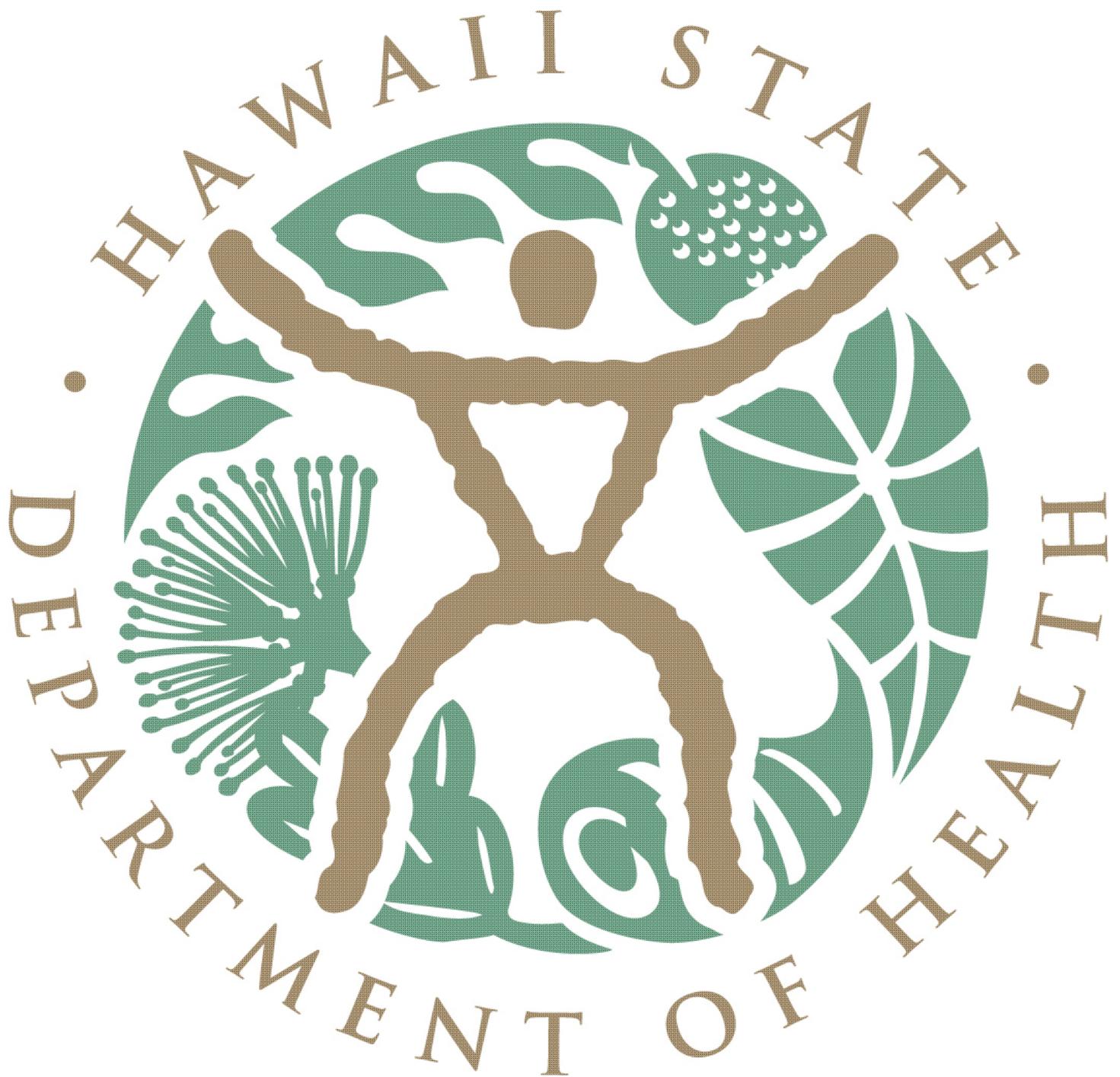
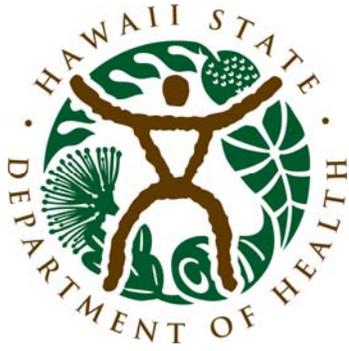


# Hawaii Journal of Public Health





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## Methodology Paper- Blend45ed ethnicity and health

Rachel Novotny & Yihe G. Daida

### Abstract

Ethnicity is an important social, cultural, behavioral and biologic measurement, for studying disparities in health. Hawaii is on the forefront of racial/ethnic mixing, providing a methodologic challenge and opportunity for health disparities research. We describe the BLEND method to measure race/ethnicity and its mixing, developed for the Female Adolescent Maturation study in Hawaii. Mixed ethnicity was associated with the same or greater health risk than the single ethnicities that composed the mix. As race/ethnic mixing, or blending, is becoming increasingly relevant to other regions, the BLEND method may be used to capture greater detail on ethnicity, including ethnic mixing.

### Introduction and Objective

Understanding reasons for racial/ethnic disparity in health and disease is an important area of study.<sup>1-3</sup> Racial/ethnic descriptors may be proxies for socioeconomic status, cultural values and behaviors, utilization of health services, and treatment adherence; race/ethnic descriptors may also indicate genetic or biologic differences among populations. Classification systems for race/ethnicity can influence reported disease rates and consequent health services targeted for these groups.<sup>4</sup> National and international trends of migration, intermarriage and the resultant racial/ethnic

mixing and diversity complicate the use of reliable and meaningful race/ethnic indicators.<sup>5</sup> The BLEND methodology will help health researchers think about race/ethnic data and its measurement, use, and interpretation for health research for increasingly mixed ethnic populations.

### Background

In recent decades, race/ethnic categories in the US decennial census and other official statistical records have followed guidelines from the US Office of Management and the Budget (OMB), which defined four races (White, Black, American Indian and Alaska Native, and Asian and Pacific Islander) and ethnicity (defined as either Hispanic or non-Hispanic origin) in 1977. For the 2000 census, the Asian and Pacific Islander category was separated, yielding five races: American Indian and Alaska Native, Asian, Black, Native Hawaiian and other Pacific Islander, and White. Moreover, people could report one or more of these races. In 2003, an OMB revision split the Asian or Pacific Islander category into two categories: Asian and Native Hawaiian or Other Pacific Islander. This change has been a critical step to disaggregate Native Hawaiian and other Pacific Islander groups so that they are not numerically “overwhelmed” by Asians who differ dramatically in many social, economic,

biologic, and health parameters. Still, the OMB Asian category includes the diverse peoples of the Far East, Southeast Asia, and the Indian subcontinent and the Asian racial/ethnic grouping does not exist as a self-identity for these people; nor is it clear that Asian is perceived as a group by the US public.<sup>6,7,8</sup> Still, the OMB change does not accurately capture race/ethnicity of individuals of mixed ethnicities. In Hawaii, 61% of babies were identified as mixed ethnicity in 2000.<sup>9</sup> And using data from the Hawaii Health Survey, Baker et al.<sup>10</sup> illustrated that there was a difference in prevalence of health conditions between the single versus mixed race/ethnicity individuals. The Pacific region is a diverse, high-risk environment with a dual burden of under- and over-nutrition and striking variability from population to population.<sup>11,12,14,15,16,17,18</sup>

## **Methods: Concepts and measurement of race and ethnicity using the BLEND method**

Race can be described the social group that a person belongs to because of a mix of physical features, themselves attributable to genetic differences arising from evolution in a particular place.<sup>19</sup> Ethnicity, on the other hand, refers to the social group a person belongs to because of a shared culture, history, geographical origins, language, diet and other such features.<sup>19</sup> Thus, race could be seen as one component of ethnicity while ethnicity becomes a group identity based on a shared set of biological, cultural and socio-political characteristics.<sup>19</sup> Ethnic differences in disease risk results from a complex mix of genetic differentiation and ecological factors.<sup>20</sup> We use of the term ethnicity to encompass racial (biologic), behavioral, and cultural aspects of identity, and we add further measurement if the focus is on “racial” biologic factors (a genetic trait or physical trait, for example), or behavioral measure (a dietary factor or a cultural preference, for example). We coin the term “blended ethnicity” to indicate mixed ethnicity, to emphasize the mixing rather than classification. Blended ethnicity, as we will describe, can be measured in proportion of each ethnic contributor or in an ethnic group classification scheme described by the component ethnicities.

We derived the BLEND methodology to describe multiple ethnicities (Figure 1) for The Female Adolescent Maturation (FAM) study, though the method has subsequently been applied to other studies in the Pacific

region. The tool is completed by the study subject to the best of their ability, by estimating the percent of each of the parent’s ethnicities, filling in any missing ethnicity on the “other” line, and making sure that each parent’s ethnicity sums to 100%. The tool can be adapted to the population under study, detailing specific ethnicities prevalent in the area (eg. Japanese, Korean, Chinese) that may be of interest for a particular study, and that can be collapsed back to the OMB categories. This information is probed and checked by the interviewer, assisting with the math if necessary.

In FAM Study 1, female adolescents, aged 9 to 14 years, were randomly selected from the Kaiser Permanente Oahu membership database by age and sex. We asked parents/guardians to provide every race/ethnicity of the biologic parents of the subject, in percent using the BLEND method. Each girl’s blended race/ethnicity was derived from the sum of her mother’s and father’s race/ethnicity. For example, if a girl’s father was 50% Asian and 50% White, while her mother was 25% Asian, 75% White, the girls’ race/ethnicity was calculated at 37.5% Asian and 62.5% White. Asian ethnicities included Japanese, Korean, Chinese, Filipino, Indian, Thai, and Vietnamese, as specified in the OMB directive.

For a highly ethnically mixed population such as Hawaii’s, this method captures more information and variability than other standard methods, including details of ethnic subgroups (Chinese in addition to Asian, for example), and percent of this ethnic group in the mix. The questionnaire

<b>Mother</b>	<b>Percent</b>	<b>Father</b>	<b>Percent</b>
<b><u>Native American</u></b>	_____	<b><u>Native American</u></b>	_____
<b><u>African American/Black</u></b>	_____	<b><u>African American/Black</u></b>	_____
<b><u>Asian</u></b>		<b><u>Asian</u></b>	
Chinese	_____	Chinese	_____
Filipino	_____	Filipino	_____
Japanese	_____	Japanese	_____
Korean	_____	Korean	_____
Other (Write in)_____		Other (Write in)_____	
<b><u>Hispanic</u></b>	_____	<b><u>Hispanic</u></b>	_____
<b><u>Native Hawaiian or Other Pacific Islander</u></b>		<b><u>Native Hawaiian or Other Pacific Islander</u></b>	
Hawaiian/Part-Hawaiian	_____	Hawaiian/Part-Hawaiian	_____
Other Pacific Islander ( <i>specify</i> ) _____		Other Pacific Islander ( <i>specify</i> ) _____	
<b><u>White</u></b>	_____	<b><u>White</u></b>	_____
<b><u>Other</u></b> ( <i>write in</i> ) _____		<b><u>Other</u></b> ( <i>write in</i> ) _____	

Figure 1. The BLEND Measurement Tool, as Used for Hawaii

has a detailed ethnic breakdown of ethnic blend that can be combined for national reporting. Ethnic subgroups can be added or removed from the questionnaire to adapt to the population under study. When needed, this questionnaire can be phrased to ask about genetic or cultural heritage.

The flexibility in handling this information also allows different types of analyses, depending on the research question. For example, when the research question deals with biologic outcomes such as age at menarche and bone, we can evaluate the contribution of a certain ethnic/ race group across the study population by treating ethnicity as a percent (Figure 2). This method also allows for analysis when there is too much mixing within the study population to be adequately sub-grouped. Thus, the

BLEND method allows data output as a classification scheme or as a continuous variable (proportion or percent); for example, proportion of Asian (Figure 3), or proportion of a particular Asian subgroup (e.g., Japanese). To summarize data for some reporting purposes, we classify these proportions as Asian (100%), White (100%), or mixture of Asian and White, as defined by OMB.

**Results: Examples using the BLEND method**

Using the BLEND method to classify ethnicity in the FAM study we have shown that girls classified as Asian and White Blended ethnicity had more total and upper body fat than girls who were classified as 100% Asian or White.<sup>21,22</sup> Blended girls weighed the most, had the highest BMI and were the most sedentary. Blended girls carried more body fat centrally, followed by Asian, then White girls. Using the

BLEND method, we were also able to show that girls who had a higher proportion of Asian ethnicity had more upper body fat than those who had a higher proportion of White ethnicity,<sup>21</sup> controlling for maturational stage, physical activity, energy intake, bi-acromial breadth, and height. We also showed that girls with a higher proportion of Asian ethnicity had higher calcaneal bone ultrasound measures than girls with a higher proportion of White ethnicity<sup>23</sup>. Speed of Sound ultrasound measures increased with the increased proportion of Asian ethnicity and reached a significant level only when 100% Asian ethnicity was compared with 100% White ethnicity. The study was approved by both Kaiser Permanente and the University of Hawaii Institutional Review Boards.

