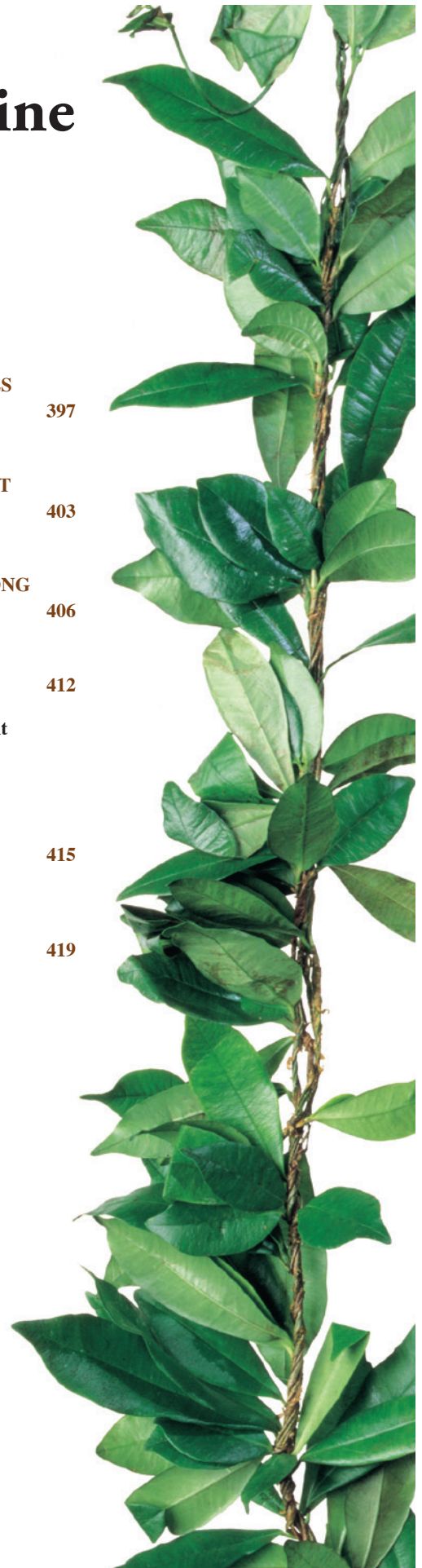


Hawai'i Journal of Medicine & Public Health

A Journal of Asia Pacific Medicine & Public Health

December 2015, Volume 74, No. 12, ISSN 2165-8218

- DISPARITIES IN INFANT MORTALITY DUE TO CONGENITAL ANOMALIES ON GUAM** 397
Jonathan K. Noel MPH; Sara Namazi MS; and Robert L. Haddock DVM, MPH
- ASSESSING THE PREVALENCE OF TRAUMATIC HEAD INJURY AMONGST RECREATIONAL SURFERS IN THE UNITED STATES** 403
Christian Swinney BA
- SOCIOCULTURAL FACTORS THAT AFFECT CHEWING BEHAVIORS AMONG BETEL NUT CHEWERS AND EX-CHEWERS ON GUAM** 406
Kelle L. Murphy DPE, CAPE and Thaddeus A. Herzog PhD
- MEDICAL SCHOOL HOTLINE** 412
Liaison Committee on Medical Education Accreditation, Part III: Educational Program Content, Curriculum Management, and Student Assessment
Sheri F.T. Fong MD, PhD; Jill S.M. Omori MD; Damon H. Sakai MD; Stephanie Nishimura MSW; Noelani Ching BA; Kenton Kramer, PhD; and Richard T. Kasuya MD, MSED
- INSIGHTS IN PUBLIC HEALTH** 415
Newborn Screening Saves Babies Using Public/Private Partnerships
Sylvia Mann MS, CGC
- THE WEATHERVANE** 419
Russell T. Stodd MD





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ISSN 2165-8218 (Print), ISSN 2165-8242 (Online)

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Published by University Clinical, Education & Research Associates (UCERA)

Hawai'i Journal of Medicine & Public Health
677 Ala Moana Blvd., Suite 1016B
Honolulu, Hawai'i 96813
<http://www.hjmph.org>; Email: info@hjmph.org

The Hawai'i Journal of Medicine & Public Health was formerly two separate journals: The Hawai'i Medical Journal and the Hawai'i Journal of Public Health. The Hawai'i Medical Journal was founded in 1941 by the Hawai'i Medical Association (HMA), which was incorporated in 1856 under the Hawaiian monarchy. In 2009 the journal was transferred by HMA to University Clinical, Education & Research Associates (UCERA). The Hawai'i Journal of Public Health was a collaborative effort between the Hawai'i State Department of Health and the Office of Public Health Studies at the John A. Burns School of Medicine established in 2008.

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Disparities in Infant Mortality Due to Congenital Anomalies on Guam

Jonathan K. Noel MPH; Sara Namazi MS; and Robert L. Haddock DVM, MPH

Abstract

In the 1970's and 1980's, there were large inter-village disparities in infant mortality due to congenital anomalies on Guam. A village-level analysis was conducted to determine if these disparities can be explained by behavioral (ie, median age of village females, village fertility ratio), structural (ie, population density, persons per household, single mother households per village, married females per village), and environmental (ie, living in a village where Agent Orange (AO) spraying was conducted) factors. Village-level data for live births and infant mortality due to congenital anomalies (1970-1989) was collected from Guam's Office of Vital Statistics. Data on median age of village females, village fertility ratio, population density, persons per household, single mother households, and married females were obtained from the 1980 US Census. Estimates of village-level AO use were provided through personal communications, and villages were dichotomized into AO and non-AO spray areas. Village location was classified by usual residence of the mother. Linear regression was used to determine associations between infant mortality due to congenital anomalies and the behavioral, structural, and environmental factors. The association between AO spray area and infant mortality due to congenital anomalies was statistically significant under univariable (B [95%CI]= 1.88 [0.64,3.11], P=.005) and multivariable conditions (B [95%CI]= 2.02 [0.08,3.96], P=.042). These results suggest that infants born to mothers whose usual residence was in an AO spray area on Guam are at an increased risk of mortality due to congenital anomalies. Further studies using individual-level data are needed to validate these results.

Keywords

Agent Orange, Guam, Infant, Mortality

Introduction

Guam is a United States (US) territory located in the Western Pacific Ocean. It is the southernmost island of the Mariana Archipelago and is the largest and most populous island in the Micronesian region.¹ In the 1970's and 1980's, Guam experienced large disparities in infant mortality due to congenital anomalies that have gone unexplained. While some villages reported no infant deaths due to congenital anomalies, others reported cause-specific infant death rates as high as 5.62 deaths per 1,000 live births, a figure that was two times greater than the overall cause-specific death rate on Guam (2.43 deaths per 1,000 live births) and in the US (2.5 deaths per 1,000 live births).²

There are several possible behavioral, structural, and environmental explanations for these differences. At the behavioral level, mothers in high-risk villages may give birth at older ages compared to mothers in other villages. Several studies have identified advanced maternal age as a significant risk factor for genetic anomalies and stillbirth.^{3,4} In a review of 142 studies, advanced maternal age was associated with a 2.31-5.46 greater odds of stillbirth, and the odds of stillbirth due to congenital anomalies was found to be 7.5 (OR [95%CI]= 7.50 [3.2, 17.4]).⁵ Mothers in high risk villages may also have more children than

mothers in low risk villages. Statistically significant associations between high fertility rates and child mortality were found in a study of 47 low and middle income countries, although the authors were unable to explain the mechanism that drives this relationship.⁶

Structurally, community and family dynamics may explain differences in infant mortality due to congenital anomalies. Urban environments have been associated with significant increases in congenital anomalies and infant mortality in Asia and Europe.⁷⁻¹⁰ For example, congenital anomalies decreased significantly in rural areas of Henan Province in China between 1997 and 2011 ($P < .001$) but increased significantly in urban locations ($P = .003$).⁹ Family dynamics may encompass both the number of individuals living in a household or single parent households. The Particulate Matter and Perinatal Events Research (PAMPER) study discovered that both infant mortality and family size decreased between 1961 and 1992,¹¹ and in a separate study of 28,647 children conducted in Nigeria, small family size was associated with decreased under-5 mortality.¹² Moreover, a study of approximately 49,000 children in Cameroon, Nigeria, and the Democratic Republic of the Congo determined that under-5 mortality was significantly, or marginally significantly, higher in children of non-widowed single mothers.¹³

Certain environmental exposures, such as herbicides, may also be associated with infant death due to congenital anomalies. In 2005 and again in 2013, the Department of Veterans Affairs (VA) concluded that herbicides, particularly Agent Orange (AO), were used on Guam from 1968 to 1970.^{14,15} AO is a mixture of two herbicides: 2,4,5-trichlorophenoxyacetic acid (2,4,5-T) and 2,4-dichlorophenoxyacetic acid (2,4-D),¹⁶ and has been linked to numerous health effects, primarily caused by contamination of 2,5,4-T with 2,3,7,8-tetrachlorodibenzodioxin (TCDD). TCDD has been classified as carcinogenic to humans by the International Agency for Research on Cancer and as a probable human carcinogen by the US Environmental Protection Agency (EPA).^{17,18} There is also evidence suggesting that AO exposure is associated with ischemic heart disease, Parkinson's disease, and respiratory cancers.¹⁹

Infant and fetal AO exposure can occur through paternal and maternal mechanisms, with recent evidence showing breast milk as an important AO vector.²⁰ The potential effects of AO on offspring have been known since 1969 when offspring of mice exposed to contaminated 2,4,5-T were shown to be at an increased risk of developing congenital anomalies.¹⁶ A meta-analysis on human AO exposure concluded that AO significantly increased the risk of birth defects, although significant between-study

heterogeneity occurred and the authors expressed concern about publication bias.²¹ Moreover, children of fathers who served in southeast Asia during the Vietnam War and participated in Operation Ranch Hand, the US Department of Defense's defoliation program during the war, had significantly greater risk of infant death compared to children of fathers who served in southeast Asia but did not participate in the operation.²²

The reason for the disparities in infant mortality due to congenital anomalies on Guam are currently unknown. The purpose of this study is to determine if behavioral, structural, or environmental factors are associated with village-level infant mortality due to congenital anomalies.

Methods

Total births by village and infant mortality due to congenital anomalies were made available from the Office of Vital Statistics in the Guam Department of Public Health and Public Services for each year from 1970-1989. Infant mortality due to congenital anomalies was determined using ICD-8 and ICD-9 codes 740-759, and the cause specific mortality rate was defined as deaths per 1,000 live births. Village assignment for each birth and death was based on the usual residence of the mother. All villages on Guam were included in the analysis (N=19); however, births and deaths from mothers whose usual residence was a military base or unknown were excluded because of the inability to assess potential behavioral, structural, or environmental exposure levels and their relatively brief exposure to the Guam environment.

Village-level estimates for behavioral and structural exposures were obtained from the 1980 US Census. Census data was included due to the standardized methodology and completeness of data collection. The 1980 Census was used because data collection occurred near the mid-point of the study period. Median age of village females (in years) and the village fertility ratio (ie, the number of children under 5 years old per 1,000 women 15 to 49 years old) were used to assess behavioral exposures. Population density (persons per square kilometer) was used to control for difference in community dynamics. Persons per household, single mother households (per 1,000 families), and married females (per 1,000 females 15 years old and over) were used to control for differences in family dynamics.

