged only 8% of the absolute cost of the care rendered.

Complex medical cases cannot be treated at Kosrae State Hospital, and physicians may ask the Medical Referral Committee (MRC) to consider sending a patient to an off-island medical facility. The MRC is chaired by the Director of Health and comprised of physicians and hospital administrators. Meetings are held on a case-by-case basis to determine whether a patient will be transferred to another facility for care. Patients must have a good prognosis. If an off-island referral is approved and the person is insured, the insurance will pay up to $50,000 of the bill. If the person is uninsured, the care is paid for by the government with the understanding that the patient will pay back 50% of the total cost. There are limited funds available for the off-island medical referral program.

The Division of Preventive Health Services of the DHS provides services in nine key areas as specified in the State Preventive Health Plan (2001-2006). These include: 1) maternal and child health; 2) immunizations; 3) non-communicable diseases; 4) communicable-disease control and prevention; 5) AIDS prevention; 6) mental health promotion and substance abuse prevention; 7) STD control and prevention; 8) environmental health; and 9) family planning. Eight programs receive funds from the U.S. government. The Division provides services through six community clinic centers, at 11 schools, at the jail, and to home-bound residents. It also sponsors preventive health workshops.

The needs assessment portion of the Health Plan notes a general need for residents to increase the level of self responsibility and family health and the need for the Division to increase its capacity to provide community outreach, health education, and screening. Division personnel include three physicians, ten nurses, a mental health/substance abuse counselor, two environmental health staff, a health educator, an immunization data clerk, and 21 community outreach workers[3].

Methods

The cancer needs assessment was conducted in Kosrae in spring 2003 by medical residents affiliated with the Department of Family Practice and Community Medicine at the John A. Burns School of Medicine, University of Hawai'i.

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Kosrae does not have a centralized cancer database. Rather, cancer cases are documented in several unrelated data sources, which were reviewed by the authors. These sources included: 1) death certificates; 2) inpatient manual logbooks; 3) inpatient and outpatient medical records; 4) operating room manual logbooks; 5) Pap smear logbooks; 6) lab manual logbooks; 7) the Medical Referral Committee logbook; and 8) a computerized patient tracking system based on ICD (*International Classification of Diseases*) coding. For this report, data from all of these sources were combined to create a complete, unduplicated list of patients diagnosed with cancer in Kosrae.

Data on mortality in the State of Kosrae are compiled by the Office of Health Statistics. The mortality statistics are divided into 16 categories, and summary charts were available for the years 1998 and 1999. Summaries were not available for 2000-2002; hence all death certificates for those years were manually reviewed by the authors.

This information was cross-referenced with other data sources noted above to confirm the cause of death. In some cases, an individual may have been suspected of having cancer or a co-morbidity of cancer even though the cause of death was attributed to another disease.

The reliability of the other data sources is limited as well. For example, due to poor storage conditions, many of the inpatient logbooks have been damaged by the weather or by insects. Inpatient and outpatient medical records are maintained in a single chart; however, pertinent information from other sources often was missing. Manually maintained logbooks for surgeries, Pap smears, and other laboratory tests include date, patient name, procedure, and whether a specimen was obtained. Funding restrictions limit the volume of specimens and samples that can be processed and analyzed. People with and without insurance must pay out of pocket for these tests, and those with insurance can request reimbursement. Also, results recorded in the laboratory logbook generally were not repeated in other logbooks, even when the diagnosis of cancer was evident. These conditions contribute to a possible undercount of cancer cases in Kosrae.

Information about the health care system and cancer-related services in Kosrae was obtained through key informant interviews with physicians and public health staff. Needs were identified by these key informants as well, and these were organized in four categories: data; training; equipment and supplies; and services and programs. From these needs, a list of recommendations was developed by the authors. Needs were prioritized and preliminary planning was done by the Pacific Islander delegates of the Cancer Council of the Pacific Islands in the Republic of the Marshall Islands in August 2003. These plans were further refined, and a strategic action plan was developed in November 2003 at a meeting in Pohnpei, FSM.