## Conclusions and Implications

Ethnic data cue us in to important issues such as how environment, diet and culture affect health behaviors and chronic diseases.<sup>24,25, 26</sup> FAM data show that the blended individuals possess the same or higher risk behaviors and body parameters when compared to the single ethnic groups. Given the ongoing trend of ethnic mixing in the Pacific, and our data indicating that blended individuals have health risks similar to or higher than non-blended individuals, further investigation is needed to clarify the components of blending that contribute to the health risk. Differences in type and degree of ethnic mixture may have different influences on disease outcomes. The BLEND methodology provides a needed tool to continue research into further understanding of ethnic mixing and health disparity. Together with other tools (genetic, cultural, and environmental), measuring ethnic mixing will further our understanding of the role of

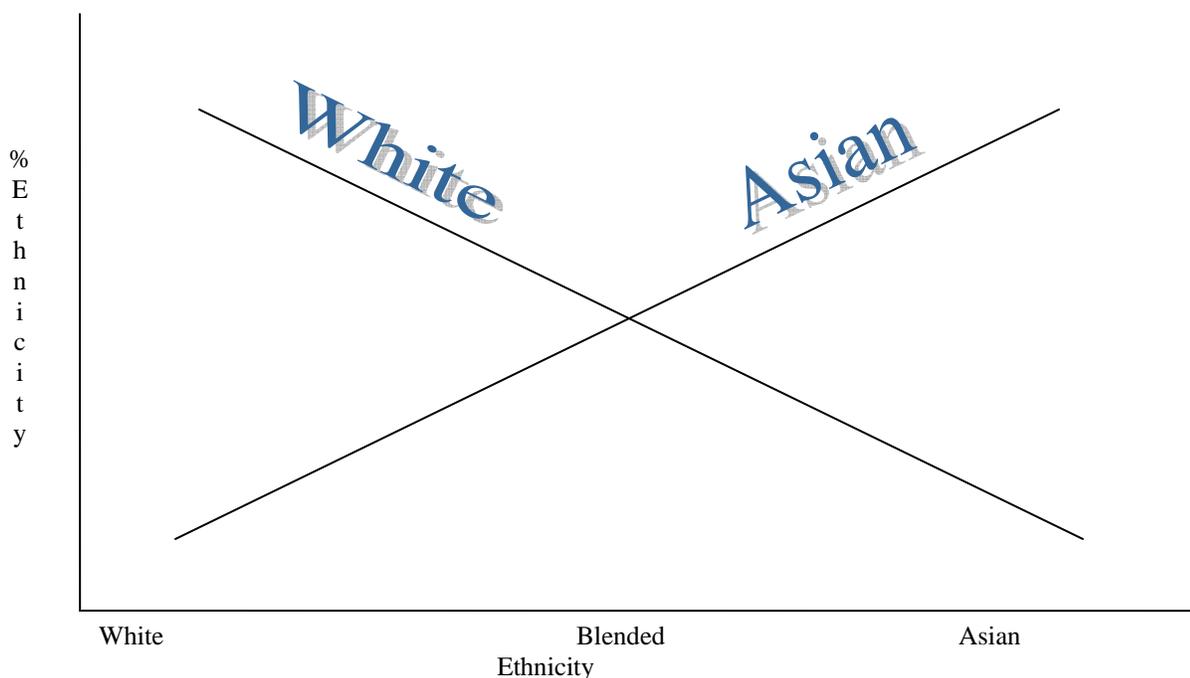


Figure 2. Depiction of Blended Asian and White Ethnicity



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# Evaluation of Birth Outcomes by Medicaid Status in Hawaii: An Analysis of Hospital Discharge Records

Ashley H. Schempf, PhD, Donald K. Hayes, MD, MPH, Loretta J. Fuddy, ACSW, MPH<sup>2</sup>

## Abstract

**Objectives:** A central goal of the Medicaid program is to reduce socioeconomic disparities in health. The objective of this analysis is to provide the first evaluation of perinatal health indicators by Medicaid/QUEST status in Hawaii.

**Methods:** Hospital discharge data from 2002-2006 were analyzed by type of health insurance coverage. Outcomes examined included low birth weight (<2,500 grams), cesarean delivery, maternal and newborn length of stay, infant mortality, and short birth intervals (<15 months).

**Results:** There were minimal differences by Medicaid/QUEST status in low birth weight, cesarean delivery, or length of stay. However, infant mortality was 1.44 times higher among newborns with Medicaid/QUEST versus private insurance (95% CI: 1.14, 1.84). Short birth intervals were also more than twice (RR= 2.27, 95% CI: 2.03, 2.53) as common among women insured by Medicaid/QUEST compared to private insurance.

**Conclusions:** These findings suggest that Medicaid/QUEST in Hawaii may be helping to reduce certain perinatal risk indicators, including low birth weight, among low-income mothers. However, greater efforts are needed to understand and reduce infant mortality and short birth intervals among the Medicaid/QUEST population.

**Implications:** The adoption of a revised birth certificate that collects delivery payor or other linkage between the birth/death certificate and hospital discharge data, would enable determination of the causes of excess infant mortality among the Medicaid/QUEST population and, consequently, facilitate the identification of effective interventions.

## Background

Individuals of lower socioeconomic status suffer a disproportionate burden of adverse health outcomes due to a variety of factors, including poorer access to quality health care and other environmental stressors and behavioral factors. Birth outcomes are no exception, with low birth weight (<2,500 grams or 5.5 pounds) nearly twice as common among infants born to white women living below the poverty level versus 200% or more.<sup>1</sup> Similarly, low birth weight is at least 1.5 times higher among women with less than a high school education compared to those with a college degree.<sup>2</sup> There is emerging evidence that health status at birth—a product of maternal health—is linked to morbidity and mortality not only in infancy but throughout the lifespan. Low birth weight is the single greatest risk factor for infant death and is also related to cognitive deficits, educational attainment, and adult

cardiovascular and metabolic disorders that exact substantial social and economic tolls.<sup>3-6</sup> Thus, with lifelong repercussions, it is imperative to promote equity in health from the beginning of life.

Medicaid is a federal program, administered and jointly funded at the state level, to provide health insurance and access to care for low-income individuals. Income eligibility varies by state and ranges from 133 to 300% of the federal poverty level (FPL) for pregnant women.<sup>7</sup> In Hawaii, eligibility expands from 100% FPL outside of pregnancy to 185% FPL during pregnancy and continues through eight weeks postpartum. An estimated 23.8% of all births are financed by Medicaid, also known as QUEST.<sup>7</sup> This figure is well below the national average of 41.3%, in part because of a unique health care act that requires employers to provide a health plan for employees working 20 or more hours a week.<sup>8</sup>

To evaluate Medicaid performance in helping to eliminate disparities in birth outcomes, a requirement of the Federal Maternal and Child Health Block Grant (Title V) is to report various pregnancy health indicators according to Medicaid versus non-Medicaid status. While it is not expected that enrollment in the Medicaid program will address all of the factors that contribute to socioeconomic disparities, and therefore produce equivalent outcomes as the non-Medicaid population, the indicators can be used as a baseline against which to compare trends over time and to spur more detailed investigations and interventions in the case of extreme differences. It is important to recognize that Medicaid versus non-Medicaid comparisons may be influenced by demographic differences (e.g. maternal age and race/ethnicity) as well as programmatic features such as eligibility thresholds and coverage rates that do not reflect true program effects.

The State of Hawaii has never reported data for the Title V Health Systems Capacity Indicators (low birth weight, infant mortality, first trimester prenatal care, and Kotelchuck index of prenatal care adequacy) by Medicaid/QUEST status.<sup>8</sup> Payor source is not available on the birth certificate as it is in some other states and linkage of birth certificates with Medicaid records has proven difficult due to funding issues and staff turnover in the State Medicaid Office. Using hospital discharge data acquired with funding from the State Systems Development Initiatives (SSDI) Grant, this analysis was undertaken to perform the first evaluation of perinatal indicators by insurance status in Hawaii.

## **Methods**

### Data Sources

Hospital discharge data were obtained from the Hawaiian Health Information Corporation (HHIC)—a private, non-profit corporation that maintains a database of health care encounters in the State that occur in the emergency department or result in an inpatient hospitalization. The data collected is primarily administrative in nature, but does include DRG codes, ICD codes, length of stay, birth weight, age, gender, and other limited data. Two datasets were furnished by the HHIC: 1) A cohort file of all delivery discharges between 2002-2006, and 2) A period file of all inpatient and emergency department (ED) discharges between 2000-2005 for infants up to 1 year old.

#### Birth Cohort File

A cohort file was constructed by HHIC to link maternal and infant delivery records to subsequent infant inpatient and ED visits within the same hospital. It includes 98% of all births from 2002 to 2006 using vital statistics counts as a reference (99% of all hospital births). This file was used to examine the perinatal indicators of birth weight, delivery mode (cesarean v. vaginal), and maternal and newborn length of stay. These outcomes are reported for the most recent 3 year period (2004-2006) to provide the most current estimates. Since the file does not contain inpatient and ED visits made to hospitals other than the delivery hospital, it is not complete and cannot be used to examine longitudinal outcomes such as visit counts or infant death.

However, with five years of data available, women who delivered more than one infant during the study period provide an opportunity to examine birth spacing. Birth spacing was examined with this cohort file, under the assumption that subsequent deliveries to the same hospital are fairly common.

#### Period File

A period file was constructed by HHIC to include all infant inpatient and ED visit records from 2000-2005 whether or not they could be linked to a birth record. This file was used to provide a numerator of infant deaths in the calculation of infant mortality rates. Based on comparison with vital statistics data, this file captured 97% of all infant deaths from 2003 to 2005. Due to a lower capture rate (85%), data from 2002 were not analyzed so for the purpose of this report, infant mortality was assessed only using this period file covering the years 2003-2005.

### **Outcomes**

#### Birth Weight

Infant birth weight, a product of both the rate of fetal growth and gestational duration, is highly predictive of newborn morbidity and mortality. Birth weight was obtained from newborn hospital discharge records and analyzed both continuously and categorically as low birth weight (LBW: <2,500 grams). Although LBW is more predictive of severe morbidity and mortality, differences in continuous birth weight within normal ranges are also associated with school performance and learning disabilities.<sup>9</sup>

#### Cesarean delivery

Cesarean sections are performed in the presence of pregnancy complications that jeopardize the health of the mother and/or fetus. The rate of cesarean section has been steadily rising possibly due to increasing maternal request and physician willingness in the face of mounting malpractice suits for birth injuries.<sup>10, 11</sup> Cesarean versus vaginal delivery was determined by the maternal Diagnostic Related Group (DRG 370 and 371).

#### Maternal and Newborn Length of Stay

The length of stay related to delivery is a function of institutional/insurance policies as well as the extent of complications. Length of stay was determined from the delivery discharge record for both mothers and newborns. Length of stay was capped at 365 days (3 newborns with length of stays >365 days) and analyzed according to delivery mode since the recovery period is longer for cesarean as compared to vaginal deliveries.

#### Infant Mortality

Infant mortality, defined as a death before 1 year of life, is a sentinel indicator of population health—reflecting our ability to care for the most vulnerable segment of society. The rate of infant mortality is defined as the number of deaths to infants under one year of life divided by the number of births per calendar year (expressed per 1,000 live births). The period file (2003-2005) listing all inpatient and ED encounters with a death recorded

(disposition='Expired') provided the numerator for the infant mortality rate (IMR), whereas, the linked cohort file (2003-2005) provided the denominator of all births. For this outcome, no exclusions were made on the basis of missing or invalid birth weight range or multiple births from either file, as this information was not available in the unlinked period file. Infant mortality was further classified according to the timing of death in the neonatal (<28 days) or postneonatal periods (28 to 364 days) from the infant age at discharge. Cause of death could not be determined as the ICD-9 codes listed in hospital records were unreliably recorded and did not follow the rules for coding the underlying cause of death as listed on a death certificate.

#### Birth Interval

Sufficient spacing of births helps to promote optimal maternal and infant health outcomes. Birth to conception intervals shorter than 6 months are associated with adverse perinatal events including preterm birth and growth restriction.<sup>12</sup> With only lengths between successive births available, a dichotomous indicator of birth intervals <15 months and 15 months or more (6 months + 9 month normal gestation) was created for analysis. Some caution should be exercised in the interpretation of this indicator given that it reflects spacing among women with successive live births at the same hospital within the study period. Thus, stillbirths, deliveries that occurred at two different hospitals, and births before or after the study period are not included. It should be well noted that this indicator does not reflect the overall probability of having a

successive birth within 15 months but is instead conditioned on having had a subsequent birth within a restricted study period. Therefore, the range of possible birth intervals is artificially constricted.