Although the VA has concluded that herbicides and AO were used on Guam, exact levels of AO used were unavailable, and the EPA concluded that there are no historical documents related to hazardous chemical use or disposal on Guam.²³ However, a US Air Force Veteran who conducted ground-level AO spraying for vegetation control was able to provide village-level spray estimates based on the recollection of this spray routine (Foster L., Personal Communication). This information was used to dichotomize villages into AO and non-AO spray areas. The Veteran has provided documentation substantiating his claims that he conducted AO spraying on Guam. These include a notarized statement describing the Veteran's use of AO on Guam, a notarized photo identifying AO spray areas from a second Veteran who personally witnessed our Veteran spraying AO,

medical records demonstrating that the Veteran has suffered from physical reactions consistent with AO exposure, including severe acne consisting of skin eruptions and scarring,²⁴ images of the Veteran being sworn into active duty with the Air Force, and photos of polydactyly occurring in the Veteran's granddaughter. Additionally, his claims have been reported and confirmed by The Japan Times and the Daily Beast.^{25,26} All documents made available to the authors regarding the Veteran's AO claims have been turned over to the journal editors.

All variables included in the analysis were examined for symmetry and skewness prior to analysis. No transformations were needed. Villages were classified based on whether the village infant mortality due to congenital anomalies rate was above (high risk) or below (low risk) the overall rate for the island. Chi-square analysis, Fisher's exact test, and independent sample t-tests were used to identify significant differences in the included factors between high and low risk villages. Univariable linear regression models were created to determine unconditional associations between infant mortality due to congenital anomalies and the selected factors. AO spray area was dummy coded and non-AO spray areas were used as the reference group. The remaining independent variables and village infant mortality due to congenital anomalies were treated as continuous variables. R² values were used to estimate the percent variance in infant death due to congenital anomalies explained. A multivariable linear regression model was created to determine conditional

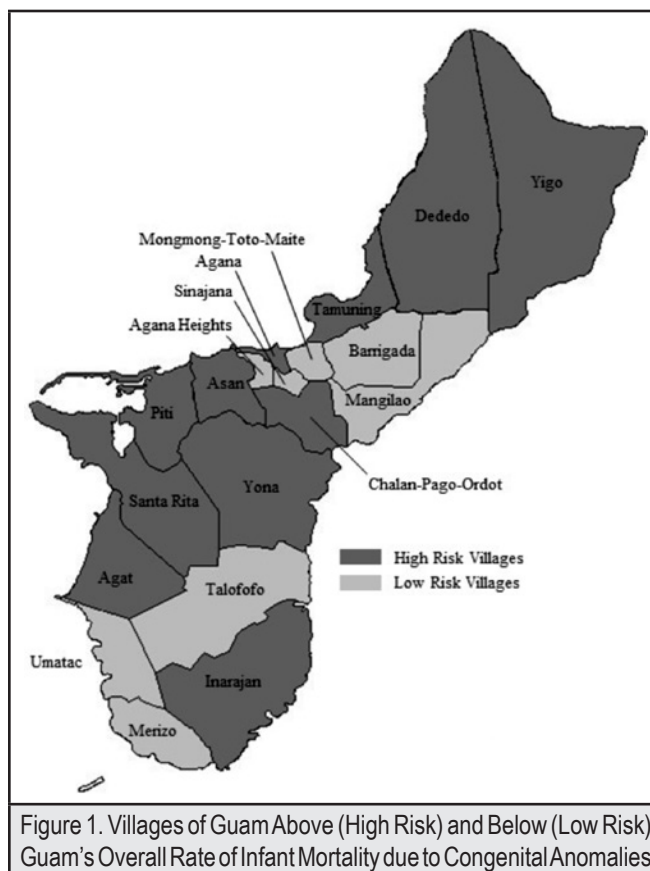


Figure 1. Villages of Guam Above (High Risk) and Below (Low Risk) Guam's Overall Rate of Infant Mortality due to Congenital Anomalies

significant associations. Multicollinearity was assessed using variance inflation factors (VIF). Variables with a VIF greater than 10 were examined and removed if significantly correlated with other variables in the model. The analysis was conducted using IBM SPSS Statistics for Windows, Version 21.0 (Armonk, NY, USA), and statistical significance was set at 0.05 a priori.

Results

Eleven villages on Guam were classified as high risk villages and eight were classified as low risk villages (Figure 1). From 1970-1989, there were 121 infant deaths due to congenital anomalies among 49,841 live births on Guam, resulting in a cause-specific death rate of 2.43 per 1,000 live births (Table 1). Congenital anomalies included congenital heart disease, anencephaly, and diaphragmatic hernia. Within high risk villages, the cause-specific death rate was 2.96 per 1,000 live births while the rate was 1.31 per 1,000 live births among low risk villages. The difference between these values was statistically significant ($\chi^2(1) = 11.628, P < .001$).

Village	Infant Deaths	Live Births	Infant Mortality Rate (/1,000 Live Births)
High Risk			
Asan	5	889	5.62
Piti	5	948	5.27
Chalan-Pago-Ordot	8	1,905	4.20
Agat	10	2,999	3.33
Yona	8	2,412	3.32
Inarajan	4	1,308	3.06
Agana	3	1,106	2.71
Santa Rita	4	1,516	2.64
Dededo	29	11,257	2.58
Tamuning	17	6,635	2.56
Yigo	7	2,797	2.50
Sub-Total	100	33,772	2.96
Low Risk			
Merizo	2	1,022	1.96
Barrigada	6	3,620	1.66
Mongmong-Toto-Maite	5	3,036	1.65
Agana Heights	2	1,413	1.42
Mangilao	4	3,278	1.22
Sinajana	2	1,926	1.04
Talofoto	0	1,271	0.0
Umatac	0	503	0.0
Sub-Total	21	16,069	1.31
Total	121	49,841	2.43

*Village of mother's usual residence

Overall mean median age of village females was 21.7 years (SD = 2.27) and the mean fertility ratio was 468.9 children under 5 years old per 1,000 women 15 to 49 years old (Table 2). There were approximately 367 persons per square kilometer and 4.24 persons per household. There were 90.8 single mother households per 1,000 families, and there were 384.0 females married per 1,000 females 15 years old and over. Twelve villages were classified as AO spray areas. There was a statistically significant association between village type and AO spray area ($P = .006$). No other statistically significant differences based on village type were detected (P 's = .065-.921).

Variable	Overall	High Risk Villages ^b	Low Risk Villages ^b	T ^e	P ^f
Median Age of Village Females ^c	21.7 (2.27)	22.1 (2.32)	21.0 (2.18)	1.05	.307
Fertility Ratio ^c	468.9 (81.0)	470.4 (101.7)	466.9 (45.7)	0.10	.921
Population Density ^c	366.5 (401.5)	246.7 (245.7)	531.3 (524.2)	1.43	.187
Persons per Household ^c	4.24 (0.67)	4.11 (0.69)	4.42 (0.64)	1.01	.326
Single Mother Households ^c	90.8 (31.6)	81.9 (29.8)	103.0 (31.7)	1.49	.155
Females Married ^c	384.0 (51.5)	402.5 (50.3)	358.6 (43.9)	1.98	.065
AO Spray Villages ^d	12 (63.2)	10 (90.9)	2 (25.0)		.006

^aMean (SD); ^bData from the Office of Vital Statistics in the Guam Department of Public Health and Public Services; ^cData from the 1980 US Census; ^dFisher's exact test was used, no t-statistic was produced; ^ethe T statistic is calculated by dividing the difference between groups by the standard error of the total sample; ^f $P < .05$ is considered statistically significant. AO, agent orange.

Univariable linear regression determined that the association between AO spray area and infant mortality due to congenital anomalies was statistically significant (B [95%CI] = 1.88 [0.64, 3.11], $P = .005$) (Table 3). AO spray area explained approximately 38% of the variance ($R^2 = 0.38$). There were no other statistically significant associations with infant mortality due to congenital anomalies (P 's = .111-.400).

In the multivariable linear regression model, median age of village females, persons per household, and married females exhibited high multicollinearity (VIF's = 12.17-25.83). Therefore, three multivariable models were created, each using only one of the correlated variables plus three additional covariates (fertility ratio, population density, and single mother households). Under multivariable conditions that included median age of village females (Model 1), the association between AO spray area and infant mortality due to congenital anomalies was statistically significant (B [95% CI] = 2.02 [0.08, 3.96], $P = .042$), and the model explained approximately 51% of the variance ($R^2 = 0.51$) (Table 4). No other covariates were statistically significant (P 's = .244-.687). Similar statistically significant coefficients

for AO spray area were produced when median age of village females was replaced by persons per household (Model 2) (B [95% CI] = 1.71 [0.04, 3.39], $P = .046$) and married females (Model 3) (B [95% CI] = 1.82 [0.08, 3.55], $P = .042$).

Discussion

Infants of mothers whose usual residence was in AO spray areas had an increased risk of mortality due to congenital anomalies compared to infants of mothers whose usual residence was in non-AO spray areas. AO spray area was the only statistically significant predictor of infant mortality due to congenital anomalies under univariable and multivariable conditions. This increased risk is unlikely to be due to overall greater rates of infant mortality due to congenital anomalies on Guam. Indeed,

the mean US infant mortality rate due to congenital anomalies between 1970 and 1989 was 2.5 deaths per 1,000 live births, slightly greater than that of Guam found here.²

Significant associations between AO and infant mortality are consistent with previously published literature. In a meta-analysis of 9 peer-reviewed and 13 unpublished studies, parental exposure to AO resulted in a 95% increased risk of birth defects (RR 95% CI) = 1.95 (1.59, 2.39).²¹ The risk of birth defects was dose dependent, with studies in Vietnamese populations producing greater relative risk estimates (RR (95% CI) = 3.00 (2.19, 4.12)) than studies in non-Vietnamese populations (RR (95% CI) = 1.29 (1.04, 1.59)). A later meta-analysis of 4 peer-reviewed and 3 unpublished studies determined that the pooled relative risk for spina bifida, a birth

Table 3. Associations between Village-Level Variables and Infant Death due to Congenital Anomalies, Univariable Linear Regression

Variable	B	95% CI	T ^a	P ^b	R ²
AO Spray Area	1.88	0.64, 3.11	3.21	.005	0.38
Median Age of Village Females	0.20	-0.13, 0.53	1.30	.213	0.09
Fertility Ratio	-0.004	-0.01, 0.01	0.86	.400	0.04
Population Density	-0.001	-0.003, 0.001	1.14	.270	0.02
Persons per Household	-0.73	-1.83, 0.37	1.41	.178	0.05
Single Mother Households	-0.01	-0.04, 0.01	1.03	.317	0.06
Married Females	0.01	-0.003, 0.03	1.68	.111	0.14

^athe T statistic is calculated by dividing B by the standard error of B; ^b $P < .05$ is considered statistically significant. AO, agent orange; CI, confidence interval.