Findings: mortality and morbidity

Leading causes of death, 1998-2002

There were 231 deaths in Kosrae from 1998 through 2002 (Table 1). The leading cause of death in Kosrae was diseases of the circulatory system (35.5%). The second-leading cause of death was diseases of the endocrine system (12.1%), which were primarily due to diabetes and its secondary complications. The third most common cause of death was infectious disease (7.4%), chiefly sepsis. Of the 231 deaths, only 11 (4.8%) were attributed to cancer, making cancer the eighth-leading cause of death. However, it is likely that cancer is under-reported as a cause of death because of limited screening and diagnostic services in Kosrae.

Table 1. Leading causes of death in Kosrae State, 1998-2002

Cause of death	N	(%)
Total Deaths	231	(100.0)
Diseases of the circulatory system	82	(35.5)
Endocrine, nutritional, and metabolic diseases	28	(12.1)
Infectious and parasitic diseases	17	(7.4)
Injury and poisoning	16	(6.9)
Perinatal conditions	14	(6.1)
Diseases of the respiratory system	14	(6.1)
Diseases of the genitourinary system	13	(5.6)
Cancer	**11**	**(4.8)**
Diseases of the nervous system	6	(2.6)
Diseases of the digestive system	5	(2.2)
Ill-defined signs and symptoms	4	(1.7)
Mental disorders	4	(1.7)
Complications of pregnancy, childbirth, and the puerperium	3	(1.3)
Congenital anomalies	1	(<1)
Skin and subcutaneous tissue diseases	1	(<1)
Unknown	12	(5.2)

Cancer deaths, 1998-2002

Of the 11 cancer deaths on record for 1998 through 2002, six cases occurred in women and five in men. The types of cancers included prostate, ovarian, thyroid, colon, sinus, breast, parotid, lung, renal, and squamous cell carcinoma of the hand (Table 2). No single cancer type dominated.

Table 2. Detailed diagnosis for 11 cancer deaths, State of Kosrae, 1998-2002

Male cancer deaths
Prostate cancer
Adenocarcinoma of the colon, with metastasis
Adenoid cystic carcinoma of the maxillary sinus, with metastasis to the lungs
Parotid cancer
Squamous cell carcinoma left hand, with metastasis to the lung
Female cancer deaths
Ovarian cancer
Thyroid cancer
Breast cancer, with metastasis to the lungs, brain, bone
Cervical cancer, with regional metastasis
Pulmonary carcinoma and breast myoepithelial cancer
Renal tumor

Table 3. Cancer cases by type of cancer, Kosrae State, 2000-2002

	N	(%)
Total cancer cases	34	(100.0)
Breast	6	(17.6)
Cervical	5	(14.7)
Ovarian	5	(14.7)
Blood	3	(8.8)
Colon	2	(5.9)
Endometrial	2	(5.9)
Lung	2	(5.9)
Prostate	2	(5.9)
Acoustic Shwanoma	1	(2.9)
Brain	1	(2.9)
Maxillary sinus	1	(2.9)
Parotid	1	(2.9)
Renal	1	(2.9)
Skin	1	(2.9)
Thyroid	1	(2.9)
Total precancerous cervical conditions	43	(100.0)
ASCUS	31	(72.1)
CIN I	8	(18.6)
CIN II	1	(2.3)
CIN III	3	(7.0)

Cancer cases

The data from the above resources were combined to give a rough estimate of known and suspected cases of cancers (Table 3). There were 34 cases of cancer, including 6 (17.6%) cases of breast cancer, 5 (14.7%) cervical cancer, 5 (14.7%) ovarian cancer, 3 (8.8%) cases of cancer of the blood, and one or two cases of cancer of the colon, endometrium, lung, prostate, brain, maxillary sinus, parotid, kidney, skin, and thyroid. Additionally, the statistics include 43 cases of precancerous cervical lesions, including 31 (72.1%) of ASCUS, 8 (11.6%) cases of CIN I, a case of CIN II, and 3 (7.0%) cases of CIN III – 3 cases). Women with precancerous cervical lesions are referred for appropriate treatment, thus preventing the potential development of cervical cancer in these individuals.