#### Analytic Sample and Plan

Analyses of outcomes at birth were restricted to singleton deliveries with valid birth weights for the three most recent years of data, 2004-2006. Multiple births (n=1,598, 3%) carry uniquely elevated risks of adverse perinatal events and are not appropriate to include in general analyses of birth outcomes. Due to concerns about the reliability of designating live births versus fetal deaths at the threshold of viability, all newborn records with birth weights less than 500 grams were excluded from analysis (n=69, 0.1%). There were an additional 38 records with missing/unknown values for birth weight or insurance, resulting in a total of 52,513 births.

Of the identified 9,982 mothers with successive births in the cohort dataset from 2002-2006, 96% had private or Medicaid/QUEST insurance in both first and second deliveries. During this time, the military hospital did not assign unique patient ID numbers so successive births among the military population could not be identified. Among women with private insurance for their first delivery in the dataset, 86% had private insurance for the second delivery and 13% switched to Medicaid/QUEST. Among women with Medicaid/QUEST insurance for their first delivery, 85% had Medicaid/QUEST insurance for their second delivery and 13% switched to private insurance.

Based on this information, a four category variable indicating insurance status for both deliveries was created for analysis. Due to a lack of importance of valid birth weight or plurality for birth spacing, these exclusions were not made for this outcome. The unlinked nature of the infant death data also prevented exclusions on the basis of birth weight or plurality in the calculation of infant mortality rates.

Statistical comparisons were made according to maternal insurance at delivery, except for infant mortality which was calculated according to infant insurance at the time of death. Insurance categories include Medicaid/QUEST, private, military, and self-pay or uninsured.

Primary insurance category comparisons made to Medicaid/QUEST were all non-Medicaid/QUEST and private insurance. For ease of computation, all non-Medicaid is the required comparison group for the Title V Maternal and Child Health Block Grant, whereas private insurance may be considered a more homogeneous reference group that is most often considered to be the standard of care. In contrast, the military has a unique universal access system of health care and the active-duty population is healthier than the general population. The very small self-pay population in Hawaii is likely to be comprised of a heterogeneous mix of the self-employed, the near-poor or those who may have declined employer based coverage, and non-residents. Maternal age and geographic zip code aggregates based on billing address, the only sociodemographic characteristics available from hospital discharge records, were examined as potential

adjustment factors through direct standardization and regression analysis.

## Results

Maternal age varied significantly by insurance type with Medicaid/QUEST mothers averaging four years younger than all non-Medicaid/QUEST mothers and five years younger than privately insured mothers (Table 1). The rate of LBW was slightly higher among births to Medicaid/QUEST-insured mothers (7.0%) than to those without Medicaid/QUEST insurance (6.4%) and not significantly different from those with private insurance (6.7%). The highest rate of LBW was observed among the uninsured (7.9%) and the lowest among those insured by the military (5.4%). The mean birth weight was only 39 grams lower for those with Medicaid/QUEST versus non-Medicaid/QUEST. The highest mean birth weight was observed among the military-insured and the lowest among the uninsured. In general, adjustment for maternal age through direct standardization and regression-based analyses did not explain these minimal differences, which are unlikely to be clinically meaningful (not shown).

The rate of cesarean delivery varied significantly according to insurance type from 20.1% among the uninsured to 27.5% among the privately insured. Women insured by Medicaid/QUEST were slightly less likely than all non-Medicaid/QUEST mothers and those with private insurance to have a cesarean section. Because teen mothers are more likely to be insured by Medicaid/QUEST and less

likely to have cesarean deliveries, adjustment for differences in maternal age appeared to explain the lower rate of cesarean delivery among the Medicaid/QUEST versus non-Medicaid/QUEST and private insurance populations (Table 2). Geographic zip code aggregates did not alter any differences in outcomes.

Maternal and newborn length of stay were longer for cesarean than vaginal delivery but varied minimally by insurance status (data not shown). There were no differences in maternal or newborn median length of stay, irrespective of insurance status (2 days for vaginal, 3 days for cesarean).

Disparities in infant mortality and short birth intervals by insurance category were more pronounced. Infant mortality rates ranged from 4.9 per 1,000 live births among military newborns to 8.0 per 1,000 among Medicaid/QUEST newborns (Table 3). The IMR among Medicaid/QUEST insured newborns was significantly higher than that of privately insured or all non-Medicaid/QUEST newborns. The rate ratios were 1.44 (95% CI: 1.14 , 1.84) compared to the privately insured and 1.38 (95% CI: 1.11 , 1.72) compared to all non-Medicaid/QUEST newborns.

The neonatal mortality rate for Medicaid/QUEST infants was higher than the rate for all non-Medicaid/QUEST (RR: 1.24, 95% CI: 0.95 , 1.60) or privately insured infants (RR: 1.25, 95% CI: 0.95 , 1.65) at a level of marginal statistical significance. The postneonatal mortality rate of Medicaid/QUEST infants was significantly higher than the rate for all non-Medicaid/QUEST (RR: 1.93, 95% CI: 1.22 , 3.04) or

privately insured (RR: 2.30, 95% CI: 1.37 , 3.89) infants. However, because neonatal mortality comprises a larger share of overall infant mortality, the gap between Medicaid/QUEST and private or all non-Medicaid/QUEST infants is equally apportioned to neonatal and postneonatal periods.

Among women who delivered at least two births at the same hospital within the study period, the proportion of women who delivered another infant within 15 months varied significantly by insurance, ranging from 7% among women who switched from Medicaid/QUEST to private insurance to 21% among women who were consistently Medicaid/QUEST insured (Table 4). Women who were consistently Medicaid/QUEST insured were more than twice as likely as women who were consistently privately insured to experience a short birth interval (RR: 2.27; 95% CI: 2.03 , 2.53).

Figure 1 summarizes the rate ratios for perinatal outcomes comparing Medicaid/QUEST to non-Medicaid/QUEST and private insurance. Differences are both large and statistically significant for infant mortality, postneonatal mortality, and short birth intervals.

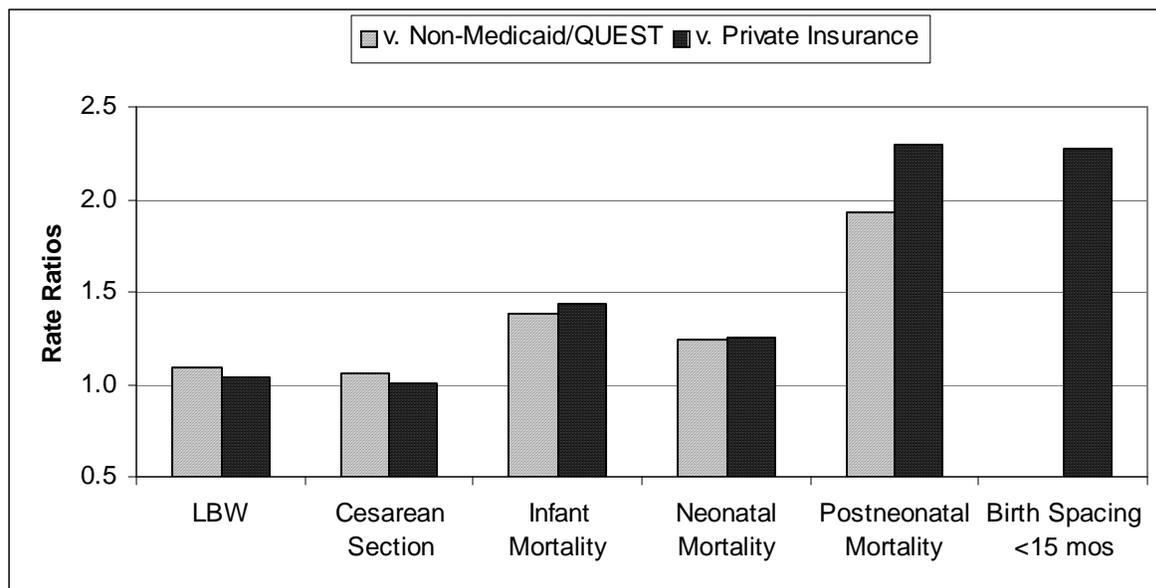
## Discussion

Compared to the privately insured, the results of this analysis notably show minimal differences in birth weight, cesarean delivery, and length of stay for delivery among those with Medicaid/QUEST coverage, particularly after adjustment for maternal age. Theoretically, there should be few differences in quality of care between Medicaid/QUEST and private insurance as Medicaid/QUEST was

transitioned to managed care from fee-for-service beginning in 1994, allowing participants to subscribe to three private providers. However, there are differences in the extent of coverage between private and Medicaid/QUEST insurance and not all network providers accept Medicaid/QUEST insurance. Case management and other ancillary services funded by Medicaid/QUEST or other government-supported programs such as the Supplemental Nutrition Program for Women, Infants, and Children (WIC) and Community Health Centers (CHCs) may be responsible for the relative absence of differences in birth outcomes between the Medicaid/QUEST and privately insured. According to a 2003 report, Hawaii is one of only seven states in which CHCs serve more than 20% of the state population living below 200% of the federal poverty level.<sup>13</sup> Evidence suggests that the

psychosocial and enabling services provided at CHCs may mitigate socioeconomic and racial/ethnic disparities in birth outcomes.<sup>14, 15</sup> The Maternal and Child Health Branch provides subsidies for CHCs to provide support to high risk pregnant women through its perinatal support services and Baby Substance Abuse Free Environment (Baby SAFE) programs.

Relative to the privately insured, however, women on Medicaid/QUEST were significantly more likely to experience a short birth interval and infants on Medicaid/QUEST were about 1.5 times more likely to die within the first year of life. These adverse risks likely reflect the sociodemographic vulnerability of Medicaid/QUEST participants and indicate that greater focus on family planning access and infant death prevention within the



**Figure 1.** Rate Ratios for Perinatal Outcomes Comparing Medicaid/QUEST to Non-Medicaid/QUEST and Private Insurance  
<sup>^</sup> p<0.05  
p<0.01  
Note: Data for this figure are presented in Tables 1 to 4. The cesarean section rate ratio is age-adjusted. Medicaid/QUEST serves as the reference group for all rate ratios.

Medicaid/QUEST program may be warranted. Although the birth interval variable is not ideal, it is more likely to underestimate differences between Medicaid/QUEST and private insurance in the overall probability of experiencing a short birth interval given that low-income mothers may be more likely to experience mobility<sup>16</sup> and to deliver at different hospitals within the study period (having an uncounseled short interval); and those with higher socioeconomic status (private insurance) are more likely to have only one child<sup>17</sup> and/or intervals that may be longer than the study period allowed (having an uncounseled long interval). Implementation of a family planning waiver in Hawaii (currently adopted in 27 states), which extends coverage for contraceptive counseling and services for one to five years beyond the immediate postpartum period, could help to improve birth spacing and reduce unwanted pregnancy<sup>18, 19</sup>—both important risk factors for infant mortality.<sup>12, 20</sup> Such waivers are also shown to be cost-effective in averting Medicaid expenses for the care and delivery of unwanted births, with cost savings of \$2.50 for every dollar spent.<sup>18, 21</sup> In Hawaii, it has been estimated that Medicaid/QUEST spends approximately \$15.6 million dollars per year delivering unwanted births and this figure does not include any postnatal costs of pediatric care throughout childhood.<sup>22</sup>

The disparity in infant mortality for Medicaid/QUEST infants was equally apportioned to neonatal and postneonatal periods. Thus, a similar number of excess deaths occurred in both periods. The minimal birth weight differences according to Medicaid/QUEST status,

including the smallest and most at-risk newborns (<1,500 grams, data not shown), suggests that neonatal mortality differences are due either to less healthy low birth weight infants among the Medicaid/QUEST population or to differences in quality of care. Because the hospital of birth was not identified in the file procured from HHIC, it is not known whether Medicaid/QUEST very low birth weight infants are equally likely to be born at Kapi'olani Hospital—containing the only level III neonatal intensive care unit in the state—rather than being transferred after birth. This is a critical indicator of the appropriateness of care and highly related to the risk of death. If the excess postneonatal infant death for Medicaid/QUEST infants arises from chief postneonatal mortality determinants such as Sudden Infant Death Syndrome, injury, and infection, these factors may be amenable to preventive education in the context of primary care. Additional research will be necessary to determine the exact causes of excess infant death among the Medicaid/QUEST population. The differential exclusions applied to LBW versus infant mortality are unlikely to explain the Medicaid/QUEST differences observed for these outcomes. Infants born at <500 grams comprised an equally small proportion of all births for those on Medicaid/QUEST and private insurance (0.12%). And the inclusion of multiple births, which have higher mortality risks and were more common among the privately insured, would tend to underestimate mortality differences by Medicaid/QUEST status. The reliance on newborn versus maternal insurance for infant mortality statistics is also unlikely to account for differences between LBW and infant mortality given that the

correlation between maternal and newborn insurance was 0.91.