Table 4. Associations between Village-Level Variables and Infant Death due to Congenital Anomalies, Multivariable Linear Regression

Variable	B	95% CI	T ^a	P ^b
Model 1^c				
AO Spray Area	2.02	0.08, 3.96	2.25	.042
Median Age of Village Females	-0.16	-0.82, 0.50	0.53	.607
Fertility Ratio	-0.008	-0.02, 0.01	1.22	.244
Population Density	-0.001	-0.003, 0.002	0.78	.450
Single Mother Households	-0.005	-0.03, 0.02	0.41	.687
Model 2^d				
AO Spray Area	1.71	0.04, 3.39	2.21	.046
Persons per Household	0.48	-2.08, 2.17	0.05	.962
Fertility Ratio	-0.005	-0.02, 0.01	0.82	.427
Population Density	-0.001	-0.004, 0.001	1.10	.290
Single Mother Households	-0.003	-0.04, 0.03	0.19	.852
Model 3^e				
AO Spray Area	1.82	0.08, 3.55	2.26	.042
Married Females	-0.003	-0.03, 0.02	0.26	.798
Fertility Ratio	-0.01	-0.02, 0.004	1.26	.230
Population Density	-0.001	-0.003, 0.001	1.25	.232
Single Mother Households	-0.01	-0.05, 0.03	0.33	.745

^athe T statistic is calculated by dividing B by the standard error of B; ^b $P < .05$ is considered statistically significant; ^c $R^2 = 0.51$; ^d $R^2 = 0.50$; ^e $R^2 = 0.50$. AO, agent orange; CI, confidence interval

defect resulting in the incomplete closer of the spinal column around the spinal cord, after paternal AO exposure was 2.02 (95% CI = 1.48, 2.74).²⁷ Moreover, paternal AO exposure has been previously linked with increased risk of infant death.²²

There are two possible explanations for why all other included independent variables were non-significant. First, there may be a high degree of homogeneity within Guamanian communities and in individual behavior patterns. Indeed, at only 571 square kilometers, Guam is the smallest US territory,²⁸ and in 1980, the island's population was only 106,000 individuals.²⁹ Second, non-significant associations may have occurred due to inadequate sample size. Because the analysis was conducted at the village-level, the maximum sample size available was 19, regardless of how many births and infant deaths had actually occurred. This value may have been insufficient to detect true associations between non-significant variables and infant mortality due to congenital anomalies.

There are several limitations to this study. Exact levels of AO spraying that occurred on Guam during the Vietnam War could not be specified and official records likely do not exist.²³ The study relied primarily on the recollection of one individual who claimed to be in charge of AO spraying. Although his claims have been verified by others, caution is required because he may harbor significant biases due to suffering from conditions associated with AO exposure. Furthermore, confirmatory laboratory testing to determine whether any individual included in the study was exposed to AO could not be performed, although environmental AO may pose a threat for years after initial spraying due to its long half-life, that is typically 11-15 years in humans and has been observed to be as long as 20 years.³⁰ In the environment, AO's half-life is heavily dependent on soil type and depth of penetration. When exposed to sun, primarily on leaf and soil surfaces, TCDD will break down in 1 to 3 years.³¹ When under the soil surface or deep within the sediment of rivers and other bodies of water, TCDD's half-life can be more than 100 years.

Village-level data on some potential confounders were identified, although the list is not exhaustive. Data on race, ethnicity, socioeconomic factors, infectious disease rates, maternal nutritional status, and other environmental factors were not included. It is possible that survival could be a function of socioeconomic status because of restricted healthcare access. Healthcare access for many Pacific Islanders has often been limited, with many needing to travel to Hawai'i or the US mainland to see a specialist. Only recently has healthcare access been expanded in the Pacific Islands, primarily through telemedicine programs.³² Additionally, the reliance on vital statistics data may diminish study validity because such databases may be incomplete and data quality may be poor.³³

The study presented here is the first to identify associations between AO and infant mortality in civilian populations outside of Southeast Asia, but it is important to stress that the ecological design of the study makes causal inferences of the study results impossible. The results, however, do propose intriguing hypotheses regarding the impact of AO on Guam, and there are several follow-up studies that are needed to confirm the

association between AO and infant mortality due to congenital anomalies. Case-control and retrospective cohort studies need to be conducted to determine if the association remains when individual data is used. These studies should use multiple control groups, including populations from non-AO spray areas on Guam, other Pacific islands where AO was never used or stored, and unexposed areas of the contiguous US. Because of AO's potentially long half-life, environmental studies are also required to determine if AO has persisted in the Guamanian soil, and if present, studies of the current population on Guam area needed to determine if AO continues to be a public health threat.

In conclusion, the results suggest that infants born to mothers who resided in AO spray areas were at an increased risk of infant mortality due to congenital anomalies. This is the first study to examine the link between AO and infant mortality on Guam. Further studies using individual-level data are required to validate the claims of the Veteran and confirm a link between AO and infant mortality on Guam. Additional studies should also determine if excess risk of infant mortality on Guam exists decades after AO spraying ceased.

Conflict of Interest

None of the authors identify a conflict of interest.

Acknowledgement

The assistance of Carolyn R. Garrido, Registrar, Office of Vital Statistics, Guam Department of Public Health and Social Services and her staff is gratefully acknowledged.

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Assessing the Prevalence of Traumatic Head Injury amongst Recreational Surfers in the United States

Christian Swinney BA

Abstract

Surfing is a popular recreational sport that carries a substantial risk of injury. Although head injuries are frequently documented in the surfing population, an in depth assessment of the prevalence of surfing-related head injury has not been reported. A web-based survey was conducted in May of 2015. Participants were asked a series of questions regarding surfing-related injuries and demographic characteristics. A total of 50 responses were obtained, of which 35 (70%) reported sustaining a head injury. The most common injury was laceration of the head/face (n=27), followed by concussion (n=13). Other injuries, such as skull fracture and broken nose, were also reported. Only 2 of the 50 participants reported wearing a protective helmet. Neurosurgical intervention was required in 2 instances. Increased emphasis on preventative measures by the medical community may reduce the future incidence of such injuries. Medical professionals should be aware of the most common forms of injury sustained by the surfing population in order to better recognize and treat these conditions.

Keywords

Head Injury, Surfing, Concussion, Sports-related injury

Introduction

Surfing is a popular recreational sport in the United States. This is particularly true in the Hawaiian Islands, where the sport has great cultural and historical significance. However, there are many dangers inherent to the sport, leading to a significant risk of injury. A recent study found head injuries to be the most commonly sustained injury amongst surfers, comprising 24% of all injuries.¹ In the United States, sports-related injuries, such as those from surfing, account for more than 10% of the staggering 2 million traumatic brain injuries that are reported each year.² Other studies also found that lacerations, regardless of body part, are another common injury among surfers.^{3,4} To-date, most published studies have been general in focus and no investigations specific to surfing related head injury have been conducted. Thus, an investigation into the prevalence of such injuries is warranted. The purpose of this study is to assess the prevalence of traumatic head injury and the use of protective equipment in a sample of surfers living in the United States. This study may provide the medical community with a better understanding of how to best prevent and treat this potentially devastating form of morbidity.

Methods

Data was obtained using an anonymous interactive web-based survey that was made available to multiple surf associations and clubs in the United States throughout the month of May 2015. Initially, a google search was conducted to identify United States-based surfing organizations and clubs. Those that had an online section, including either an online directory with

member email addresses or an online forum through which members could be contacted, were eligible. In the former situation, all members in the online directory were invited to participate. In the latter setting, any registered member logging into the online forum during the study period could respond to the survey. The web-based survey application ensured that each member could only respond once to the questions. Thus, responses were obtained from members with online involvement who accessed the associated websites during the study period.

The study consisted of 10 multiple choice questions with an option to write in "other" responses. The survey was original and not based off previously published questionnaires. No incentives were offered. Demographic characteristics, including age group, gender, and surfing experience, were obtained. Age was categorized into 5 subgroups: 18-24, 25-34, 35-44, 45-55, and 56-64. Surfing experience was defined based on individuals' self-reported years of experience. Possible categorizations included less than 1 year, 1-5 years, and greater than 5 years of experience. Participants were then asked about their history of surf-related head injuries, diagnostic measures taken, treatments received, and preventative measures taken to prevent head injury. Any surfer over the age of 18 was considered eligible for this study. No other inclusion or exclusion criteria were applied. Data was initially collected utilizing a web-based survey service. It was then compiled and analyzed using Microsoft Excel 2010. A 2 sample homoscedastic t-test was used to compare the rate of head injury between age groups.

Results

A group of 50 individuals participated in this study. Demographic data is displayed in Table 1. Most responders were between 18 and 34 years old (51%) and male (88%), with more than 5 years surfing experience (76%). Of the 50 participants, 35 (70%) reported sustaining a head injury (Table 2) which did not differ by age group ($P > .05$). The most common head injury was laceration of the head/face (77%), followed by concussion (37%). Other head injuries included skull fracture (6%), loss of consciousness (9%), broken nose (9%), and severe traumatic brain injury (3%). Four participants reported wearing a protective helmet. Two participants, neither of whom wore a helmet, also reported sustaining an injury that required neurosurgical intervention.

Discussion

A recent article by Woodacre and colleagues established that head injuries are common amongst surfers.¹ While this study has many merits, it does not provide specific details regarding the types of head injuries sustained. Furthermore,

Table 1. Demographic Characteristics of Participants, United States, May 2015		
	Participants (N= 50)	%
Age Group		
18-24	11	22.0
25-34	15	30.0
35-44	9	18.0
45-54	6	12.0
55-64	9	18.0
Gender		
Male	42	87.5*
Female	6	12.5*
Not Disclosed	2	
Surfing Experience (years)		
<1	0	0
1-5	12	24.0
>5	38	76.0

*Percentages exclude unknown values.

it does not include athletes from the United States who may surf in distinct environmental conditions, which may lead to a unique pattern of injury. Thus, a study focusing on specific head injuries relevant to surfers in the United States is needed.

Injuries to the head and face were common within the present study's cohort, reported by 70% of participants. These findings suggest that lacerations, which have been reported to be the most common injury that surfers experience in general,^{3,4} are also the most common form of injury sustained specifically to the head region. While lacerations do not often produce functional neurological deficits, they are still a significant health concern. Even simple lacerations have the potential to lead to serious infections.⁵ Additionally, inadequate healing of lacerations may lead to permanent disfigurement and cosmetic defects.

More severe injuries were also reported. Thirteen participants, 26% of all subjects, reported experiencing a concussion/mild traumatic brain injury while surfing. This is alarming given the potential long term impact of concussive injuries, which have been reported to impair recall, cognitive function, and academic performance.⁶ Although less common, skull fractures, a potentially deadly injury, were also reported in 2 instances. Such injuries put athletes at risk for a variety of dangerous complications, such as epidural hematoma, a neurosurgical emergency. Multiple forms of head protection are available to surfers, including helmets, surf hoods, and goggles. Of note, there are lightweight helmets (Gath Sports, Margaret River, Australia) that are specifically designed for surfing and other water sports. However, head protection, which has been reported to decrease the incidence of head injury in athletes,⁷ was only worn by 2 individuals in this study. This underutilization may be due to a lack of awareness of potential injury, as well as aesthetic concerns. It is reasonable to conclude that an increased emphasis on preventative measures, such

Table 2. Characterization of Reported Surfing-Related Head Injuries, United States, May 2015		
	Participants Reporting a Head Injury (N=35)	%
Type of Injury		
Concussion (Mild Traumatic Brain Injury)	13	37.1
Severe Traumatic Brain Injury	1	2.9
Skull Fracture	2	5.7
Head/Face Laceration	27	77.1
Loss of Consciousness	3	8.6
Broken Nose	3	8.6
Received Diagnostic Assessment (CT/MRI/X-Ray)	4	11.4
Required Neurosurgical Intervention	2	5.7

as helmet use, by the medical community has the potential to decrease the frequency of surfing-related head injury.