Findings: cancer-related services

Administration, planning, and data

There is little mention of cancer in the Kosrae Health Plan, although physicians agree that cancer is a problem. There is limited funding, infrastructure, and training programs specifically for cancer prevention, education, diagnosis, treatment, or management. It should be noted that Kosrae's existing preventive health programs are about 90% federally funded; if these funds were to stop, preventive programs would cease to exist. This has been a problem in the past, when programs established with federal funds were later closed due to discontinued funding.

The DHS Office of Health Statistics has a staff that includes a health statistician, data technicians, and data clerks. This office manages data related to deaths and hospital admissions. A computerized inpatient tracking system, *WinPAS*, which has a cancer registry component, is in use. Inpatient diagnoses provided by the physician are assigned ICD-10 codes, which are entered into the computer program by medical records staff. Needs for training in ICD coding, data retrieval, and data analysis were identified, as was the need for a back-up computer system.

Kosrae has no cancer registry. The *WinPAS* data system potentially could be used as a cancer registry. However, it does not include cancer cases identified through outpatient and screening services or at death, leaving this list as a partial and incomplete representation of cancer cases in Kosrae. Also, cancer cases are undercounted. Kosrae lacks equipment, supplies, and staff needed to diagnose and stage cancers. Thus, a cancer diagnosis may not be included in the hospital discharge summary and death certificate, and a cancer death may be classified under a different category.

Public health services

The Division of Preventive Health Services provides some cancer-related programs in the areas of awareness, outreach, prevention, and screening.

Breast and Cervical Cancer Screening. The Division has programs to increase cancer awareness and screening related to breast and cervical cancer. Pap smear tests and breast exams are provided through the Maternal and Child Health and the Family Planning programs and are performed in the antenatal, postpartum, family planning, and gynecology clinics. A nurse is assigned to conduct Pap smears and maintain the Pap smear logbook, and another nurse has been designated for STD screening. Two female physicians and the nurse practitioner perform clinical breast exams. The cost of performing, processing, and reading Pap smears is covered by the government, and it is impressive to note the number of precancerous cervical lesions that are identified and treated through these clinics.

The Division feels that its programs are reaching the young women of reproductive age. However, more resources for staff, supplies, and outreach services are needed to reach the women in the older age groups. Another obstacle is that many women are hesitant about screening, and some are afraid that they have cancer and do not want to know.

Division personnel also noted that, although federal funds are available for analysis of Pap smears, there is a delay in sending specimens for analysis and in receiving

results. The fax machine often is not available or needs repair, and results that are mailed may be delayed by several weeks or lost. Although Pap smear results are logged, they are not cross-referenced with prior Pap smears. Colposcopy and cervical biopsy are not available on a regular basis.

Prostate Cancer Screening. Routine prostate cancer screening is not done. Symptomatic men, however, are screened and referred for appropriate management.

Tobacco Prevention. A recent survey showed that at least 30% of school-aged children under the age of 18 have tried tobacco or currently use it on a regular basis. FSM regulations forbid the sale of tobacco to minors (anyone less than 18 years of age). Compliance checks are conducted twice a year, and the majority of stores are non-compliant with the law. Youth do not need to buy tobacco in the store, however, because they can buy cigarettes for 15 cents a piece and a small pack of tobacco for 50 cents from adults who buy and split packs and pouches. Prevention efforts also are thwarted by tobacco companies that sponsor contests and give prizes (including free t-shirts and hats) to attract youth and adults to smoking.

The Substance Abuse and Mental Health Division has a total of nine personnel of which one, the Tobacco Educator, is devoted to tobacco awareness, education, and prevention activities. He is assisted by the health educators in the community who provide tobacco prevention education services as part of a substance abuse prevention program at schools, youth groups, and churches. There are six elementary schools and one high school on the island, and the Tobacco Educator visits each of the schools approximately six times each year. Other tobacco prevention services include radio public service announcements, television commercials, and participation in the FSM National Smoke-Out Day.