According to current Title V state reports, Hawaii is one of only four states with comparable LBW rates for the Medicaid and non-Medicaid populations.<sup>23</sup> However, state-to-state Medicaid v. non-Medicaid comparisons are compromised by differences in factors such as eligibility thresholds, the proportion of low-income or uninsured in the non-Medicaid population, and compositional differences by race/ethnicity or multiple birth rates. For example, states with lower eligibility thresholds may have larger outcome differences by virtue of starker income contrasts between those in Medicaid versus other types of insurance. Hawaii has a higher eligibility threshold for pregnant women (185%) but also one of the lowest Medicaid coverage rates (23.8%).<sup>7</sup> This could mitigate differences since many poor and near-poor women may be covered by private insurance due to a state employer mandate to offer insurance benefits to full and part-time workers. Regardless of comparability issues, however, substantial infant mortality differences by Medicaid/QUEST status are consistently reported. In general, there are larger socioeconomic gaps observed for infant death than LBW.<sup>1</sup>

Although this is the first evaluation of perinatal outcomes by Medicaid/QUEST status in Hawaii, the absence of data on the causes of infant mortality is a major limitation of this analysis. Adoption of the 2003 National Birth Certificate that collects delivery payor (currently collected by 25

states)<sup>24</sup> or other linkage between the birth/death certificate and hospital discharge data, would enable determination of the exact causes of excess infant death and the evaluation of differences in other indicators, including prenatal care utilization and preterm birth. Such a linkage would also facilitate the comparison of outcomes according to additional sociodemographic factors including maternal education and race/ethnicity. Maternal education is not available in discharge records and race/ethnicity is not consistently collected (40% were categorized as other, N/A, unknown or not collected).

Adoption of the revised national birth certificate would improve data comparability between states for a variety of outcomes but will require several years after implementation to collect complete data for analysis. By contrast, feasibility studies conducted by HHIC to link already available hospital discharge data to infant birth/death certificates have proved successful but will require a grant or other source of funding to perform.

Another avenue for further research is to use the Hawaii Pregnancy Risk Assessment and Monitoring System (PRAMS) to examine additional outcomes not available on the birth certificate or discharge records such as unintended pregnancy and the timing of Medicaid/QUEST enrollment in relation to prenatal care entry. Continued monitoring to track changes in these indicators and evaluate Medicaid/QUEST performance will be vital to improve outcomes for Hawaii's most vulnerable low-income mothers and their babies.

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## Tables

Table 1. Perinatal Indicators by Insurance Status, Singletons 2004-2006\*

Table 2. Age-specific and Age-standardized Cesarean Rates among singleton deliveries by Medicaid/QUEST status and Private Insurance, 2004-2006

Age	Overall	Medicaid/QUEST		Non-Medicaid/QUEST		Private	
	%	Total %	Cesarean Rate (%)	Total %	Cesarean Rate (%)	Total %	Cesarean Rate (%)
10-19 yrs	8.5	16.4	18.4	5.0	16.9	5.0	17.9
20-24 yrs	25.0	37.7	22.2	19.3	19.5	14.6	21.5
25-29 yrs	26.6	25.0	23.3	27.3	22.0	26.1	22.9
30-34 yrs	22.9	13.4	29.9	27.2	27.7	29.6	28.5
35+	17.0	7.6	34.0	21.2	35.8	24.7	36.5
Total	100.0	100.0	23.8	100.0	25.7	100.0	27.5
Standardized Rate			26.0		24.6*		25.7
95% CI			(25.0 - 27.0)		(24.1 - 25.1)		(25.1 - 26.4)

Table 3. Infant, Neonatal, and Postneonatal Mortality Rates (per 1,000) by Insurance Status, 2003-2005\*

Insurance	Infant Mortality Rate (95% CI)	Neonatal Mortality Rate (95% CI)	Postneonatal Mortality Rate (95% CI)
Medicaid/QUEST	8.0 (6.6 - 9.3)	5.7 (4.0 - 7.7) <sup>†</sup>	2.3 (1.7 - 3.2) <sup>†</sup>
Non-Medicaid/QUEST	5.8 (5.0 - 6.6)	4.6 (3.9 - 5.3) <sup>^</sup>	1.2 (0.9 - 1.6) <sup>†</sup>
Private Insurance	5.5 (4.6 - 6.4)	4.5 (3.7 - 5.3) <sup>^</sup>	1.0 (0.7 - 1.4) <sup>†</sup>
Military	4.9 (3.5 - 6.6) <sup>†</sup>	3.6 (2.6 - 5.0) <sup>^†</sup>	--
Self Pay	--	--	--

Table 4. Short Pregnancy Interval (%) by Maternal Insurance at Each of Two Successive Pregnancies, 2002-2006\*

<b>Insurance at Each Delivery</b>	<b>N</b>	<b>&lt;15 mos</b>
Medicaid/QUEST, Medicaid/QUEST	3,360	21.3
Private, Medicaid/QUEST	758	14.3
Medicaid/QUEST, Private	525	7.1
Private, Private	4,978	9.4

\*All estimates significantly different from Medicaid/QUEST, Medicaid/QUEST (p<0.05)

Note: Based on 9621 women who had two deliveries at the same hospital during 2002-2006 period and who had Medicaid or private insurance at each delivery; data source is birth cohort file

# The Hawai'i Healthy Aging Partnership: Partnership Development - An Investment for Program Success

Michiyo Tomioka, MS<sup>1</sup>, Tammy Tom, MA, MS<sup>2</sup>, Paula Higuchi, MSW<sup>3</sup>, Shirley Kidani, MPH<sup>4</sup>, Noemi Pendleton, MBA<sup>5</sup>, Barbara Yamashita<sup>6</sup>, and Kathryn Braun, DrPH<sup>7</sup>

## Abstract

**Objective.** Significant attention is being given to implementing evidence-based interventions. Previous studies suggest challenges to replicating evidence-based programs, including lack of knowledge and skills among planners and providers. This paper describes a 3-phase cycle trialed by the Hawai'i Healthy Aging Partnership (HHAP), illustrating the usefulness of partnership development and capacity-building activities in helping service networks prepare for the replication of evidence-based programs in their communities.

**Methods.** HHAP built community capacity to implement evidence-based interventions by: 1) bringing partners from state and county offices on aging and service agencies together to develop a 5-year strategic plan on healthy aging; 2) providing and evaluating training in needs assessment, evidence-based programming, grant writing, and evaluation; and 3) providing funds and technical assistance to pilot evidence-based programs.

**Results.** Program stakeholders were engaged in partnership development and completed a strategic plan in 2004. Training helped trainees gain awareness, confidence, and understanding of needs assessment and evidence-based planning concepts. Partners applied new knowledge and skills by piloting evidence-based programs in 2005. These planning, training, and pilot programming activities enabled program partners to successfully win a federal grant in 2006 to replicate evidence-based programs. Members reported applying skills to other job areas, generally improving community programs and health.

**Conclusions & Implications.** Continued resource sharing, commitment, and supportive environments were key elements to motivate community partnership development. The time and resources required to build capacity are good long-term investments. This case study provides an example to communities in building capacity to replicate evidence-based programs.

## Background

Advances in public health and medicine have helped delay mortality. Although Hawai'i has the longest life expectancy of any state,<sup>1</sup> the proportion of elderly who report poor physical activity and diet and have chronic diseases is increasing, with health disparities seen among

ethnic groups.<sup>2</sup> Hawai'i Behavioral Risk Factor

Surveillance System (BRFSS) 2007 data show that among adults age 60 years and older:

- Almost 60% have high blood pressure
- Almost 50% are overweight or obese
- Almost 20% have diabetes

- More than 50% do not meet recommended physical activity levels

- Almost two-thirds consume less than the minimum recommended five fruits/vegetables daily.

Government and service providers are looking for programs to keep elders healthy and delay morbidity, as well as mortality.<sup>3</sup>

During the last decade, significant attention has been given to replicating health promotion programs that are evidence based. Evidence-based programs are those that have been proven effective through rigorous evaluation.<sup>2</sup> The US Administration on Aging (AoA), Centers for Disease Control and Prevention, Agency for Healthcare Research and Quality, National Institute on Aging, Centers for Medicare and Medicaid Services,

Substance Abuse and Mental Health Services

Administration, and private foundations have joined forces

to encourage states to use evidence-based health

promotion interventions in aging service community

programs.<sup>4-5</sup> Among evidence-based programs to help

older adults improve their fitness levels and gain control

over chronic illnesses, are the EnhanceFitness (EF)

program of Seattle and the Chronic Disease Self-

Management Program (CDSMP) from Stanford

University.<sup>6-8</sup>

The literature outlines the many challenges of transferring scientific knowledge to community practice and the need to build organizational capacity to implement evidence-based programs.<sup>9-13</sup> Investigators conclude that

*Table 1: HHAP stages of capacity building, 2003-2006.*

2003	2004	2005	2006
<b>Ongoing Partnership Development -----&gt;</b>			
<b>Phase I:</b> Preparation & Strategic Planning		<b>Phase II:</b> Training	
		<b>Phase III:</b> -- Support for pilot projects -- Grant writing	

collaborative partnership is one of the predominant influences on expanding community capacity. It enhances resource availability and needed skills across organizations. Evidence-based interventions require viable community-based planning approaches to empower partners and transfer knowledge in local communities. In this paper, we report on capacity-building efforts undertaken by the Hawai'i Healthy Aging Partnership (HHAP), a statewide aging coalition of professionals from state, county, and service agencies. These capacity-building were essential in helping HHAP secure federal grants to select, replicate, and begin to institutionalize EF and CDSMP in Hawai'i.

**Methods**

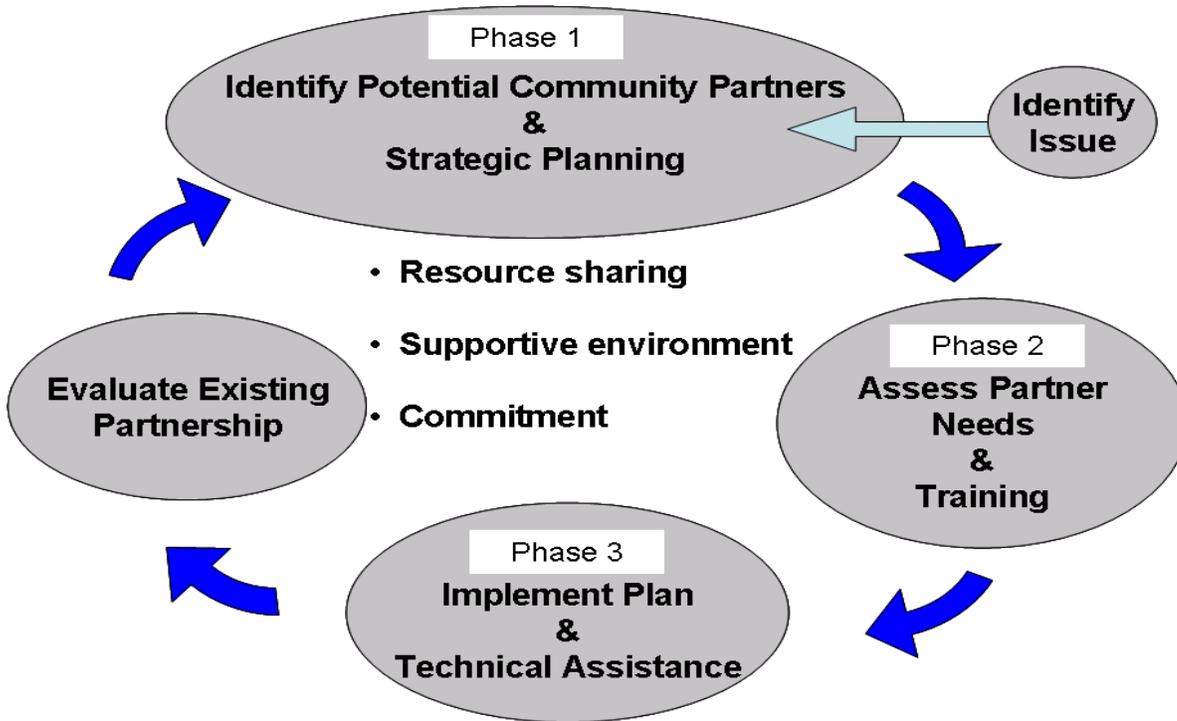
Partners from the Executive Office on Aging (EOA),

the four county-based Area Agencies on Aging (AAAs), the Department of Health (DOH), non-governmental organizations that offer elder care services, and the University of Hawai'i (UH) came together to discuss ways to expand health promotion programming for older adults in Hawai'i. Initially, our efforts were focused on identifying supports and barriers among community partners who wanted to expand health promotion programming for older adults in Hawai'i. Partners begin to create the sense of connection to other organizational members to achieve shared goals to adapt evidence-based programs to improve the health of older adults. Our process included three phases: 1) preparation, partnership development, and strategic planning; 2) training in needs assessment, planning, grant writing, and evaluation (with assessment

**Table 2.Strategic Planning**

<p><b>Goals</b></p>	<p><b>Long term:</b> Reduce morbidity and premature mortality <b>Intermediate:</b> All older adults will eat five or more serving of fruits and vegetables a day All older adults will participate in moderate physical activity of 30 minutes or more a day <b>Short term:</b> All older adults will start or continue to exercise and eat right</p>
<p><b>Guiding principles</b></p>	<ol style="list-style-type: none"> <li>1. Promote community involvement and ownership of activities.</li> <li>2. Assure that cultural and ethnic diversity are respected and differences in process are embraced.</li> <li>3. Measure outcomes through the collection of quality data.</li> <li>4. Focus on the prevention aspect of activities.</li> <li>5. Encourage partner involvement in planning, delivery and evaluation of initiatives.</li> <li>6. Support the development of infrastructure that will sustain efforts and activities.</li> </ol>

**Table 3. Summary Training Results**



of training impact through pre-post tests); and 3) support for pilot projects (to test implementation of promising programs) and grant writing (to find funding for evidence-based replication). Partners continue to be added throughout the process (Table 1).