While the nature of this study, an anonymous online survey, was effective at maximizing the response rate, there are certain limitations that should be acknowledged. Notably, patient responses could not be cross-referenced with actual medical records, making it impossible to confirm the validity of the reported diagnoses. The study also operates under the assumption that the sample population is representative of the United States surfing population as a whole. However, no comprehensive study characterizing the demographic and geographic distribution of United States surfers currently exists. Thus, the extent that this sample is truly representative of all surfers in the United States, including those in Hawai'i, is unknown. The study's small sample size also limits the generalizability of our findings. Using a web-based survey may have also unintentionally excluded older members of these organizations, who may be less likely to utilize the internet and online membership components. Similarly, it should be noted that some surfing organizations may not have an online component, excluding them from consideration.

Going forward, additional studies with a larger sample size and focus in preventative strategies are warranted. This study establishes that head injury is a serious problem for the surfing population, but the literature is lacking when it comes to the efficacy of specific preventative measures. Additionally, a longitudinal assessment could provide insight into trends in head injury over time, as the current study captures a single moment in time.

Conclusion

This study establishes the notable prevalence of surfing related head injury, as well as the lack of utilization of protective headgear. Future initiatives should focus on increasing the

use of preventative measures to reduce morbidity. Medical professionals should be aware of the most common forms of injury sustained by the surfing population in order to better recognize and treat these conditions. Increasing awareness of surfing related head injuries and encouraging preventative measures, such as the use of helmets and exercising caution during adverse weather conditions, has the potential to reduce both the incidence and severity of surfing related injury. This is particularly relevant in the Hawaiian Islands and Pacific Rim, where surfing continues to be a popular activity amongst both recreational and professional athletes.

Conflict of Interest

The author does not identify any conflict of interest.


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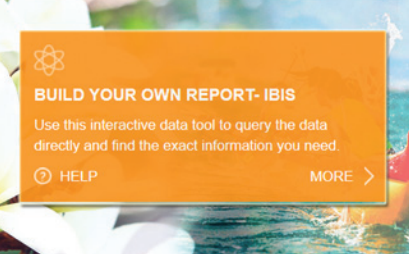
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Sociocultural Factors that Affect Chewing Behaviors among Betel Nut Chewers and Ex-Chewers on Guam

Kelle L. Murphy DPE, CAPE and Thaddeus A. Herzog PhD

Abstract

Areca nut (betel nut) is chewed by an estimated 10% of the world's population which is equivalent to about 600 million people. It is classified as a Group 1 carcinogen by the World Health Organization (WHO) and has been linked to various types of oral cancer. Chewing areca predominates in South and South East Asia, East Africa, and the Western Pacific and has important social and cultural implications. The purpose of the pilot study was twofold: (1) to examine sociocultural factors that affect why people on Guam chew betel nut, their chewing behaviors, perceptions of risks, probability of changing behaviors, and methods that could be used to reduce use or quit; and (2) to pilot two surveys (one for chewers and one for ex-chewers) to be used in a larger study in the future. A mixed methods design was employed that included surveys pertaining to their status (chewer or ex-chewer) and in-depth interviews. A total of 30 adults participated in this pilot study: adult betel nut chewers (n = 15) and ex-chewers (n = 15). Chewing betel nut is a learned behavior, embedded within the culture, and is viewed as an important cultural identifier. Socially, chewing is viewed as positive. Chewers stated that they were not as aware of health issues; however, ex-chewers stated health reasons for quitting.

Introduction

An estimated 600 million people worldwide chew areca nut, or betel nut.¹⁻⁴ Areca nut chewing is ranked as the fourth most frequently abused substance following nicotine, ethanol, and caffeine.^{1,5} The behavior and practice are indigenous predominantly to South and South East Asia, East Africa, the Western Pacific, and are an important expression of social and cultural identity.^{2,3,6,7} The prevalence of areca nut chewing is expanding.⁴

Areca nut chewing is a Group I carcinogen by the International Agency for Research on Cancer (IARC).⁸ It is associated with oral and oropharyngeal cancer, oral lesions, oral leukoplakia and submucous fibrosis, gum disease, along with cancer of the pharynx and oesophagus.^{4,9,10} Oral cancer rates are high in the Western Pacific¹¹⁻¹³ and the rate of mouth cancer is much higher in some Micronesian groups on Guam compared to rates among Caucasians.^{11,12} Feelings of euphoria, feelings of warmth throughout the body, oral fixation, rituals associated with preparation, and a desire to prevent withdrawal symptoms are among the reasons given for chewing.^{6,10,14,15}

Origins and Constituents

The areca nut originates from the areca catechu tree.³ The areca nut is a hard brown kernel similar in size to a plum stone and can be consumed in a variety of ways: raw, roasted, or boiled.^{3,14,15} The term betel quid is defined as a mixture of various substances.^{8,10,15-17} The most common preparation is to cut the nut in half and fold it into a Piper betel leaf, with slacked lime added.^{8,10,15} The term "betel nut" evolved from the combination of the areca nut with the Piper betel leaf.⁸ Tobacco and alcohol may be added to the quid.^{8,18} Other variations include: chew-

ing the areca nut by itself as the mature nut, or chewing the areca nut in combination with the betel vine, stem, flower, or pods.^{8,19,20} The betel quid is then placed in the mouth against the mucosa and chewed to extract the juice from the mixture.^{8,10} In the current manuscript, the term betel nut is used to refer to any preparation of the areca nut (alone or with ingredients added).

Betel Nut Chewing on Guam

Betel nut chewing practices vary by geographical region.^{2,3,6} Two distinct groups of chewers exist on Guam:

- **Chamorro Style:** This group includes predominantly native Chamorros of Guam which are a mix of Malayo-Polynesian, Spanish, Mexican, and Filipino descent.²¹ They chew the red, mature nut by itself and ingest the nut. Some chewers in this group occasionally add betel leaf.²⁰
- **Yapese Style:** The second group includes predominantly other Micronesians who migrated from the neighboring islands of Micronesia (Chuuk, Kosrae, Palau, Pohnpei, Saipan, and Yap) along with the Philippines.²² This group prefers to chew a custom-made betel quid which includes unripe nut, betel leaf, slacked lime, and tobacco (often from a cigarette stick). These chewers often spit out the betel quid and juices.^{19,20,23}

Chemical composition

The areca nut is composed of "carbohydrates, fats, proteins, crude fibre, polyphenols (flavonols and tannins), alkaloids and mineral matter."⁸ There are six related alkaloids contained in the areca nut; arecoline being the main alkaloid.⁸ Arecoline is a central nervous system stimulant that increases the amount of acetylcholine in the brain which results in an increase of the transmission of nerve impulses across the synapses.¹⁰ It is also responsible for many side effects, including an acceleration of the cardiorespiratory system in humans and an induced arousal response in animals.⁶ The chemical composition varies according to the manner in which the betel nut is prepared (raw, quid with tobacco, quid without tobacco).¹⁵ Adding tobacco to the mixture or taking it with alcohol has been found to increase the dependency.^{4,18}

Cultural context

Betel nut chewing is an expression of cultural and social identity and is woven into the cultures of South and South East Asia and the Pacific Islands.^{2,3,6,14} To our knowledge, risk reduction and cessation programs for betel nut do not exist. Little is known

about what people think about chewing and how they think about changing chewing behaviors. The purpose of the current study was to examine the sociocultural factors that affect why people on Guam chew, chewing behaviors, perceptions of the risks, probability of changing behaviors, and methods that could be used to reduce use or quit. An additional purpose was to pilot two surveys (one for chewers and one for ex-chewers). Data from the surveys will be used for a larger study to develop a culturally appropriate risk reduction and cessation program.

Methods

Participants

The following inclusion criteria were employed: self-identified as a betel nut chewer or ex-chewer and 18 years old or older. Current chewers are defined as having chewed betel nut for 3 years at least once a week. Ex-chewers were defined as having chewed betel nut at least once per week for 3 or more years and having stopped chewing for 6 weeks or longer.

Procedures

The study was conducted on Guam. Participant recruitment techniques included: newspaper advertisements, flyers in the community and at the mayor's office of each village, and word of mouth. Targeted recruitment was used to ensure diversity and representativeness of the sample. Interested participants contacted the researcher and were screened. Initially, surveys were distributed through the mail and included addressed and stamped envelopes for participants to return surveys. The protocol was later changed to face-to-face due to a low response rate with the mailed surveys (2% vs 98% response rate).^{24,25} Researchers conducted the interviews in a location that was convenient for participants. The procedures were explained to the participants, who then signed the informed consent prior to completing the survey. Once the surveys and interviews were completed, the participants received a \$25 gift card. Institutional Review Board approval was granted from the University of Hawai'i at Manoa and the University of Guam.

Surveys and Interviews

Participants completed a survey pertaining to their status (chewer or ex-chewer) followed by a separate, in-depth interview. The phases for distribution of surveys and conducting interviews were as follows:

- Phase one: Develop two surveys, one for chewers and one for ex-chewers;
- Phase two: Mail surveys to 8 chewers and 8 ex-chewers;
- Phase three: Conduct interviews regarding clarity of survey items, add and delete items, and learn about their betel nut use and probability of changing their chewing behaviors; and
- Phase four: Revise surveys based on comments from phase three. Mail revised survey to an additional 7 chewers and 7 ex-chewers. Repeat phases three and four to obtain final survey.

Instruments. Pilot surveys were developed for both betel nut chewers and ex-chewers to be used during the current pilot study and intended for use in a future larger study. Because the literature is limited on measurement tools regarding betel nut chewing and cessation,²⁶ the researchers adapted items from existing smoking cessation surveys. The surveys consisted of multiple response questions and Likert scale questions.

The survey for chewers consisted of 37 questions related to the following categories: demographics; background; chewing behaviors; type of betel nut; cultural importance; social importance; quitting behaviors; Betel Nut Dependence Scale (with 16 sub-questions);²⁷ quit methods; risk perception; and ingredients added to quid. Examples of survey questions used to elicit information pertaining to social and cultural implications include: "Did you feel that chewing betel nut or betel quid was expected in your culture?" and "Rate how negatively people would think of you if you decided to give up chewing betel nut or betel quid."

The survey for ex-chewers was similar to the survey for chewers, with additional questions added related to cultural and social importance and behaviors since quitting (total of 45 questions). Examples of survey questions include: "Which method(s) did you use to quit chewing betel nut or betel quid (cold turkey; motivation/desire; substitution; diagnosed with medical condition; changed social group, other); and "Have you ever been diagnosed by a doctor as having any of the following conditions (cardiovascular disease; metabolic syndrome; oral cancer; oropharyngeal cancer; oral lesions; oral leukoplakia; submucous fibrosis; gum disease; cancer of the pharynx; cancer of the esophagus; heart disease)."

Interviews. Interviews were conducted to give participants the opportunity to: clarify answers given in the survey; expand on answers; and answer additional questions regarding psychological, social, and cultural reasons as to why people on Guam chew(ed). Questions were open-ended and developed from a list of possible survey topics (Appendix A). All interviews were audiotaped and transcribed verbatim and sent to participants to check for accuracy.