Medical services

Medical services related to the diagnosis and treatment of cancer are provided primarily by a surgeon and the hospital staff physicians. Although physicians have received some training in cancer care, they would welcome additional training in the diagnosis, treatment, and management of cancer patients.

Available services related to the diagnosis of cancer include biopsies and aspirations, upper gastrointestinal (GI) studies, bronchoscopy, and ultrasound. Related to colorectal cancer screening, the surgeon is able to perform proctoscopy when necessary. However, there is no equipment available for performing sigmoidoscopy or colonoscopy. Treatment services are limited to surgical intervention. There is no capability for initiating chemotherapy or providing radiation therapy, nor do cancer patients have access to clinical trials on Kosrae. Telemedicine consultations are available, but telemedicine equipment needs upgrading, and internet connections are slow. Aside from cervical cancer patients, many patients with cancer are identified in the late stages when they are symptomatic and require medical intervention.

Out-of-State Care for Kosraean Cancer Cases. Between 1996 and 2002, the MRC logbook suggests that 23 of the 210 referrals for out-of-state care were for cancer or suspected cancer. Financial constraints, as well as the requirement that people referred off island have a good prognosis, limit the number of cancer patients that can be treated abroad.

Laboratory and radiology services

Problems with equipment failure and lack of appropriate reagents sometime leave the lab unable to perform even these simple essential tests. The lab can perform routine blood and urine tests, but cannot analyze Pap smears and tests for prostate-specific antigen (PSA) and for liver and colon cancer markers. These tests are sent to Honolulu for processing and reading. Even if Kosrae has funds to pay for analysis, results may not be received for several weeks. As mentioned previously, funding restrictions limit the volume of samples and specimens that can be processed.

Radiological services are limited to diagnostic X-rays and ultrasound. Diagnostic studies that can be performed include upper gastrointestinal (GI) series, barium enemas, and intravenous pyelograms. The portable X-ray machine is non-functional, so all patients must be brought to the stationary X-ray machine. The physicians read their own X-rays. There are no fluoroscopic units, mammograms, CT scans, or MRI scans.

Non-Governmental Organizations

The Kosrae Women's Association sponsors cancer awareness activities in partnership with the Department of Health.

Findings: cancer-related needs

Data needs

No cancer registry exists in Kosrae State, and the use of the *WinPAS* program or another software program can be explored. Data staff requested training in coding cancer using the ICD-10 coding system, in using the *WinPAS* computer software, in establishing and maintaining a cancer registry (whether this is using *WinPAS* or another system), and in using data to answer cancer-related questions. Data staff also requested computers and data-

Table 4. Action plan for Kosrae's three cancer-related priority areas

Objectives	Activities
1. Establish a Cancer Registry	a. Acquire a desktop computer system b. Train 10 people in computer & data management c. Train 16 staff (8 physicians, 4 nurses, 4 medical records staff) in ICD coding. d. Hire nurse to oversee cancer program e. Hire data clerk
2. Increase public awareness and education on cancer	a. Develop and produce cancer PSAs for radio. b. Develop and produce PSAs for cable and local TV broadcast on cancer info c. Develop and produce printed materials d. Conduct community workshops (5 per municipality)
3. Increase screening capacity by maintaining breast & cervical cancer screening and implementing prostate, lung, and GI cancer screenings	a. Develop screening protocols for each of prioritized cancers b. Train clinical staff to do rectal exams c. Purchase serum marker for prostate cancer

related software.

Personnel and training needs

Personnel. A pathologist is needed to help interpret diagnostic tests and to improve the determination of cause of death. Also recommended was a full-time staff person to coordinate cancer awareness and services for the DHS.

Training. Physicians asked for training in the diagnosis of various cancers and refresher training on equipment used in cancer detection, e.g., ultrasound, flexible sigmoidoscopy, colonoscopy, endoscopy, colposcopy, fine-needle aspiration, and biopsy. In the area of cancer care, physicians wanted training in maintenance of chemotherapy, complementary healing, pain management, care of terminal patients, and hospice care. Physicians wanted access to telemedicine conferencing and written cancer guidelines and updates. They also requested training through teleconferencing mechanisms and wanted to receive Continuing Medical Education credits for participating.