**Results**

The following section provides detail descriptions of each of the three phases of capacity building toward HHAP’s goal of replicating evidence-based health promotion programs in their communities.

**Phase 1. Preparation, Partnership Development, and Strategic Planning**

In 2003, informal discussions between the state’s EOA and DOH led to the development of a statewide partnership among the EOA, DOH, the four county AAAs, UH, and various provider agencies. The partners had a emerging awareness of evidence-based public health and wanted to learn more.<sup>14, 15</sup> To adapt evidence-based programs in Hawai’i, stakeholders recognized the need for training in how to assess community preferences for health promotion programs, find evidence-based programs to fit identified needs, implement the program,

and evaluate its impact.<sup>14, 16, 17</sup> Partners identified needs related to healthy aging by reviewing data from the BRFSS and identifying priority health issues. A UH librarian assisted by trained partners how to search the scientific literature to locate articles related to evidence-based programming. The group named itself the Hawai'i Health Aging Partnership (HHAP) and pledged itself to "improve the health status of Hawai'i's older adults by building partnerships to expand community capacity and embed evidence-based interventions that increase physical activity, nutritional health, and control over chronic diseases into Hawai'i's aging services network."<sup>18</sup>

Partners next embarked on a strategic planning process to meet their goal. Local experts helped provide a workshop to help partners collectively design a strategic planning process. Over a 3-month period, HHAP identified major external forces and trends, priority issues, and resources each partner could provide, and developed short-term, intermediate, and long-term objectives and a timeline. The partners agreed that they wanted to

implement evidence-based interventions that were community-based, culturally appropriate, and sustainable. Partners agreed that programs should be tested through systematic data collection and outcomes evaluation.

The plan, *On Creating a Legacy: Healthy Aging Project—A Strategic Plan on Achieving Outcomes (2005-2009)*, was completed in 2004. It enumerated six guiding principles, as well as long-term, intermediate, and short-term goals (Table 2). HHAP partners knew they would need to implement appropriate evidence-based programs to meet its short-term goal--All older adults will start or continue to exercise and eat right--by 2009. Thus, strategic tasks included training and technical assistance to increase partners' knowledge and skills in supporting evidence-based programming; these were provided in Phase 2.

Organizationally, the partners decided that each county should develop its own Healthy Aging Partnership to receive training and to champion local replication of evidence-based programs. County HAPs designed

representatives to the statewide HHAP, one of which was from the county AAAs. Statewide HHAP meetings were held bimonthly in Honolulu to keep stakeholders informed and working together, and each county reported on their progress at these meetings. For the most part, HHAP-sponsored training was provided in each county so that county HAPs could develop their own capacity.

### **Phase 2) Training: Sponsoring training in needs assessment, planning, grant writing, and evaluation**

The first step in Phase 2 was to assess the training needs of the HHAP partners, particularly the county AAAs, which were charged with developing local HAPs and stimulating replication of evidence-based programs in their counties. AAAs requested training in needs assessment, evidence-based programming, grant writing, and evaluation. In 2004, EOA contracted with local experts to develop and offer county training programs in these areas.

In 2004, two training topics, needs assessment and evidence-based programming and evaluation, were offered in each of the four counties. Pre-post tests were administered to measure changes in awareness,

understanding, confidence, perceived knowledge, and content knowledge. McNemar's  $\chi^2$  test analysis was used to determine statistical significance between pre- and post-test responses. A summary of findings is provided in Table 3.

**Needs Assessment Training.** Full-day county-based needs assessment trainings were designed to help participants: 1) identify four steps in conducting needs assessments; 2) discern the relative strengths of surveys and focus groups, 3) develop questions for surveys and focus groups they might conduct, and 4) learn to facilitate a focus group. A 21-item questionnaire developed by the trainer and EOA was administered prior to and following each session. The questions tested content awareness and proficiency, confidence in performing skills, and knowledge acquired in workshop training. Thirty participants (7-8 in each county) attended training, and 29 (97%) completed the pre- and post-test.

Participants reported a statistically significant increase in their understanding of what needs assessment

involves ( $N = 24$ ,  $\chi^2 = 16.06$ ,  $p < 0.001$ ). Over three-fourths (78%) reported increased confidence in their ability to conduct secondary data review and focus group ( $N = 27$ ,  $\chi^2 = 8.10$ ,  $p < 0.001$ ). Only 22% demonstrated knowledge gains on the multiple-choice questions (not statistically significant). However, all counties successfully demonstrated their ability to conduct a focus group designed during the training, and all counties went on to conduct focus groups independently with older adults in their counties to identify preferences for health promotion programs and ideas for maximizing elder participation.

### **Evidence-based Programming and Evaluation**

**Training.** Full-day, county-based training on evidence-based programming and evaluation was designed to help participants: 1) describe the major components of full-scale program proposals and 2) learn about evidence-based interventions, logic models, and evaluation. A questionnaire developed by the trainer was administered prior to and following each session. The 15-item measured perceived knowledge and skills covered in the

training. Forty-three participants (10-11 in each county) attended training, and 37 (86%) completed the pre- and post-test.

Participants had diverse backgrounds, with over half having very little or no previous training in designing public health programs (57%) or reading scientific publications (51%). Almost two-thirds (65%) had very little or no experience in designing public health programs. More than half (54%) did not know or was not sure what was meant by the term “evidence

based public health program.” After the training, 91% of participants scored higher on the perceived-knowledge questions, indicating that they gained knowledge and understanding of evidence-based concepts ( $N=33$ ,  $\chi^2 = 25.04$ ,  $p < 0.001$ ). Additionally, a large majority (89%) of participants felt that the training was useful in relation to their work tasks and duties.

**Telephone Follow-up Interviews.** The effectiveness of the needs assessment and evidence-based training

was further assessed by administering a telephone survey in early 2005. AAAs were asked to submit names of appropriate partners who were active in the county HAPs, and 12 partners were interviewed from three counties. The survey consisted of 20 questions, scored using a 5-point Likert scale, and four open-ended questions.

Interview results confirmed gains in knowledge and confidence from the needs assessment training. Participants were comfortable using the information gained from the training in developing a program proposal. About nine people reported understanding the importance of evidence-based interventions and evaluation. However, only three people expressed confidence in their ability to apply the knowledge gained from the training to develop a full-scale proposal for funding to replicate an evidence-based program in their county. Assessment of training expectation revealed that partners felt they needed more hands-on practice, wanted training that resulted in tangible products (e.g., completed grant proposals), and wanted continued access to trainers

after the training as they applied new knowledge and skills.<sup>19</sup> Thus, the provision of technical assistance to county HAPs became a focus of Phase 3.

### **Phase 3) Support for Pilot Projects and Grant Writing**

In response to the feedback on Phase 2 training, Phase 3 afforded for county-specific training and technical assistance in program/research design and grant writing. A HHAP member provided general training on grant writing, and then a UH professor helped county-based HAPs develop logic models, outcome measures, and data collection tools to be used in piloting a health promotion program that might work in their counties, as learned through the focus groups they had conducted with elders. For example, Oahu seniors identified walking as a preferred activity, and a model for a senior walking program was identified through review of the literature.<sup>20-21</sup> Then, the UH professor provided individual support to counties to write grant proposals for small amounts of funding from EOA to implement their proposed pilot projects. All four counties submitted proposals and were

funded to conduct their pilots.

Experiences in developing, piloting, and testing their own health promotion programs increased the skills and confidence level of county HAP and statewide HHAP partners. In August 2006, HHAP submitted to the AoA a grant proposal titled *Empowering Older People to Take More Control of their Health through Evidence-Based Prevention Programs*, which was subsequently funded. By August 2007, HHAP had trained local providers in two evidence-based programs—EF and CDSMP—which counties began offering.<sup>7-8</sup> In 2008, HHAP received a grant from the National Council on Aging to help institutionalize these two evidence-based programs.

### **Conclusions and Implications**

As illustrated by HHAP, partnership development is a key component in community building.<sup>22</sup> The process is best illustrated by a four-step cycle (Figure 1): 1) partner engagement & strategic planning; 2) assessment of needs and provision of training; 3) implementation with technical assistance; and 4) evaluation.<sup>11, 13</sup>

At the beginning of the process, the EOA identified issues and invited partners. By the end of 2005, the number of HHAP members had expanded to 40 partners with ties to aging services. Members developed a strategic plan, including goals and guiding principles, based on community needs. After assessing partner training and technical assistance needs, two trainings and hands-on technical assistance were offered. HHAP partners had successfully piloted evidence-based pilot programs which addressed local needs in 2005, successfully competed for an AoA award to replicate evidence-based programs in 2006, and began offering CDSMP and EF in 2007.

Currently, HHAP is working to implement, evaluate, and sustain its evidence-based programs. To complete the Capacity Building Partnership Development Cycle (Figure 1), we have instituted several ways to evaluate HHAP efforts. For example, we are evaluating our CDSMP and EF offerings by monitoring the fidelity with which evidence-based programs are being replicated and by tracking participant attendance and outcomes.

Additionally, providers respond to an annual survey about their perceived knowledge gain and skills improvement. Future activities include a new planning cycle in which the 2003 strategic plan will be revisited (evaluated) and current successes, challenges, and trends will be assessed. A new 5-year strategic plan will be developed, focusing on sustaining the evidence-based health promotion programs that are being implemented in our four counties. These activities will emphasize continued sharing of resources, skills building, collaborative problem-solving, and broadening of networks.

Sharing of resources, commitment, and a supportive environment have been essential components of this partnership development. Sufficient resources are needed to implement community-based programs.<sup>11,13</sup> Although HHAP itself did not have sufficient funds to fully embed evidence-based programs, the partnership tapped into existing resources and strengthened relationships by offering additional trainings in conjunction with other programs. HHAP meetings played an important role in

leveraging resources by enabling partners to share information, discuss, plan, and organize healthy aging activities.

HHAP's experience also verifies the importance of training and technical assistance to build organizational capacity. Partners varied in knowledge and experience with needs assessment and evidence-based concepts, and trainings were insufficient to fully develop or deliver successful evidence-based programs. Individualized technical assistance overcame this limitation. The two-pronged approach of training and technical assistance helped HHAP partners successfully conduct focus groups in their communities, use data to plan programs, and participate in grant writing and program evaluation.

A major challenge in the community-building process was lack of time and resources for ongoing training and technical assistance. Findings from our 2007 survey of HHAP partners, more training and technical assistance in programming and evaluation are desired, even though partners report significant increases in personal and

community capacity in evidence-based programming.

We believe that the time and resources required to build capacity are good long-term investments. This case study provides an example that other communities can follow in building capacity to replicate evidence-based programs.