Data Analyses

Data analysis followed the same process as Gould, Finch, & Jackson (1993); Murphy (2007; 2010 a, b); and Murphy, Brown & Nelson (2009).²⁸⁻³¹ Inductive reasoning was used.³² Three phases of coding were used.³³ The purpose during each phase of coding was to compare data to research questions, condense, and eventually arrive at overall higher order themes.³² This is referred to as a constant comparison method.^{28,30,33,34,35} Two researchers and two research assistants participated in the coding process. Initially, the lead researcher began the process by counting the total number of individual sentences from all of the transcribed interviews. Individual sentences were referred to as raw data units.^{28,30,31,35}

The objective during the first phase of coding was to examine raw data units and identify any references to psychological,

social, and cultural reasons for chewing; chewing behaviors; perceptions of the risks; and probability of changing behaviors. When any of these references were found, they were extracted as quotes.²⁸ They were placed into concept maps to demonstrate a visual representation of the connections among raw data units.^{28-31,35,36}

The objective during the second phase of coding was to reduce raw data even further by using the constant comparison method described above.^{28,30,33,35} Individual raw data units with the same meaning were combined into lower order themes and labeled with two to three words to identify the theme. If individual raw data units did not have the same meaning they were not combined. If the researchers and research assistants did not unanimously agree on the theme then raw data units were placed into different lower order themes.^{28-31,35}

The constant comparison method continued during the third phase of coding.³⁴ In this phase of coding,³³ lower order themes with the same meaning were condensed into higher order themes that could be explained by existing research and labeled with two to three words to identify the higher order theme.^{28-31,35}

“Trustworthiness” is used to describe the “overall quality of the results”.³² In the current study, the following was used to measure trustworthiness: (a) audit trail and a pilot study;³⁷ (b) in-depth description of participants and the setting; (c) triangulation by the use of interviews and surveys; (d) member checking; and (f) purposeful selection of participants which is used when the researcher deliberately selects from a population in which he or she can learn the most rather than random sampling.^{29-32,35,37}

Results

A total of 30 individuals, including adult betel nut chewers (n = 15; 6 males, 9 females) and ex-chewers (n = 15; 7 males, 8 females) from Guam volunteered to participate in the pilot study (Table 1). The ethnic breakdown for chewers was: Chamorro - 7; Palauan - 5; Yapese - 2; and Caucasian - 1. The average age for chewers was 41.29 years (SD - 13.89). The average years of chewing was 20.27 (SD - 12.74). The average amount of times per day they reported chewing was 14.85 (SD - 11.81) times. The ethnic breakdown for ex-chewers was: Chamorro - 11; Filipino - 3; Hispanic - 1. The average age for ex-chewers was 43.47 years (SD - 18.81). Average years of chewing was 9.27 (SD - 12.25) years and they reported chewing an average of 6.36 (SD - 8.11) times per day. The average amount of years that they had stopped chewing was 6.33 (SD - 5.96) years.

Among chewers, 13,045 raw data units were condensed into 12 lower order themes and 6 higher order themes (Table 2). For ex-chewers 9,660 raw data units were condensed into 12 lower order themes and 6 higher order themes. Results were combined because themes that emerged were similar for chewers and ex-chewers (N = 30).

Variable	Chewers (n=15) N (SD)	Ex Chewers (n=15) N (SD)
Average Age	41.29 (SD - 13.89)	43.47 (SD - 18.81)
Average Years of Chewing	20.27 (SD - 12.74)	9.27 (SD - 12.25)
Average Chewed Per Day	14.85 (SD - 11.81)	6.36 (SD - 8.11)
Average Years Stopped Chewing	--	6.33 (SD - 5.96)
Ethnicity		
Caucasian	1	0
Chamorro	7	11
Filipino	0	3
Hispanic	0	1
Palauan	5	0
Yapese	2	0
Employment		
Administrative Assistant	1	0
Airline Employee	1	0
Butcher	1	0
Cook	0	1
Government Employee	0	3
Graphic Artist	1	0
Homemaker	2	4
Maintenance	1	0
Program Coordinator	2	1
Retired	2	1
Student	2	1
Teacher	0	2
Unemployed	2	2

SD, standard deviation

Lower Order Themes	Higher Order Themes
Availability Preparation for Others	Reasons Started
Medicinal Properties Sign of Beauty	Reasons to Chew
Availability at Ceremonies Cultural Identifier	Cultural Importance
Peer Pressure Social Acceptance	Social Importance
Expense Medical Issues	Reasons to Quit
Cold Turkey Substitution	Methods to Quit

Reasons Started

Availability. Out of the 30 current and former betel nut chewers, 30% (n=9) started chewing because it was readily available and they were constantly exposed to the practice. A chewer explained this by stating: “I picked it up at the house [...] everyone that stays at my house chews betel nut, my uncles, everybody.”

Preparation for Others. A common practice for participants (n = 9; 30%) is to prepare the betel nut for elders in the family to chew because of their lack of teeth. Part of the process of preparation included: placing the betel nut in their mouths and chewing on it to soften it up and get it ready for the elders to chew. As a result of constantly preparing the betel nut and chewing it, they began to chew themselves. An ex-chewer told a story of preparing the betel nut for both parents by stating: “I never really wanted to try it. I had to chew it to prepare it for other people. I had to and I did it for 11 years. Both of my parents chewed betel nut.”

Reasons to Chew

Medicinal Properties. Seven participants (23%) believed that betel nut offers medicinal properties and learned to use the betel nut to treat ailments. An ex-chewer stated: “They used betel nut [...] for medicine when you are feeling nauseous. You would swallow it to make you feel better.”

Sign of Beauty. Mixing the piper betel leaf with the nut causes a red stain in the mouth and on the teeth. It is a sign of beauty (n = 2; 13 %) to have red stained and black stained teeth and it is expected in the culture. A chewer stated: “In my culture, women with red teeth are beautiful.” Another chewer supported this concept by stating: “... girls with white teeth are considered ugly in our culture.”

Cultural Importance

Availability at ceremonies. Forty-three percent of participants (n = 13) stated that betel nut is an integral part of rosaries and other ceremonies. A chewer stated: “It’s cultural, especially at rosaries and anniversaries (of death), they pass it out. They pass out the betel nut- it’s cultural and traditional.” An ex-chewer explained: “It’s very big at weddings. The first thing the manamko (older people) would say is where’s the mama (chew)? Where is the betel nut? Where is the pupulu (leaf)? They don’t want any food. That’s the first thing they want.”

Cultural identifier. Half of participants (n = 15; 50%) stated that chewing betel nut was an important cultural identifier. An ex-chewer stated: “It’s Chamorro culture.” Interestingly, one chewer stated: “It’s an identifying marker. It identifies the group and who we are- Micronesians in general- we all chew betel nut.”

Social Importance

Chewing betel nut was not only viewed as an integral part of the culture but socially significant.

Peer pressure. Eight participants (27%) felt that there was peer

pressure to chew. An ex-chewer stated: “If you didn’t chew, you were kind of an outcast.” Similarly, a chewer stated: “The first time I tried it, I got sick so I said I didn’t want to do it anymore, but peer pressure, they kept telling me to do it.”

Social acceptance Thirteen participants (43%) stated that it was an important venue to connect and interact socially. An ex-chewer explained: “I didn’t want to feel left out...this is what’s making us hang out, is the betel nut.” Participants stated that often times it was the socializing with friends that initiated the chewing of betel nut.

Reasons to Quit

Expense. The amount of money spent per week buying betel nut varied (n = 9, \$0-\$10; n = 2, \$11-\$20; n = 2, \$21-\$30, and n = 1, \$71-\$80; data not shown). An ex-chewer stated: “It was really expensive and being around that age, I did not have a job.” When additional ingredients are added the expense increased. A chewer stated: I taught my daughter not to chew because it’s an expensive habit and once you get addicted, it’s hard to stop.”

Medical Issues. Nine participants (30%) cited experiencing serious medical issues. An ex-chewer explained: “I got a lot of acid reflux from it [chewing because] I swallowed them.” Another ex-chewer explained: “Right after eating (betel nut) my throat started to swell up really bad [...] it was the turning point of my betel nut chewing and that is what stopped me from chewing.”

Ex-chewers cited medical reasons for quitting; however, even though chewers experienced medical issues from chewing betel nut, this did not deter them. They stated that taking a temporary break from chewing alleviated the symptoms and then they were able to resume chewing betel nut again. A chewer stated: “Sometimes I switch sides (of the mouth) if one side is burnt. If both sides are burnt, then I would relax until the next day because then it would heal.” An ex-chewer reiterated a similar story involving parents: “Usually when they have sores, they will gargle with warm water just to help with the pain. Then after that, they’ll still continue on. They will not stop.”

Methods to Quit

Cold turkey. Among ex-chewers, eight quit “cold turkey” (53%). One ex-chewer was motivated for cosmetic reasons and stated: “When I finally put my braces on that’s when I decided I’m going to just go cold turkey and I just never went back.” Another ex-chewer was motivated for medical reasons. The ex-chewer stated: “Actually I quit chewing after I was diagnosed with cancer. I just quit.”

Substitution. Additional methods such as substitution (n = 7; 47%) were used to successfully quit. An ex-chewer stated: “Of course you have to cut down so every time they offer me, I would just take half and then half of that.” In relation to replacement therapy, another ex-chewer also stated: “But then once I just stopped and started chewing gum more, so every time I wanted to chew, I would just chew gum.”

Discussion

The current pilot study was designed to examine psychological and sociocultural factors that affect why people on Guam chew betel nut, their chewing behaviors, their perceptions of the risks, probability of changing behaviors, and methods that could be used to reduce use or quit.

The results are supported by the social cognitive theory³⁸ and are consistent with other studies.^{24,25,39,42} According to the social cognitive theory people learn through observation of others.³⁸ Participants stated that chewing betel nut was a learned behavior that was influenced by their environment in addition to the people they were surrounded by in the environment. Participants picked up the habit of chewing betel nut because it was readily available around the home and at social gatherings. Participants learned that it was an acceptable behavior to demonstrate in social situations and somewhat expected. Little, et al, also supported the fact that the social significance attached to chewing betel nut had an impact on the desire to change behaviors or even quit.^{24,25}

According to Bandura and colleagues,⁴³ people react to situations according to what they perceive the outcomes to be, based on their observations. People are more likely to model the same behavior if the outcomes are perceived as desirable and positive. In the current study, chewing betel nut was viewed as a positive social behavior by everyone. Chewing was also viewed as an important cultural identifier and an integral part of many cultural rituals (rosaries and anniversaries of death). As a result of these perceived positive factors, participants modeled the behavior of chewing betel nut. In this case, the importance of the cultural values influenced how participants behaved. Paulino, et al, (2011) supported these results by also finding that chewing was an important social identifier and in some cases they began chewing as a result of peer pressure and the desire to be included in the group.⁴⁴

Dijkstra, et al, and Wang, et al,^{39,40} examined smokers' motivation to change behaviors. In this study, chewers stated that they were experiencing health issues such as sores in the mouth, inability to open their mouth, and other related issues, but that it was not enough to convince them to cease the behaviors. Chewers stated that if they took a rest, stopped for a while, allowed the sores to heal, then they could resume chewing betel nut. In this case, perception of risk did not influence chewing behavior. However, most of the ex-chewers stated that they quit because they were experiencing serious health issues such as losing their teeth, burns in the back of their throats, and other negative side effects. For the ex-chewers, the connection between perceived health risks was enough to make them stop chewing betel quid. Griffin, et al, supported this by finding that participants continued chewing even with the awareness of known health risks and did not indicate an intention to quit chewing.⁴¹ Herzog, et al, found that participants who added tobacco were less likely to quit due to the increased dependence created by the tobacco.⁴² Tobacco is also a widely known health risk and those who added tobacco did not show an intention to quit.⁴²

Limitations

Several limitations should be taken into consideration. First the study sample may not be fully representative of all chewers and ex-chewers on Guam. Second, the sample size was small. This was a pilot study utilizing a mixed methods (quantitative surveys and qualitative interviews) design. This will limit the generalizability of our results. Third, results are limited to the honesty of the participants in their responses. Fourth, participants in phase four received a revised version of the two surveys completed by participants in phase one. Questions pertaining to demographics and research questions were similar for both versions of surveys in both phases. The main revisions for phase four were the addition of the Betel Quid Dependence Scale including the addition of 8 questions to the ex-chewer survey specifically related to quitting, quit attempts, and methods used to quit. Thus, comparisons between responses from participants in phase one and phase four may be inappropriate, and the generalizability of our findings may be limited.