Nurses asked for more information about screening guidelines and protocols and about establishing outreach programs. They also requested training in specialized nursing care for cancer patients, and in palliative and terminal care. They would prefer on-site, hands-on training. They also asked for increased staffing if their responsibilities were to be expanded, noting that the system was already stressed.

Laboratory staff wanted to expand their capabilities so that they could distinguish normal Pap smears from abnormal Pap smears, reducing the number of smears that would need to be sent out of country. They wanted to learn to read blood smears. They also wanted training on proper handling and storage of specimens. Radiology personnel wanted to upgrade their skills, including skills in tele-radiology and training in equipment management and maintenance. Pharmacy staff requested training on the newer medications and on medication storage, distribution, and inventory systems. Public Health staff asked for help to update their knowledge and skills in cancer education and screening.

Needed equipment and supplies

Physicians noted a constant shortage of medication. They requested telemedicine equipment (with a functioning link) and computers with internet access for digital libraries and journal searches. Nurses also wanted computers so that they maintain their logbooks in spreadsheet format.

For diagnosis, physicians wanted the equipment and necessary supplies to perform endoscopy, sigmoidoscopy, colonoscopy, rhinolaryngoscopy, colposcopy, and bronchoscopy. For laboratory and radiography, staff wanted a new refrigerator, a chemistry analyzer, and reagents and supplies to perform existing and new lab tests. Public Health staff requested Hemoccult® cards and developer, as well as educational materials, e.g., posters, handouts, and videos about cancer.

Needed services and programs

There is a need to develop a comprehensive and coordinated system of services to address the problems of morbidity and mortality related to cancer. There also is a need for a steady source of funds to pay for the analysis of specimens and to reduce the turn-around time for diagnostic tests.

Recommendations by the assessment team

Based on the findings of this report, the assessment team offered ten recommendations for improving cancer-related services in Kosrae State.

- Recommendation 1: Expand funding for diagnostic and treatment services for cancer.
- Recommendation 2: Develop and implement an early detection screening program for all cancers.

- Recommendation 3: Provide public awareness on cancer risk, prevention, and early detection.
- Recommendation 4: Establish a telemedicine link for consults, radiology, and continuing medical education.
- Recommendation 5: Increase access of cancer patients to medication, including support for a pharmacist or pharmacy technician who can prepare chemotherapy.
- Recommendation 6: Establish a centralized cancer registry system.
- Recommendation 7: Restructure and fund the off-island referral system.
- Recommendation 8: Increase the number of nurses.
- Recommendation 9: Educate government leaders and community leaders about the need for resources to develop and maintain an infrastructure to address problems related to cancer morbidity and mortality.
- Recommendation 10: Reassess cancer needs and evaluation implementation strategies in the future.

Prioritizing and setting objectives

Needs were prioritized and preliminary planning was done by the Pacific Islander delegates of the Pacific Cancer Council in the Republic of the Marshall Islands in August 2003. These plans were further refined, and a strategic action plan was developed in November 2003 at a meeting in Pohnpei, FSM. This group designated three priority areas:

- Priority 1. Establish a cancer registry.
- Priority 2. Increase public awareness about cancer risk, prevention, and detection.
- Priority 3. Expand cancer screening and detection programs.

A summary of a one-year action plan for Kosrae, which was shared with the National Cancer Institute, is shown in Table 4.

Conclusions

According to death records, cancer is the eighth-leading cause of death in Kosrae. A number of factors, however, contribute to a possible undercount of cancer cases in Kosrae. Cancer-related services are limited. Kosrae State wants assistance in establishing a cancer registry, increasing public awareness about cancer, and expanding cancer screening programs.

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E a le puga nisi, a le 'ana nisi.
Let each do his share of the work.
Samoan proverb