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Author affiliations:

(1) Doctoral Candidate, School of Social Work, University of Hawai'i, [mtomioka@hawaii.edu](mailto:mtomioka@hawaii.edu) (2) Statistician, Center on Disability Studies, University of Hawai'i, formerly with the Hawai'i Executive Office on Aging, [tammy\\_m\\_tom@yahoo.com](mailto:tammy_m_tom@yahoo.com) (3) Partnership Program Manager, National Cancer Institute's Cancer Information Service at the University of Hawai'i's Cancer Research Center of Hawai'i, and formerly an MSW intern MSW with the Hawai'i Executive Office on Aging, [PaulaH@crch.hawaii.edu](mailto:PaulaH@crch.hawaii.edu) (4) Comprehensive Health Planning Coordinator, State Health Planning and Development Agency, formerly with the Hawai'i Executive Office on Aging, [shirley.kidani@doh.hawaii.gov](mailto:shirley.kidani@doh.hawaii.gov) (5) Director, Hawai'i Executive Office on Aging, [noemi.pendleton@doh.hawaii.gov](mailto:noemi.pendleton@doh.hawaii.gov) (6) Chief, Community Health Division Hawai'i Department of Health, [barbara.yamashita@doh.hawaii.gov](mailto:barbara.yamashita@doh.hawaii.gov) (7) A Professor of

Public Health and Social Work, University of Hawai'i, and Research Director, 'Imi Hale – Native Hawaiian Cancer Network, [kbraun@hawaii.edu](mailto:kbraun@hawaii.edu).

**Corresponding Author:** Michiyo Tomioka, MS, PhD (c), University of Hawai'i, 1800 East-West Road, Henke Hall 226, Honolulu, Hawai'i 96822. Telephone: (808) 956-5001. Fax: (808) 956-5964 E-mail: [mtomioka@hawaii.edu](mailto:mtomioka@hawaii.edu).

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## Health disparities in Hawai'i pt 2 – obesity

David M K I Liu MD<sup>1</sup> and Andrew Grandinetti, PhD<sup>2</sup>

### Abstract

**Objective:** The prevalence of obesity continues to increase, both in the United States in general, and in Hawai'i specifically. Although Hawai'i is depicted nationally as a state with a low overall prevalence of obesity, disaggregating this data may yield different results. Thus, this article reviews the prevalence of obesity for different ethnic groups, as well as potential factors contributing to any inequities between groups.

**Methods:** Data from the Behavioral Risk Factor Surveillance System was surveyed from the years 2003 to 2007.

**Results:** Significant inequities exist between different ethnic groups in Hawai'i, with Pacific Islanders having the highest prevalence at 61.3%, and Pacific Islanders have a prevalence of obesity of 41.3% using standard obesity definitions. A significant shift occurs, however, when ethnic specific definitions occur, where significantly higher percentages of Chinese (47.2%), Filipinos (51.1%), and Japanese (47.5%) are obese, and less Pacific Islanders (43.9%) and Native Hawaiians (31.3%) are obese.

**Conclusions:** Overweight and obesity present significant health challenges to the communities of Hawai'i. Meeting this challenge may require further research into factors other than physical activity and nutrition. More data is needed on the health status of Pacific Islanders. Additionally, future interventions to decrease the incidence and prevalence of obesity may require interventions which target factors such as the social determinants of health, in addition to increasing physical activity, im-

**Background:** Obesity is currently a global pandemic, affecting not only Hawai'i and other parts of the developed world, but increasingly the developing world as well.

Although there is some skepticism about the scale of the obesity pandemic, there is little disagreement over the potential consequences of the obesity problem. On an individual level, obesity has been linked to diabetes, hypertension and other cardiovascular disease, several types of cancer, depression, and reduced quality of life.

On a public health level, there is growing evidence that children born now may face the prospect, for the first time, of not living as long as their parents. Moreover, the impact of obesity, from healthcare costs to negative impact on productivity through days lost to illness and potentially a shorter working life of individual workers.<sup>1,2</sup>

Obesity contributes to a number of other diseases, from diabetes and hypertension to certain cancers.<sup>3</sup> Although

obesity data for children are not presented here, obesity may have effects from depression and poor self-esteem to sleep apnea and asthma, cholelithiasis and non-alcoholic steatohepatitis to diabetes, polycystic ovarian syndrome and precocious puberty.<sup>4</sup>

On an individual level, there is evidence that alterations in mitochondrial energy and amino acid metabolism contributes to the development and pathology of obesity and insulin resistance.<sup>6</sup> Obesity contributes to insulin

resistance and inflammation, as well as endothelial dysfunction and increased levels of free insulin-like growth factor<sup>7</sup>

There is some debate about the proper anthropometric definition of overweight and obesity among Polynesians.

Although the CDC uses universal cutoffs of a Body Mass Index (BMI, defined as weight in kilograms divided by height in meters squared) of under 18.5 as underweight, 18.5-24.9 as healthy weight, 25-29.9 as overweight, and

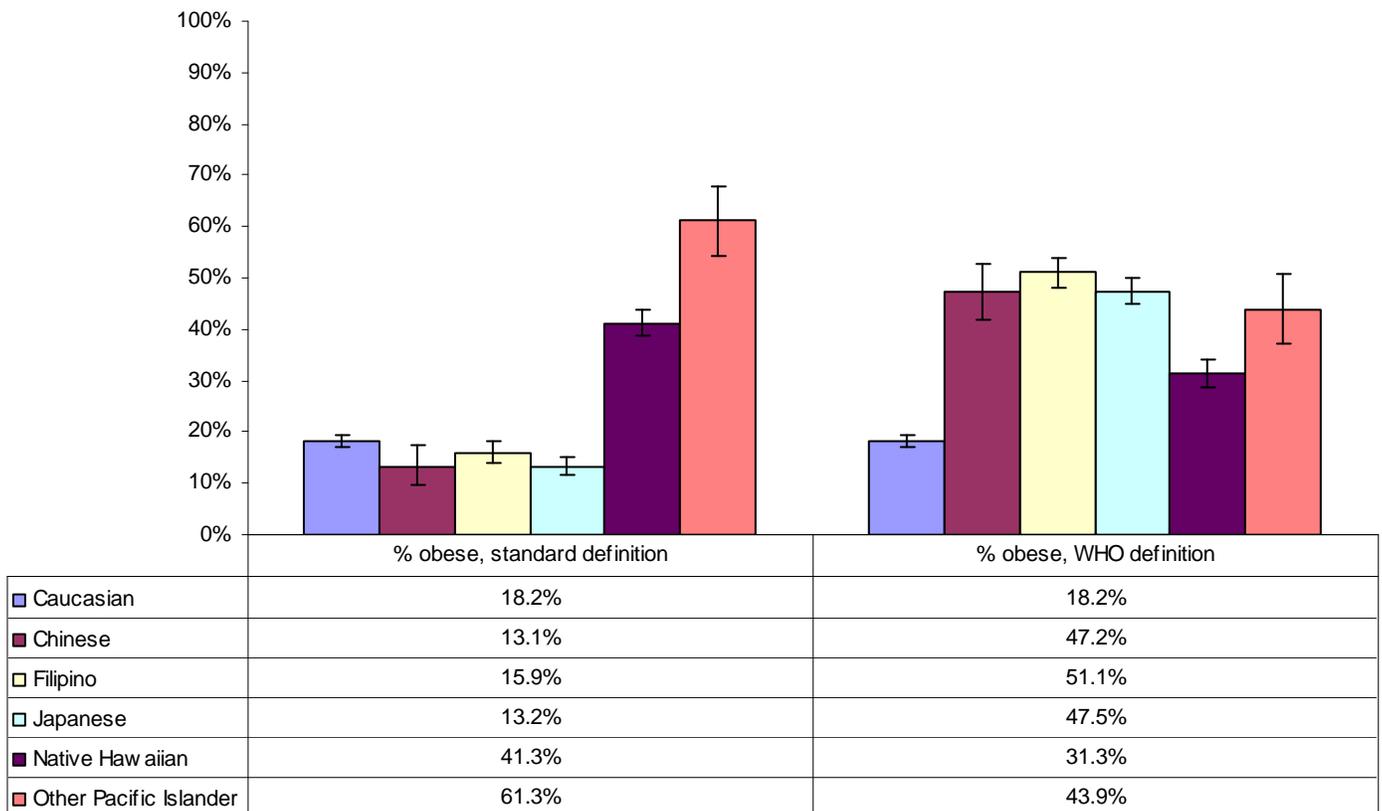


Figure 1, obesity by ethnicity, standard and ethnic-specific definitions of obesity, 3 year average, BRFSS, 2005-2007.

30+ as obese, the WHO Pacific Region has offered different definitions. For Asians, the WHO Pacific Region proposed a BMI of > 23.0 as being overweight and > 25.0 as being obese; the corresponding cutoffs for Pacific Islanders are > 26 for overweight and = 32.<sup>6,7,8</sup> In 2005, the WHO published a response to these recommendations which included a more flexible schema which incorporated the previously suggested standard set of BMI cut-offs for overweight and obesity, as well as a set of BMI criteria for public health action points appropriate for Asian populations that included lower cut-points for Asian populations; however no corresponding action points were defined for Pacific Islanders.<sup>7</sup> A recent review has recommended both country and ethnicity-specific BMI cut-points for Asians.<sup>8</sup>

Regardless of the definition, however, Pacific Islanders have the highest obesity rates in the world, ranging up to almost 88% in Samoan females.<sup>9</sup> As a sidenote, a recent study indicates that the risk for overweight and obesity in multiracial individuals is similar to that of their highest-risk monoracial component, i.e. that the higher risk that monoracial Native Hawaiians face follows those persons with Native Hawaiian as only one of several ethnicities.<sup>12</sup>

Crucial to understanding and contextualizing the obesity epidemic in Hawai'i, particularly among Pacific Islanders, but also among people of lower socioeconomic status in general, is the concept of economic rationality. Evans 2001. In the Pacific, there is a relatively high level of

*Table 1, Ethnic specific obesity definitions*

<b>Classification</b>	<b>WHO defined BMI cut-points</b>	<b>Proposed Asian BMI cut-points</b>	<b>Proposed Pacific Islander BMI cut-points</b>
Underweight	<18.5	<18.5	<18.5
Normal Weight	18.5-24.9	18.5-22.9	18.5-25.9
Overweight	25-29.9	23-24.9	26-31.9
Obese	30 or more	25 or more	32 or more

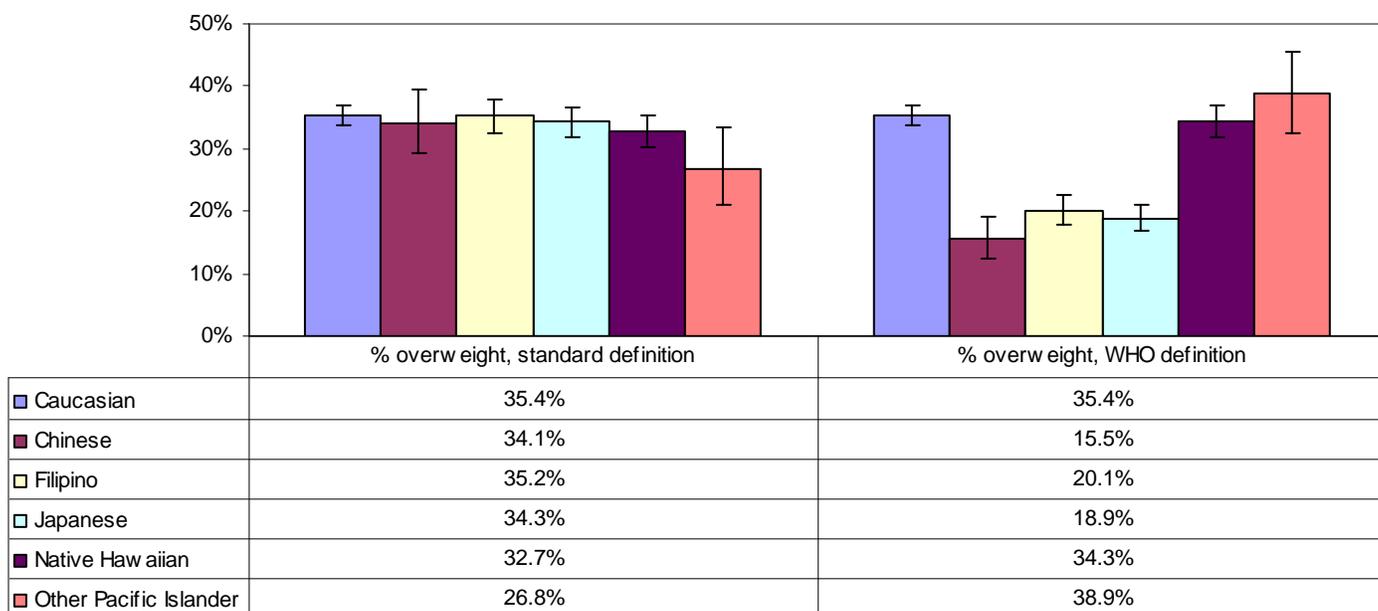
sophistication about good nutritional practices, although people tend to continue to consume foods of lower nutritional value, but higher energy density. The consumption of high energy density foods results in the higher BMI.<sup>12,13</sup> This consumption practice is based on cost and the lack of availability of traditional foods. When participants are placed on a traditional foods-diet, marked improvement in health status has been observed.