Future Research

This pilot study makes an important contribution to understanding the psychological and sociocultural reasons as to why chewers and ex-chewers on Guam chew betel nut, how they think about chewing, and their perceptions of risks. The findings suggest that cultural and social values have strong influences on behaviors and whether or not betel nut chewers are willing to quit. These findings offer insight for creating culturally appropriate and successful behavior change programs. Dijkstra, et al, (1999) examined the relationship between self-efficacy, intentions, and motivation to change. Self-efficacy was not examined in the current study. Future studies that examine the relationship between self-efficacy, betel nut chewing, and ability to change behaviors or quit among the Micronesian population, would be advantageous. Since this pilot study, the surveys were revised and sent out to 600 participants (375-chewers and 225 ex-chewers). Results from this study will be published in future works.

Conflict of Interest

The authors declare that they have no conflict of interest.

Disclosure Statement

Funding for the study was provided by the National Cancer Institute (NCI) Grant U54 CA143727. The NCI had no further role in the study design; in the collection, analysis, and interpretation of data; in the writing of the report; or in the decision to submit the paper for publication.

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Appendix A

Possible Survey Item Topics

Possible Survey Item Topics for Chewers

- Patterns of chewing behavior (when, how often, etc)
- Type of areca nut or betel quid (nut only or quid; if quid, what ingredients)
- Motivation to change chewing behavior to reduce health risk
- Reasons for chewing
- Reasons for wanting to change chewing behavior (if any)
- Perceived dependence on areca nut or quid
- Cultural importance of areca nut chewing
- Health risk perceptions associated with areca nut chewing

Possible Survey Item Topics for Ex-Chewers

- Patterns of chewing behavior when they chewed in the past (when, how often, etc)
- Type of areca nut or betel quid chewed in the past (nut only or quid; if quid, what ingredients)
- How each individual succeeded in quitting chewing
- Why they quit chewing
- Difficulties encountered while quitting chewing
- Withdrawal symptoms following cessation of chewing
- Number of cessation attempts before successfully quitting

MEDICAL SCHOOL HOTLINE

Liaison Committee on Medical Education Accreditation, Part III: Educational Program Content, Curriculum Management, and Student Assessment

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The John A. Burns School of Medicine at the University of Hawai'i at Manoa (JABSOM) is scheduled to undergo its Liaison Committee on Medical Education (LCME) accreditation visit in early 2017. This article is the third in a series that will address various aspects of the LCME accreditation process.¹ This installment provides an overview of how JABSOM addresses accreditation standards related to the educational program content, curriculum management, and student assessment.

Introduction

A significant portion of the LCME accreditation standards is related to the processes and procedures that a medical school utilizes to manage the medical student curricular experience.² These standards include specific reference as to how content is determined, mechanisms of oversight and coordination of the student educational experience, and how competency in the content areas is assessed. At JABSOM, the responsibility for maintaining compliance with these many standards is shared by the Curriculum Committee and its educational subcommittees, the various medical school departments, the Office of Medical Education, and the Dean's Office. Together, these groups ensure that the medical student curriculum at JABSOM is thoughtful, comprehensive, well-coordinated, and highly effective.

Addressing Accreditation Standards Related to Educational Program Content

There are a number of LCME standards and elements that are related to the content of the medical student curriculum. The primary standard is *LCME Standard 7: Curriculum Content*, which reads:

The faculty of a medical school ensure that the medical curriculum provides content of sufficient breadth and depth to prepare medical students for entry into any residency program and for the subsequent contemporary practice of medicine.

Examples of some of the specific elements under this standard include:

7.2 The faculty of a medical school ensure that the medical curriculum includes content and clinical experiences related to each organ system; each phase of the human life cycle; continuity of care; and preventive, acute, chronic, rehabilitative, end-of-life, and primary care in order to prepare students to:

- Recognize wellness, determinants of health, and opportunities for health promotion and disease prevention
- Recognize and interpret symptoms and signs of disease
- Develop differential diagnoses and treatment plans
- Recognize the potential health-related impact on patients of behavioral and socioeconomic factors
- Assist patients in addressing health-related issues involving all organ systems

7.5 The faculty of a medical school ensure that the medical curriculum includes instruction in the diagnosis, prevention, appropriate reporting, and treatment of the medical consequences of common societal problems.

7.9 The faculty of a medical school ensure that the core curriculum of the medical education program prepares medical students to function collaboratively on health care teams that include health professionals from other disciplines as they provide coordinated services to patients. These curricular experiences include practitioners and/or students from the other health professions.

The following examples illustrate the breadth of curricular content expected by the LCME. JABSOM addresses the specific expectations of this standard through a number of institutional practices and procedures. A small sampling of these include:

- Faculty who serve as course directors carefully consider the LCME standards and elements in creating their respective course curricula.
- The Curriculum Committee and its educational subcommittees monitor and review regularly the content of topical areas across the entire curriculum for adequacy, gaps and redundancies.
- The JABSOM Office of Medical Education is participating in the Curriculum Inventory project of the Association of American Medical Colleges, which will enable relational database functionality of the JABSOM curricular components.
- JABSOM faculty participate in collaborative efforts with the faculty of other University of Hawai'i health professions schools to provide interdisciplinary experiences.

In summary, JABSOM has a number of thoughtful and effective procedures in place to ensure that the medical student curriculum provides content of sufficient breadth and depth to prepare students for entry into any residency program and for the subsequent practice of medicine. This is reflected in the results of the Intern Survey and Program Directors Survey for the Class of 2013, in which all interns and 97% (32/33) of Program Directors responded *Good* or *Excellent* when asked to rate their preparation to provide competent medical care to patients.

Addressing Accreditation Standards Related to Curriculum Management

Curriculum management is an area of particular emphasis in the LCME standards. *LCME Standard 8: Curriculum Management, Evaluation and Enhancement*, reads as follows:

The faculty of a medical school engage in curricular revision and program evaluation activities to ensure that that medical education program quality is maintained and enhanced and that medical students achieve all medical education program objectives and participate in required clinical experiences and settings.

A sampling of some of the expectations under this standard include:

8.1 *A medical school has in place an institutional body (eg, a faculty committee) that oversees the medical education program as a whole and has responsibility for the overall design, management, integration, evaluation, and enhancement of a coherent and coordinated medical curriculum.*

8.4 *A medical school collects and uses a variety of outcome data, including national norms of accomplishment, to demonstrate the extent to which medical students are achieving medical education program objectives and to enhance medical education program quality. These data are collected during program enrollment and after program completion.*

8.5 *In evaluating medical education program quality, a medical school has formal processes in place to collect and consider medical student evaluations of their courses, clerkships, and teachers, and other relevant information.*

8.6 *A medical school has in place a system with central oversight that monitors and ensures completion by all medical students of required clinical experiences in the medical education program and remedies any identified gaps.*

The JABSOM Curriculum Committee has the primary responsibility of ensuring compliance with the elements of this standard. Examples of the institutional practices and procedures to address the elements within this standard include:

- The Curriculum Committee meets for 90 minutes twice each month. The committee is comprised of representatives from the faculty, administration and students, and has institutional responsibility for oversight of the medical education program.
- The Curriculum Committee and its subcommittees regularly review a variety of outcome data and student feedback, that include student performance on national licensing examinations and responses by students and alumni on internal and national surveys.
- JABSOM medical students have frequent opportunity to provide informal and formal feedback about their perceptions of the quality of the curriculum, learning environment and faculty, through mid-unit and end-unit surveys for each required course and clerkship.
- All required courses and clerkships are regularly reviewed by the Curriculum Committee with input from the respective course or clerkship directors. Recommendations from the Curriculum Committee are provided to the course directors, who are then required to report back to the Curriculum Committee on how they have responded to these recommendations.
- Course directors and educational committees closely monitor medical student completion of required clinical experiences and have mechanisms in place to address and remedy any identified gaps.

Along with many others, these examples ensure that JABSOM maintains and enhances the quality of the medical education program and that medical students achieve all medical education program objectives and participate in required clinical experiences and settings.

Addressing Accreditation Standards Related to Student Assessment

An area of growing importance throughout medical education is assessment of learner competency. *Standard 9: Teaching, Supervision, Assessment, and Student and Patient Safety*, includes a number of elements related to student assessment and evaluation.

A medical school ensures that its medical education program includes a comprehensive, fair, and uniform system of formative and summative medical student assessment and protects medical students' and patients' safety by ensuring that all persons who teach, supervise, and/or assess medical students are adequately prepared for those responsibilities.

The expectations that fall under this standard include:

9.3 A medical school ensures that medical students in clinical learning situations involving patient care are appropriately supervised at all times in order to ensure patient and student safety, that the level of responsibility delegated to the student is appropriate to his or her level of training, and that the activities supervised are within the scope of practice of the supervising health professional.

9.4 A medical school ensures that, throughout its medical education program, there is a centralized system in place that employs a variety of measures (including direct observation) for the assessment of student achievement, including students' acquisition of the knowledge, core clinical skills (eg, medical history-taking, physical examination), behaviors, and attitudes specified in medical education program objectives, and that ensures that all medical students achieve the same medical education program objectives.

9.7 A medical school ensures that each medical student is assessed and provided with formal formative feedback early enough during each required course or clerkship four or more weeks in length to allow sufficient time for remediation. Formal feedback occurs at the midpoint of the course or clerkship. A course or clerkship less than four weeks in length provides alternate means by which a medical student can measure his or her progress in learning.

JABSOM has developed and implemented a number of institutional procedures and practices to ensure compliance with the expectations of this standard. The following examples illustrate that JABSOM is fully committed to providing medical students with fair, timely, thoughtful feedback and ensuring that student competency is assessed accurately.

- JABSOM has clear policies that outline responsibilities for proper supervision of medical students in clinical settings. These policies ensure both patient and student safety.
- Formative feedback is a valued aspect of the JABSOM educational culture. Practice examinations, mid-course formative feedback sessions and regular group process evaluations are all fully embedded within the JABSOM curriculum.
- The transition to an electronic exam management system allows faculty to incorporate images, video, and audio to exam questions; grades examinations automatically; and allows item analyses so that the quality of each question and exam reliability can be more easily tracked.
- JABSOM utilizes a thoughtful array of assessment tools, each strategically employed to address specific learning objectives in the domains of knowledge, skill, attitude, and behavior. In addition to written and computer-based internal and standardized examinations, direct clinical observation, standardized patients, manikin simulations, and procedural checklists are employed.

