2019 NPCR Federated States of Micronesia SUCCESS STORY

Pohnpei State Cancer Registry, Federated States of Micronesia (part of the Pacific Regional Central Cancer Registry program): Mary Rose Johnny, Janos Baksa, Lee Buenconsejo-Lum, MD, FAAFP

Collaborations to improve cancer screening in resource-limited settings using personal connections to improve cancer screening in a remote island setting

NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

SUMMARY: In remote and small communities, personal relationships between cancer registrars and key members of the health care community are critical to maintaining high-quality data collection and ensuring the information is used. Effective relationships have resulted in improved access to cervical cancer screening in Pohnpei State in the Federated States of Micronesia.

CHALLENGE: Federated States of Micronesia (FSM), is comprised of 607 volcanic islands in the middle of the Western Pacific Ocean with a total population of 103,000. Pohnpei State, is home to 35,981 people, around 35% of the total population of FSM. The GDP per capita is $3000. The per capita health expenditures in Pohnpei are $207, compared to $10,224 in the United States. These health expenditures include all of public health and curative/acute care spending. Patients employed by the National Government have health insurance, but the vast remainder of the population is uninsured. The island has no public transportation and many villages have limited accessibility via car. Walking to the hospital or community health center would be a 3-4 hour trip for some. Cervical cancer screening has historically been limited to pregnant women (via US Federal Maternal Child Health block grant funds), but with generally insufficient supplies. There is one US Federally Qualified Health Center on-island that performs limited cancer screening, as well as one private clinic. There is no CDC-funded Breast and Cervical Cancer Early Detection Program in the FSM[1]. There is no pathologist or cytopathology capability on-island. The one or two obstetricians do not perform complex gynecological cases, and the hospital does not have the capacity for surgical treatment of advanced cancer cases. For women who did receive Pap smear screening, many did not receive results for more than two months and some did not ever receive feedback and results[2].

As a result of poor access to screening for a variety of reasons[3,4] (including cultural), Pohnpei State's age-adjusted cervical cancer incidence rate is 34.4 per 100,000 women which is 4.6 times higher than the US incidence rate and among the highest in the world. The average age at diagnosis is 45. 88% percent of cases are diagnosed at stage 2 or higher, with the many of those cases being diagnosed at stage 4 (or unstageable). Only 58% of patients are alive 5 years after diagnosis. (Pacific Regional Central Cancer Registry, 2007-2015).

As a result of these severe resource limitations, the FSM developed National Standards of Practice for Breast and Cervical Cancer Screening in 2010, which includes use of Visual Inspection with Acetic Acid as the primary cervical cancer screening method[3,5]. Despite the adoption of standards that are more appropriate for resource-limited settings, cervical cancer screening is still not able to be done for more than 16% of the eligible female population[6].

SOLUTION: The Pohnpei State Comprehensive Cancer Control (CCC) program and Cancer Registrar, as well as physician leadership and members of the Cancer Council of the Pacific Islands[7] identified several barriers and proposed some strategies to improve the uptake of cervical cancer screening in Pohnpei. Two major challenges were identified: siloed data and lack of communication. The Pohnpei State Cancer Registrar has been a long-time employee in the medical records department of the State hospital. She has helped to educate the laboratory, radiology and labor & delivery personnel in the hospital on the importance of keeping good track of cervical cancer screenings done and ensuring that the results are shared centrally. When the cancer registry first started in 2007, the cancer registrar actively met with all potential data sources at least every other month. She also continues to travel to the private hospital, to the one private clinic, to the community health center, to the off-island referral office and to the National Government's Health Insurance program to obtain information.

When it became more apparent how fragmented the health care and cancer-related data was, the Pohnpei State Director of Health and Hospital Directors empowered and directed all of the programs to share their information with the cancer registrar. The cancer registrar's office has been the central repository of all cervical cancer screening information for several years. Because most of the health data in the FSM is in a variety of paper formats, the cancer registrar initially did all of the data collection manually. However, this has now evolved to where the medical records staff collects the paper logs from the various staff in public health. The registrar enters the paper data into an Excel spreadsheet. As the laboratory systems have evolved to more electronic, the laboratory assistant also has granted the registrar access to their database. The cancer registrar has been engaged with leadership of public health and the hospital since 2011.

RESULTS: The cancer registrar reconciles all of these data and informs the appropriate personnel to ensure that abnormal pap smears are follow-up upon. The improved data related to both cervical cancer screening, gaps in follow-up and actual cervical cancer incidence and staging data have been shared with the Pohnpei State Non-communicable disease (NCD) Emergency Response Team (SNERT), which is the coordinating mechanism formed in response to the FSM's Declaration of NCDs as a State of Emergency in 2010. The SNERT meets monthly and includes the Cancer Registrar and the CCC program coordinator, as well as other managers of relevant public health and primary care programs. Based on this information and known challenges to screening, the current Pohnpei State Director of Health decided to decentralize many primary care/public health services and take the teams to the remote villages. Since 2018, village-based services include cervical cancer screening, HPV vaccination and other core public health services. They have piloted this program in the most remote municipality and plans are underway to expand these services to the other remote municipalities.

The collective data about cervical cancer screening was also utilized to obtain support for remote telepathology services with Japan. World Health Organization resources were mobilized to provide on-island training of laboratory personnel and primary care physicians so that they could properly prepare Pap smears and biopsy specimens. Additional resources were leveraged with the FSM Telecommunications agency to negotiate a significant discount on internet bandwidth. As a result of this coordinated effort, the turnaround time from Pap collection to the patient receiving results is now averaging two weeks.

SUSTAINING SUCCESS: To ensure continued success in cervical cancer screening and prevention, several processes need to be further institutionalized. Medical records staff should continue to be trained in using data for decision-making. Procedures and protocols related to patient care and data flow should be made into formal policy and include performance metrics. More capacity for quality improvement and quality assurance needs to be developed. Additional resources for cervical cancer screening (training, human resources, supplies and equipment) should be more overtly factored into budget planning. Resources should be sought from a combination of Compact Sector funds, FSM National funds, World Health Organization or United Nations funding. Training partners from the University of Hawaii and other academic partners are also key stakeholders in the continued improvement and success in Pohnpei State.

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