From a public health perspective, the concept that obesity may be maternally imprinted in mothers with gestational or overt diabetes points to an increased need for intervention

in the prenatal or even preconceptional milieu to decrease the velocity of the growth of the obesity pandemic.<sup>15,16,17</sup>

While there are some genetically overdetermined causes of obesity, such as Beckwith-Wiedemann syndrome, obesity is fundamentally a social pathology, whose answers lie in economic and sociocultural factors.<sup>18,19</sup>

Thus, the distribution of power and resources available in a society define the choices which individuals, families and communities can exercise. For example, even if the resources were available (and it was appropriate on any number of levels) to facilitate every obese person



**Figure 2, overweight by ethnicity, age-standardized, three year average, BRFSS 2005-2007, using standard and proposed ethnic-specific definitions for overweight for Asians and Pacific Islanders.**

receiving bariatric surgery, such an intervention would fail without addressing the environment which the patients returned to. Obesity is certainly a major public health problem, but as Cohen et al observe, a myopic focus on the individual as the origin of the obesity epidemic may obscure the underlying determinants.<sup>20</sup>

### **Hawai'i Data.**

There are significant differences in the prevalence of obesity by race/ethnicity in Hawai'i, as table 1 illustrates. Pacific Islanders have the highest percentage of obese individuals, with  $p < 0.001$  in comparison with all other ethnic groups. Native Hawaiians, also have significantly higher levels of obesity than Japanese, Chinese, Filipinos and Caucasians using standard WHO/CDC definitions of obesity ( $p < 0.001$ ).

Additionally, Caucasians have higher obesity rates than Chinese using standard definitions ( $p < 0.05$ ), as well as Japanese and Filipinos ( $p < 0.001$ ).

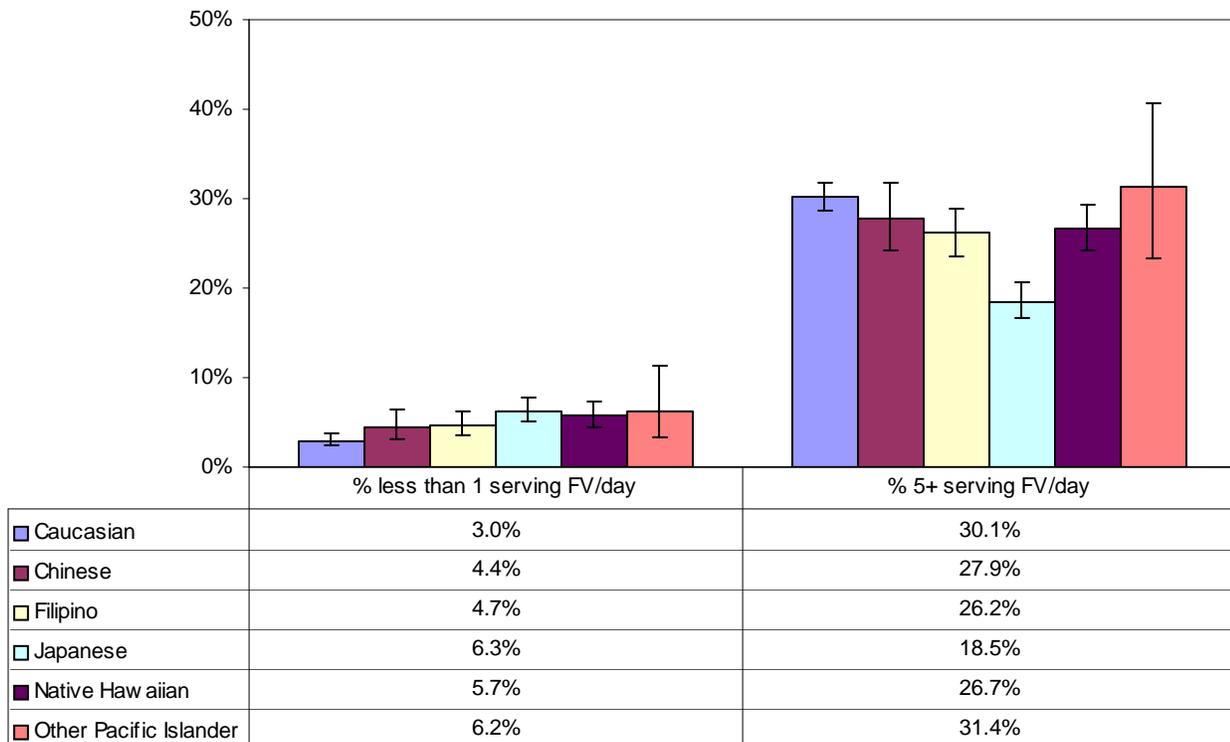
As the comparison of the data in Figure 2 indicates, there is a dramatic shift in the population profile for overweight and obesity with the use of the proposed WHO cut-points for overweight and obesity in Asians and Pacific Islanders. For Chinese, Japanese and Filipinos in Hawai'i, using ethnic-specific obesity definitions significantly increases the prevalence of obesity, so that these groups are all significantly more obese than Caucasians ( $p < 0.001$ ) and Native Hawaiians ( $p < 0.001$ ). Chinese, Filipinos and Japanese have no statistical differences in their obesity prevalence using ethnic-specific definitions. Pacific Islanders remain significantly more obese than Native Hawaiians ( $p < 0.001$ ), but are no longer significantly more obese than Japanese, Filipinos, or Chinese.

The increased consumption of fruits and vegetables has been found to be associated with reduced risk of obesity.<sup>21,22,23,24,25,26</sup> Figure 3 demonstrates the consumption of fruits and vegetables by racial/ethnic group for 2003, 2005, and 2007, and indicates that a majority of all individuals in Hawai'i are consuming five or more

servings of fruits and vegetables per day. However, Caucasians were still meeting the recommended numbers of servings at significantly higher levels than Filipinos ( $p<0.05$ ), Japanese ( $p<0.001$ ), and Native Hawaiians ( $p<0.05$ ). Chinese met the guidelines significantly more than Japanese ( $p<0.001$ ), as did Filipinos ( $p<0.001$ ). Native Hawaiians and Pacific Islanders also met the recommended servings at significantly higher rates than Japanese ( $p<0.001$ ).

At the lowest level of consumption, Filipinos ( $p<0.05$ ), Japanese ( $p<0.001$ ), and Native Hawaiians ( $p<0.001$ ) consumed significantly less fruits and vegetables than Caucasians. There were no other significant differences between ethnic groups at the less than 1 serving of fruits and vegetables per day.

Physical activity also contributes to increasing risk or resilience to overweight and obesity.<sup>27,28,29</sup> Figure 4



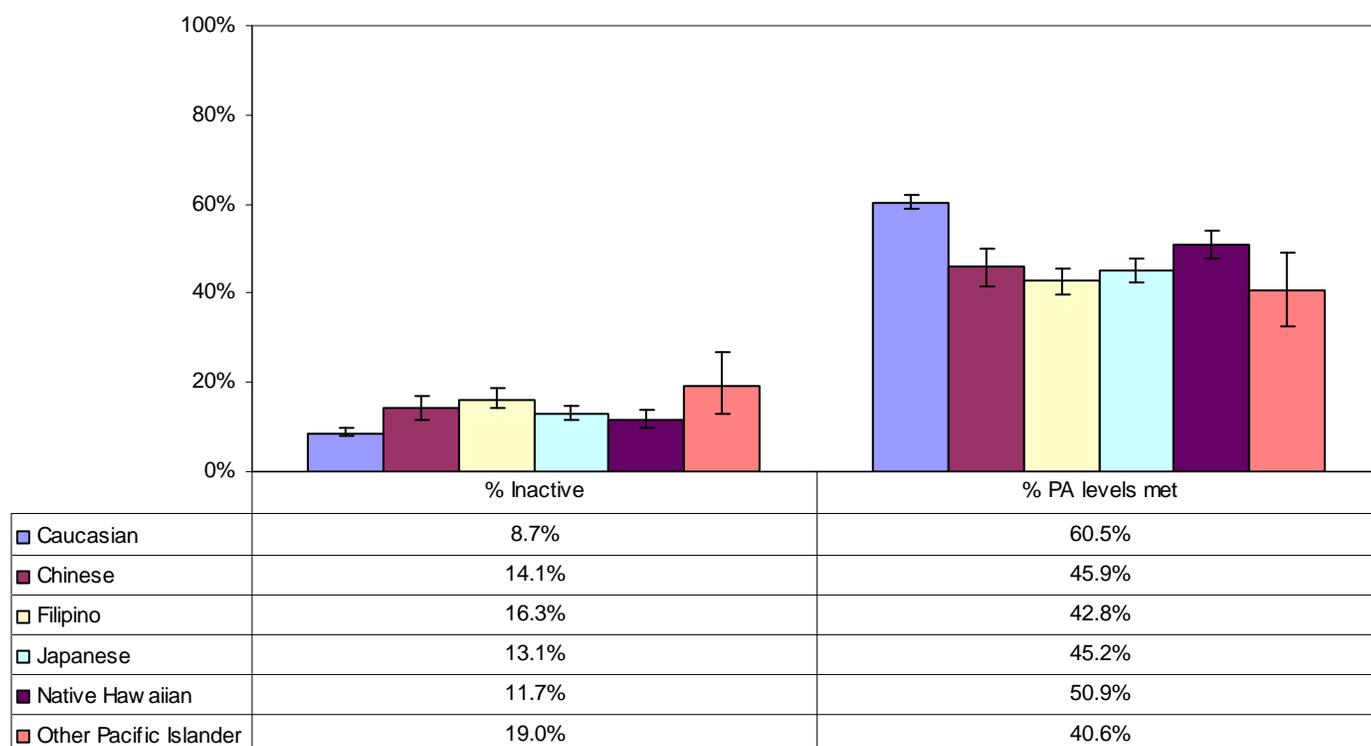
**Figure 3**, Consumption of fruits and vegetables, 3 year aggregate, BRFSS, 2003, 2005, 2007/

indicates that Caucasians were less inactive than Chinese, Filipinos or Japanese ( $p < 0.001$ ), and Native Hawaiians and Pacific Islanders ( $p < 0.05$ ). Filipinos and Pacific Islanders were more inactive than Native Hawaiians ( $p < 0.05$ ).

More Caucasians were meeting the recommendations for physical activity than members of any other ethnic group ( $p < 0.001$ ). Native Hawaiians were significantly more active than Filipinos ( $p < 0.001$ ) and Japanese ( $p < 0.05$ ).

There were no other significant differences between different ethnic groups.

While the data broadly indicate that certain ethnicities are at higher risk for obesity, it may be that identification with a certain ethnicity masks other socioenvironmental factors, such as higher levels of chronic stress, higher allostatic load, exposure to discrimination, different portion sizes, amounts of animal protein consumed, attitudes towards body image, or other factors. The data available



**Figure 4,** Meeting recommended physical activity level, 5 year grouping, BRFSS, 2002-2006.

are unable to control for such factors.

## Conclusion

Obesity presents a serious public and clinical health problem in Hawai'i for the present and into the future.

Significant inequities exist in the prevalence of overweight and obesity, and more data are required in order to define the prevalence of overweight and obesity in Pacific Islanders.

Although the use of ethnic-specific definitions of for overweight and obesity has not been resolved, the analysis presented in this article demonstrates that there may be a "silent epidemic" of obesity among Chinese, Japanese, and Filipinos. The high prevalence of overweight and obesity, using ethnic-specific definitions, may explain why some Asian groups have higher incidence and prevalence of obesity-related disease, despite "normal" BMI.

The data presented in this article also pose questions as

to the role of traditional risk factors in accounting for inequities in overweight and obesity. Initially, it must be noted that consumption of fruits and vegetables is only a proxy for eating a nutritious diet; consumption of high glycemic index carbohydrates, as well as saturated animal fats is not measured in the BRFSS survey. Even with this caveat, models which prioritize physical activity and the consumption of a low-fat, balanced diet do not appear to explain the inequities present for overweight and obesity among Native Hawaiians and Pacific Islanders.