Final Thoughts

Educational program content, curriculum management, and student assessment are three important aspects of the LCME accreditation criteria. JABSOM also believes that these are critical areas in the provision of a high-quality medical student curriculum. Through the efforts of many deeply committed faculty, staff, and administrators, JABSOM has created institutional practices and procedures that ensure that medical students are receiving the best possible curricular experience, and that graduates are well-prepared to be successful in their post-graduate residency training, and ultimately to serve the people of the State of Hawai'i.

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Newborn Screening Saves Babies Using Public/Private Partnerships

Sylvia Mann MS, CGC

Insights in Public Health is a monthly solicited column from the public health community and is coordinated by HJMPH Contributing Editors Tetine L. Sentell PhD from the Office of Public Health Studies at the University of Hawai'i at Manoa and Donald Hayes MD, MPH from the Hawai'i Department of Health in collaboration with HJMPH Associate Editors Ranjani R. Starr MPH and Lance K. Ching PhD, MPH from the Hawai'i Department of Health.

Newborn screening (NBS) is heralded as one of the most successful public health programs using early detection and intervention to prevent disability, disease, and death in children. Nationally, 4 million newborns receive NBS annually and 12,500 of these newborns are identified as having a disorder.¹ This year marks 50 years of NBS in Hawai'i and we have come a long way since the first tests for phenylketonuria (PKU) were ordered by Hawai'i pediatricians in 1965. Newborn screening has matured into a statewide program coordinated by the Department of Health (DOH), and the screening panel now includes tests for 33 metabolic disorders, hearing loss, and critical congenital heart disease. In 2014, 99.8 percent of all newborns received NBS in Hawai'i. Approximately 1 in 55 newborns have a positive test result that needs follow-up to determine if the newborn has the disorder. All newborns detected and confirmed with a disorder (1 in 624) receive appropriate follow-up and intervention services in a timely manner.²

Background

Newborn screening began over 50 years ago when Guthrie and Susi developed a method to detect PKU on a filter paper dried blood spot.³ Phenylalanine is an amino acid present in protein products. Individuals with PKU lack the enzyme to break down phenylalanine. The toxic buildup of phenylalanine causes several health issues including brain damage that results in moderate to severe intellectual and developmental disability. Using the Guthrie test, newborns with PKU can be detected early and receive dietary intervention to prevent the health problems and intellectual disability. Massachusetts was the first state to mandate PKU NBS in 1963. Eventually, all states followed including Hawai'i which mandated screening in 1965.⁴

Hawai'i Newborn Metabolic Screening Program

Many states that mandated NBS in the 1960s created programs within their health departments and/or state laboratories to provide coordination and oversight for NBS. Before 1986, NBS in Hawai'i was conducted by birthing facilities and private primary care physicians without statewide or public health coordination or oversight. Unfortunately, this system led to a missed

case of PKU resulting in profound intellectual disability in the child. Following this case, the Hawai'i legislature mandated a Newborn Metabolic Screening Program (NBMSP) within the Department of Health to provide coordination, limited oversight, and education for newborn screening starting in 1986. The legislation also updated the mandate from only screening for PKU to also require screening for congenital hypothyroidism. Parents were given the right to opt out of screening on the basis of religious tenets or beliefs.

Over the following decade, the NBMSP developed a statewide program to educate birthing facility nursery staff and health care providers, to ensure timely follow-up of newborns with positive newborn screening results, to track newborns detected with confirmed diagnoses, and to provide technical assistance on NBS. Although the increased education and oversight greatly improved NBS in Hawai'i, the work was time-consuming and not well coordinated. One major challenge was that multiple private laboratories were engaged in doing the NBS laboratory testing for a low birth rate of about 21,000 newborns per year. The small number of newborns and multiple laboratories made quality assurance of the laboratory activities very difficult since laboratory issues (e.g. machine calibrations, differences in batches of reagents, lack of experience identifying true positive results) could take months or years to identify and resolve. In addition, the limited authority and funding of the NBMSP to develop a statewide coordinated and comprehensive NBS system hampered the ability to add new disorders to the NBS panel. By 1994, Hawai'i remained the lone state screening for only PKU and congenital hypothyroidism while most states were screening for at least seven disorders (PKU, congenital hypothyroid, hemoglobinopathies, congenital adrenal hyperplasia, galactosemia, biotinidase deficiency, and maple syrup urine disease).

Public/Private Partnership to Save Babies Community Support for Newborn Screening

The state's economic crisis in the mid-1990s was the catalyst for positive and sustained change for the NBMSP. For many years in the mid-1990s, state government programs were scrutinized for cost savings and/or elimination as the state's income

continued to decline. During one of the state's worst economic years in 1995, the NBMSP was one of the programs considered for elimination. Elimination would have put all NBS activities back into the hands of the birthing facilities and primary care providers. The only hope for saving the program was to gather community support and approach the legislature to mandate a sustained program through user fees deposited to a special fund to be used for newborn screening.

To create the user fee based system and a more centralized and comprehensive newborn screening system, the NBMSP requested more authority from the legislature to collect fees for NBS activities. This was expected to allow the NBMSP to contract with one central newborn screening laboratory and fund the staff and services to coordinate the entire system of NBS for pre-screening education, testing, follow-up, and treatment. Having all NBS centralized and coordinated as a statewide system also enabled the provision of services at lower costs to birthing facilities, third party payers, and families with added quality assurance and improvement opportunities.

Fortunately, the mandate was passed during the 1996 legislative session.⁵ The legislative success surprised many since it normally takes an average of three years to introduce a bill, provide information to the legislators about the bill, and have the bill passed by the legislature in Hawai'i. The quick passage of the bill was accomplished with the enormous collaborative efforts and hard work of the Department of Health staff, birthing facilities, primary care providers, families that benefited from newborn screening, professional organizations such as the American Academy of Pediatrics, and advocacy organizations such as the March of Dimes. Act 259, Newborn Metabolic Screening, came into effect on July 1, 1996.

Fiscal Sustainability

To seed the Newborn Metabolic Screening Special Fund, birthing facilities paid four dollars per newborn into the fund from July 1, 1996 to June 30, 1997. These funds were used to support three staff positions in the NBMSP as they developed the infrastructure needed for the statewide centralized and comprehensive NBS system to meet national standards. During this phase, total costs (staff salaries, laboratory testing, specimen delivery, supplies, educational materials and activities, follow-up testing, specialty clinical services, and testing for indigent families) for the program were calculated. The estimated fee per newborn for screening was calculated as the total funding needed to sustain the NBMSP and the NBS services divided by the average annual birth rate. All fiscal calculations and contracts were transparent to the public and followed state procurement laws. The information was presented to the State Newborn Metabolic Screening Advisory Committee and the initial fee of \$27 per newborn for seven disorders was supported by the Committee. The \$27 fee supported the cost savings expected as a result of centralizing NBS. A survey of the laboratory billing and reimbursement for only PKU and congenital hypothyroidism before the legislation was passed revealed a cost of \$30-\$165 per newborn so one of the benefits of the legislation represents a significant cost savings.

Over the almost 20 years since passage of this legislation, Hawai'i increased its NBS fee using the same process. The first major fee increase occurred when a new technology, tandem mass spectrometry (MS/MS), was added to the NBS laboratory methods. The new MS/MS methodology allowed the detection of over 30 disorders using the same amount of dried blood with one machine. In 2003, Hawai'i began screening for 31 primary disorders and the NBS fee was calculated at \$47 per newborn. Cystic fibrosis was added to the NBS panel in 2007 with a minor increase in the fee. Currently, the fee is \$55 per newborn and has not been increased in over six years.

Recently, another new technique was introduced to the NBS laboratory using deoxyribonucleic acid (DNA) technology. This technology is used to detect newborns with Severe Combined Immunodeficiency (SCID) wherein the newborn fails to develop an immune system to fight off infections. Adding DNA technology was expensive since NBS laboratories had to add new DNA facilities to do the testing. The State Newborn Metabolic Screening Advisory Committee recommended the addition of SCID to the Hawai'i NBS panel in the fall of 2014. Screening began in March 2015 and now Hawai'i screens for 33 primary disorders (See Table 1). The new testing and the increase in overall costs for NBS over the past six years will increase the fee to \$99 per newborn. The fee increase was approved by the Newborn Metabolic Screening Advisory Committee in September 2015 and the NBMSP is currently working to have the fee approved in the administrative rules. This new fee still makes newborn screening one of the best values in healthcare.

The fiscal collaboration between public health and private partners has allowed the NBMSP to be self-sufficient, cost efficient, and accountable. All funds and how the funding is used is presented annually to the legislature in a report and available for public review. No general fund dollars have been used to sustain the program and its activities for almost twenty years. Only families that have babies are charged the newborn screening fee which is covered by all third party payers. Families with an inability to pay can also receive newborn screening services through the program at no cost. Annually, the NBMSP pays for less than five percent of NBS for indigent patients which is factored into the NBS fee.

National Standards

Newborn screening is a state mandated activity across the nation. Variations in NBS activities, especially the number and type of disorders on state NBS panels, were commonplace due to the lack of national standards and guidelines. In 2008, Congress passed the first Newborn Screening Saves Lives Act to create a federal advisory committee to advise the Secretary of Health and Human Services about NBS.⁶ One of the initial acts of the Secretary's Advisory Committee on Heritable Disease in Newborns and Children (SACHDNC) was to recommend 29 disorders that all states should have on their newborn screening panel, thus, creating the Recommended Uniform Screening Panel (RUSP). The Secretary accepted this recommendation and the RUSP was born. Subsequently, the SACHDNC developed a process for nomination of disorders to the RUSP which

Table 1. List of Disorders on Hawai'i Newborn Screening Panel as of November 1, 2015
Amino Acid Disorders
Arginase Deficiency
Argininosuccinate Lyase Deficiency (ASA)
Citrullinemia
Homocystinuria
Phenylketonuria (PKU)
Tyrosinemia (Types I and II)
Organic Acid Disorders
Beta-Ketothiolase Deficiency
Glutaric Acidemia (Type I)
Isobutyryl CoA Dehydrogenase Deficiency
Isovaleric Acidemia
Malonic Aciduria
Maple Syrup Urine Disease (MSUD)
Methylmalonic Acidemias
Multiple Carboxylase Deficiency (MCD)
Propionic Acidemia
2-Methyl-3-Hydroxybutyryl CoA Dehydrogenase Deficiency
2-Methylbutyryl CoA Dehydrogenase Deficiency
3-Hydroxy-3-Methylglutaryl (HMG) CoA Lyase Deficiency
3-Methylcrotonyl CoA Carboxylase Deficiency (3MCC)
3-Methylglutaconyl CoA Hydratase Deficiency
Fatty Acid Oxidation Disorders
Carnitine Uptake/Transport Defects
Glutaric Acidemia (Type II)
Long Chain 3-hydroxyacyl-CoA Dehydrogenase Deficiency (LCHAD)
Medium Chain acyl-CoA Dehydrogenase Deficiency (MCAD)
Short Chain acyl-CoA Dehydrogenase Deficiency (SCAD)
Very Long Chain acyl-CoA Dehydrogenase Deficiency (VLCAD)
Other Disorders
Biotinidase Deficiency
Congenital Adrenal Hyperplasia (CAH)
Congenital Hypothyroidism
Cystic Fibrosis
Galactosemia
Hemoglobinopathies (including Sickle Cell)
Severe Combined Immunodeficiency (SCID)

included a formal evidence review and committee deliberation and vote to recommend to the Secretary.

The advisory committee was reauthorized by Congress in 2014 and the requirement for a public health impact assessment and cost considerations be added to the committee deliberations to recommend a disorder for the RUSP.⁷ Besides development of the RUSP, the SACHDNC is also responsible for reviewing the NBS system and developing recommendations for the Secretary to improve NBS laboratory and follow-up activities.

The national standards and recommendations from the SACHDNC and the Secretary have helped guide the community decision making and quality assurance and improvement activities in Hawai'i.

Community Decision Making

An important foundation for the NBMSP is community engagement and decision making to guide the activities of the NBMSP and the disorders that are on the screening panel especially as more disorders, standards, and recommendations come from the SACHDNC and Secretary of Health and Human Services. The NBMSP convenes a state Newborn Metabolic Screening Program Advisory Committee at least once annually to provide recommendations to the DOH about NBS. The Committee consists of representatives from each birthing facility in the state, local laboratories, primary care providers, specialty care providers, parents of children with disorders detected by newborn screening, public health staff, advocacy organizations, and third party payers.

To aid the discussion and recommendations of the Advisory Committee, the DOH employs various methods to provide information to the Committee:

- (1) Collecting and analyzing data from the NBMSP and other related state public and private programs;
- (2) Collecting and disseminating information from national sources, other states, and literature searches;
- (3) Conducting surveys, focus groups, and interviews to collect community input from families and health care providers; and
- (4) Convening condition specific task forces to review evidence for adding a disorder to the panel and make recommendations to the Committee.

Quality Assurance and Continuous Quality Improvement

The authority and funding to have a coordinated and comprehensive NBS system allowed the NBMSP to develop, collect, and disseminate data for quality assurance and improvement activities. Using the data, a monthly performance report is generated for the entire state and each birthing facility. The report contains information about the timing of the collection of the blood after birth, quality of the specimens obtained from the newborns for testing, how long it took for the specimen to get to the laboratory, and any problems encountered. Recommendations for quality improvement for the birthing facility based on published or national standards are included with each performance report. The Hawai'i birthing facilities gener-

ally do very well at meeting the performance measures. When deficiencies are noted, corrective actions are executed quickly.

The collaborative relationship with clinical providers also allows the NBMSP to have information about follow-up, diagnostic testing, treatment, and management. This allows documentation of confirmation of diagnosis, initiation of treatment, and follow-up activities. Deficiencies in the process are monitored and changes are made to policies and procedures if corrective action is warranted.

Continuing Challenges

Growth of Disorders on Newborn Screening Panel

Since the original RUSP was recommended in 2010, three additional conditions, Severe Combined Immunodeficiency (2010), Critical Congenital Heart Defects (2011), and Pompe Disease (2015), have been recommended by the SACHDNC and put on the RUSP by the Secretary of Health and Human Services. In addition, the SACHDNC recommended two additional disorders to the Secretary, Mucopolysaccharidosis Type I and Adrenoleukodystrophy.

Hawai'i has responded to each new addition to the RUSP using the community decision making process with the NBMSP Advisory Committee when the NBS laboratory methodology has been validated. Currently, Hawai'i screens for 32 of the 33 disorders on the RUSP and has not started deliberation on Pompe Disease since the NBS laboratory has not identified or validated a method to do NBS efficiently for this one disorder.

The increasing number of disorders being added to the RUSP is a challenge for any state especially when most states are under budgetary constraints. The workload grows as states struggle with a reduced workforce due to retirement, attrition, and lack of funding or hiring freezes. As we add new disorders, we also have to be mindful to continue doing as well with the current disorders we detect which is difficult with a staff that is stretched thin.

Data systems need to be updated and become interoperable in both the public and private sector to provide accurate and timely tracking of the entire NBS process from the birth through resolution of screening results. Additional data systems need to be in place for long-term follow-up of infants diagnosed with disorders to improve future treatment and disease management.

Payment for treatment and management for disorders is also challenging. Coverage for treatment is variable depending on the family's health insurance plan. Some of the treatment is expensive and not always available in the state the family resides. This is especially problematic for Hawai'i since we have smaller numbers of pediatric specialists and the closest available treatment for some disorders is 2500 miles across the Pacific Ocean. Also, while we have a program that has successfully allowed children with these disorders to grow into productive adults, many adult providers and third party payers are not accustomed to caring for or covering services for adults with these disorders.

Ethical Issues

The principle of mandated newborn screening has been early detection in the newborn period to detect disorders that cannot be diagnosed easily so that the newborn can receive treatment to avoid disease, disability, and death. In recent years, late onset disorders have begun to be considered for inclusion into the NBS panel. Late onset disorders, such as Adrenoleukodystrophy, appear sometime after the newborn period with some not having any possible consequence until adulthood. Advocates argue this is the best and potentially the only method to detect those children and adults at risk for a disorder. Opponents respond that mandated newborn screening should only be used to detect disorders needing immediate treatment to preserve the principles that have been the foundation of newborn screening. All states will have to address this issue with their communities in the near future especially as the possibility of doing whole genome sequencing for the purpose of newborn screening becomes a reality.

Conclusions

Since the NBMSP started in 1986, over 1,100 children have been found with a disorder and treated to prevent disease, disability, and death. Hawai'i has become a model for creating a sustainable, community driven, cost effective, and comprehensive newborn screening system.

The continued success and sustainability of the program depends on the strong public/private partnership and community involvement that has been fostered over the last 20 years. We will need to expand and strengthen this collaborative effort as newborn screening moves into the future with the continuous addition of disorders to the screening panel and new technology for screening is developed.

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RED MEAT WILL DESTROY US ALL.

Somewhere in the World Health Organization medical panel there should be at least one person asking the committee, “are you people nuts?” Headlines in the morning paper in red letters 1.5 inches high, **CANCER WARNING! OMG**, now I am in serious danger from hot dogs, bacon, ham, corned beef, and even Hawai‘i’s favorite, Spam. Wow, think of all those people lining up at Costco for their hot dog or bratwurst, virtually skating around on the thin ice of cancer. So, am I marching toward my doom destroyed by a BLT sandwich, spam musubi, or my ever-loving porcine ball game snackeroonie? Never mind that I have survived eight decades, and no matter that baseball fans consumed seven billion (!) hot dogs this season, WHO want us all to believe we are destined to expire from eating red meat. Geez. Come ON, WHO gurus, you surely have more pressing diseases demanding your attention. Try malaria for example.

YOU WANT TO BE A DOCTOR.

Medical school applications hit an all-time high for 2015 according to the Association of American Medical Colleges. More than 52,550 students have applied, an increase of 6.2% over 49,480 of 2014. Of great interest also is that the number of first time applicants jumped 5%, considered to be a more telling measure of desire to become a physician. At a time when the nation is facing a shortage of 90,000 physicians by the end of the decade, this is good news. Diversity of applicants increased also with Hispanics moving up 1.8%, African Americans 1.1%, American Indian and Alaskan natives a remarkable 17%. What remains is for Congress to lift the 16 year-old cap on residency support, or we will have a shortfall across many areas of specialty training, according to AAMC President Gerald Kirch. He notes with students applying in record numbers and schools expanding their programs, Congress must help.

THIS SPECIMEN CAME FROM WHERE?

Forensic pathologist Silvana Tridico at Murdoch University in Perth, Australia, is active in analyzing pubic hair bacteria. She found that each person’s hair carries a unique mix of bacteria like fingerprints. The specimen can offer a forensic link between criminals and the bits of bodily debris they leave behind. Though still in early stages, her technique and other advances signal the beginnings of a seismic shift in the forensics field. One day, tiny microbes could hand investigators big clues. Bacteria shed from people’s hair, skin and footprints or fungi hidden in specks of dust, could help place suspects at the scene of a crime. Fingerprint analysis, steeped in more than a century of tradition, but not much data, gained international attention in 2004, when the FBI bungled an investigation of the Madrid train bombings. The bureau’s lab matched a single smudged fingerprint to an attorney in Oregon named Brandon Mayfield, an innocent man. He spent two weeks in jail before the Spanish National Police identified an Algerian man as the source of the print. The US government formally apologized and agreed to pay Mayfield \$2 million. The misidentification sparked renewed scrutiny of forensic techniques.

AND THE WICHITA LINEMAN IS STILL ON THE LINE.

Glen Campbell could not recall what he ate for breakfast, but he could put on a brilliant musical program of the songs we know so well. Alzheimer’s disease spares music memories. Brain areas that respond to music seem to withstand the ravages of Alzheimer’s. Described in *Brain*, scans were identified in two adjacent areas that seem to respond

to familiar songs, the caudal anterior cingulate and the ventral pre-supplementary motor area. Unlike most other brain areas, the music related areas didn’t show thinning or low metabolism as does tissue with amyloid deposits, a sticky protein linked to Alzheimer’s. Writing in *International Psychogeriatrics*, Professor Mohamad El Haj of Lille in France reported that familiar music seems to boost other memories. Okay, research neurologists, strike up the band.

ARE E-CIGARETTES HARMLESS???

According to FDA and CDC data from the annual National Youth Tobacco surveys collected for year 2014, e-cigarette use by US teenagers tripled from 4.3 to 12.3 percent among high school students. Celebrities Katy Perry, Johnny Depp and others appeared on television and magazines vaping electronic cigarettes. These high tech gadgets marketed as a healthier alternative to traditional cigarettes, are readily available at vaping shops, internet suppliers, and 24-hour convenience marts. With flavoring like bubble gum, Dr. Pepper, and cotton candy, teens have been taking the bait. A growing number of studies indicate that electronic cigarettes are far from harmless. Chemicals in E-cigarettes can damage lung tissue, and reduce the lungs’ ability to keep germs and other harmful substances from entering the body and also pose their own addiction risk. In Hawai‘i, 29 percent of more than 1,900 ninth and tenth grade students in five schools had at some time used e-cigarettes according to a study reported in the journal *Pediatrics*.

POLITICALLY CORRECT GOES BANANAS.

The president of the University of New Hampshire publicly complained about the “bias free language guide” posted on the school’s website. It denounces use of such words as “Americans” as insensitive to south Americans, “seniors” should be people of advanced years, “rich” should be termed people of material wealth. One politician suggested the state motto “Live Free or Die” should be “Live Free but upset no one.”

OH, YES. A VERY COMMON PROBLEM – NOT!

Vladimir Laurent, an insurance executive in Coral Springs, Florida, was granted a US patent September 29 and can begin mass-producing his product, “The Shield.” His brainstorm is designed to keep men’s genitalia from dragging in the toilet bowl when seated. While he personally needs this, he is aware that many others might not have his problem. The device has a suction cup that attaches to the toilet bowl and rotates with a ball and socket joint.

ADDENDA

- Chinese were the first to use a decimal system in the sixth century B.C.
- The grey whale’s pulse is nine.
- There is so much to be said of electronic journalism. By giving us the opinions of the uneducated it keeps us in touch with ignorance of the community.
- Fear and pain is being stuck in traffic after just having two cups of coffee and a bran muffin.
- There are two things that are important in politics. The first is money and I can’t remember the second.

ALOHA AND KEEP THE FAITH **rts**

(Editorial comment is strictly that of the writer.)

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