Historically, the approach to obesity has been from the perspective of genetic vulnerabilities and lifestyle choices, a "risk factor" approach. A recent study has differentiated the effects of socioeconomic status on obesity in Hawai'i, so that for Native Hawaiians and Pacific Islanders, lower levels of education significantly contributed to the higher prevalence of obesity.<sup>30</sup> However, for Asians, education was not as strong a factor in predicting lower BMI.<sup>31</sup> A different study identified environmental factors of obesity

in Native Hawaiians, particularly fast food outlets.<sup>32</sup>

To approach obesity from a different direction, it may be useful to contextualize obesity, along with diabetes and many other chronic diseases, as symptoms of underlying political/economic/historical pathology, rather than as a disease to be prevented or treated in and of itself.<sup>33,34,35</sup>

Thus, addressing the inequitable distribution of power and resources in Hawai'i may prove to be a powerful supplement to current interventions aimed at the individual or family level.<sup>36,37,38,39</sup>

Currently, the Department of Health is resurveying elementary age, public school children, through the Department of Education, to determine the prevalence of overweight and obesity in that population. The Healthy Hawai'i Initiative is engaged in a multitudes of programs, from advocating for changes in the built environment and increased physical activity and healthy choices in the schools to supporting the work of the Nutrition and Physical Activity Coalition.

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**Appendix:** Confidence intervals and p values for tables in text.

**Table A-1, Obesity, standard definitions, age-adjusted, 3 year average, 2005-2007, BRFSS**

Standard weight definitions	Lower	Upper	P-value, T-Test
Caucasian vs Chinese	1.03	9.19	<0.05
Caucasian vs Filipino	-0.09	4.8	N/S
Caucasian vs Japanese	2.86	7.11	< 0.001
Caucasian vs Native Hawaiian	-26.03	-20.05	< 0.001
Caucasian vs Pacific Islander	-50.05	-36.16	< 0.001
Chinese vs Filipino	-7.14	1.63	N/S
Chinese vs Japanese	-4.35	4.09	N/S
Chinese vs Native Hawaiian	-32.86	-23.44	< 0.001
Chinese vs Pacific Islander	-56.06	-40.37	< 0.001
Filipino vs Japanese	-0.04	5.3	N/S
Filipino vs Native Hawaiian	-28.79	-22	< 0.001
Filipino vs Pacific Islander	-52.59	-38.33	< 0.001
Japanese vs Native Hawaiian	-31.2	-24.84	< 0.001
Japanese vs Pacific Islander	-55.12	-41.06	< 0.001
Native Hawaiian vs Pacific Islander	-27.4	-12.73	< 0.001

**Table A-2, Obesity, ethnic-specific definitions, age-adjusted, 3 year average, 2005-2007, BRFSS**

Ethnic-specific weight definitions	Lower	Upper	P-value, T-test
Caucasian vs Chinese	-34.46	-23.56	< 0.001
Caucasian vs Filipino	-36.04	-29.71	< 0.001
Caucasian vs Japanese	-32.05	-26.49	< 0.001
Caucasian vs Native Hawaiian	-16	-10.25	< 0.001
Caucasian vs Pacific Islander	-32.72	-18.67	< 0.001
Chinese vs Filipino	-9.9	2.17	N/S
Chinese vs Japanese	-6.1	5.58	N/S
Chinese vs Native Hawaiian	10	21.77	< 0.001
Chinese vs Pacific Islander	-5.39	12.01	N/S
Filipino vs Japanese	-0.19	7.4	N/S
Filipino vs Native Hawaiian	15.88	23.62	< 0.001
Filipino vs Pacific Islander	-0.3	14.66	N/S
Japanese vs Native Hawaiian	12.59	19.71	< 0.001
Japanese vs Pacific Islander	-3.76	10.9	N/S
Native Hawaiian vs Pacific Islander	-19.94	-5.21	<0.001

Table A-3, Overweight by ethnicity, age-standardized, standard definitions, 3 year average, 2005-2007, BRFSS

Standard weight definitions			P-value,
	Lower	Upper	T-Test
Caucasian vs Chinese	1.03	9.19	<0.05
Caucasian vs Filipino	-0.09	4.8	N/S
Caucasian vs Japanese	2.86	7.11	< 0.001
Caucasian vs Native Hawaiian	-26.03	-20.05	< 0.001
Caucasian vs Pacific Islander	-50.05	-36.16	< 0.001
Chinese vs Filipino	-7.14	1.63	N/S
Chinese vs Japanese	-4.35	4.09	N/S
Chinese vs Native Hawaiian	-32.86	-23.44	< 0.001
Chinese vs Pacific Islander	-56.06	-40.37	< 0.001
Filipino vs Japanese	-0.04	5.3	N/S
Filipino vs Native Hawaiian	-28.79	-22	< 0.001
Filipino vs Pacific Islander	-52.59	-38.33	< 0.001
Japanese vs Native Hawaiian	-31.2	-24.84	< 0.001
Japanese vs Pacific Islander	-55.12	-41.06	< 0.001
Native Hawaiian vs Pacific Islander	-27.4	-12.73	< 0.001

Table A-4, Overweight by ethnicity, age-standardized, ethnic-specific definitions, 3 year average, 2005-2007, BRFSS

Ethnic-specific weight definitions			P-value,
	Lower	Upper	T-test
Caucasian vs Chinese	-34.46	-23.56	< 0.001
Caucasian vs Filipino	-36.04	-29.71	< 0.001
Caucasian vs Japanese	-32.05	-26.49	< 0.001
Caucasian vs Native Hawaiian	-16	-10.25	< 0.001
Caucasian vs Pacific Islander	-32.72	-18.67	< 0.001
Chinese vs Filipino	-9.9	2.17	N/S
Chinese vs Japanese	-6.1	5.58	N/S
Chinese vs Native Hawaiian	10	21.77	< 0.001
Chinese vs Pacific Islander	-5.39	12.01	N/S
Filipino vs Japanese	-0.19	7.4	N/S
Filipino vs Native Hawaiian	15.88	23.62	< 0.001
Filipino vs Pacific Islander	-0.3	14.66	N/S
Japanese vs Native Hawaiian	12.59	19.71	< 0.001
Japanese vs Pacific Islander	-3.76	10.9	N/S
Native Hawaiian vs Pacific Islander	-19.94	-5.21	<0.001

Table A-5, Fruit and vegetable consumption, <= 1 serving/day, adult age standardized PA levels, 3-year aggregate,

FV = < 1 serving/day	Lower	Upper	P-value, T-Test
Caucasian vs Chinese	-3.18	0.34	NS
Caucasian vs Filipino	-3.1	-0.23	<0.05
Caucasian vs Japanese	-4.83	-1.84	<0.001
Caucasian vs Native Hawaiian	-4.25	-1.19	<0.001
Caucasian vs Pacific Islander	-7.08	0.57	NS
Chinese vs Filipino	-2.33	1.84	NS
Chinses vs Japanese	-4.04	0.21	NS
Chinese vs Native Hawaiian	-3.45	0.85	NS
Chinese vs Pacific Islander	-5.95	2.27	NS
Filipino vs Japanese	-3.54	0.2	NS
Filipino vs Native Hawaiian	-2.95	0.84	NS
Filipino vs Pacific Islander	-5.58	2.39	NS
Japanese vs Native Hawaiian	-1.33	2.55	NS
Japanese vs Pacific Islander	-3.93	4.08	NS
Native Hawaiian vs Pacific Islander	-4.56	3.48	NS

Table A-6, Fruit and vegetable consumption, 5+ serving/day, Adult age standardized PA levels, 3-year aggregate,

FV = 5+ servings/day	Lower	Upper	P-value, T-Test
Caucasian vs Chinese	-1.73	6.26	0.2659
Caucasian vs Filipino	0.95	6.99	0.0099
Caucasian vs Japanese	9.1	14.1	0
Caucasian vs Native Hawaiian	0.49	6.42	0.0224
Caucasian vs Pacific Islander	-10.07	7.57	0.7815
Chinese vs Filipino	-2.82	6.23	0.4608
Chinses vs Japanese	5.13	13.53	0
Chinese vs Native Hawaiian	-3.31	5.68	0.6044
Chinese vs Pacific Islander	-12.96	5.93	0.4657
Filipino vs Japanese	4.34	10.92	0
Filipino vs Native Hawaiian	-4.17	3.14	0.7815
Filipino vs Pacific Islander	-14.29	3.86	0.2596
Japanese vs Native Hawaiian	-11.39	-4.9	0
Japanese vs Pacific Islander	-21.76	-3.93	0.0048
Native Hawaiian vs Pacific Islander	-13.76	4.36	0.309

Table A-7, Adult age standardized PA levels, inactive, 3-year aggregate, BRFSS 2003, 2005, 2007

PA levels = inactive	Lower	Upper	P Value, T Test
Caucasian vs Chinese	-8.29	-2.5	<0.001
Caucasian vs Filipino	-10.06	-5.15	<0.001
Caucasian vs Japanese	-6.35	-2.57	<0.001
Caucasian vs Native Hawaiian	-5.12	-0.93	<0.05
Caucasian vs Pacific Islander	-17.36	-3.28	<0.05
Chinese vs Filipino	-5.79	1.36	NS
Chinese vs Japanese	-2.28	4.15	NS
Chinese vs Native Hawaiian	-0.97	5.71	NS
Chinese vs Pacific Islander	-12.43	2.58	NS
Filipino vs Japanese	0.32	5.97	NS
Filipino vs Native Hawaiian	1.61	7.55	<0.05
Filipino vs Pacific Islander	-10.06	4.63	NS
Japanese vs Native Hawaiian	-1.09	3.95	NS
Japanese vs Pacific Islander	-13.04	1.32	NS
Native Hawaiian vs Pacific Islander	-14.53	-0.06	<0.05

Table A-8, Adult age standardized PA levels, meets physical activity recommended levels, 3-year aggregate, BRFSS 2003, 2005, 2007

PA levels = met	Lower	Upper	P Value, T Test
Caucasian vs Chinese	10	19.04	<0.001
Caucasian vs Filipino	14.38	20.96	<0.001
Caucasian vs Japanese	12.17	18.34	<0.001
Caucasian vs Native Hawaiian	6.18	13.03	<0.001
Caucasian vs Pacific Islander	11.3	28.46	<0.001
Chinese vs Filipino	-1.98	8.28	NS
Chinese vs Japanese	-4.27	5.74	NS
Chinese vs Native Hawaiian	-10.13	0.31	NS
Chinese vs Pacific Islander	-4.08	14.81	NS
Filipino vs Japanese	-6.34	1.51	NS
Filipino vs Native Hawaiian	-12.26	-3.87	<0.001
Filipino vs Pacific Islander	-6.71	11.13	NS
Japanese vs Native Hawaiian	-9.69	-1.6	< 0.05
Japanese vs Pacific Islander	-4.22	13.47	NS
Native Hawaiian vs Pacific Islander	1.31	19.25	NS

## Tell Us What You Need: Health Care Perspectives of Guam Families with Genetic Diagnoses

Lianne E. Hasegawa, Sylvia M. Au, and Roselie Zabala<sup>1</sup>

### ABSTRACT

**Objectives:** Guam's geographic isolation and lack of community resources have resulted in unique healthcare needs. In 2006, the Western States Genetic Services Collaborative (WSGSC) conducted a newborn screening and genetics needs assessment in Guam and made recommendations for system improvement.

**Methods:** This article reports on results from two focus groups conducted with twelve parents of children and adults with genetic conditions. The focus groups were part of a larger assessment of genetics and newborn screening needs completed with families, physicians, nurses, and public health staff on Guam.

**Results:** The parents identified four needs: 1) Increase access to specialty services; 2) Improve genetics education for providers and families; 3) Create a Guam-based family support group; and 4) Improve insurance coverage for people with special needs.

**Conclusions:** Although the focus group discussions centered on genetics and newborn screening, the needs identified by parents were much broader and not unique to Guam. Issues surrounding parental support, accessibility of services, and healthcare affordability are prevalent throughout the U.S. The WSGSC has drawn on regional resources and successful state strategies to address the issues identified by the families and to make specific recommendations.

**Implications:** Since 2006, the WSGSC has implemented a genetics outreach clinic to Guam, helped Guam develop a plan to improve newborn screening follow-up, provided genetics education, and begun a dialogue with Guam insurance companies about genetic testing and newborn screening. The WSGSC continues to collaborate with Guam to improve its newborn screening and clinical services.

### INTRODUCTION

Guam is a U.S. territory located in Micronesia and is geographically closer to urban centers in Southeast Asia than the closest U.S. state, Hawai'i. The health care system in Guam is similar to that of the U.S., with comparable medical licensure requirements, health care providers, and public and private insurance companies. However, Guam lacks many government and community

resources, including pediatric specialists, a medi-

cal school, and an academic medical center.

These limitations create obstacles to the develop-

ment and maintenance of successful clinical and

public health programs, especially when com-

pared to the rest of the United States. As such,

two needs assessments have been conducted in

Guam to identify issues specific to public health

and to make recommendations for the improve-

ment of Guam's clinical and public health genetics programs. exploring telemedicine opportunities to improve access to specialty services, increasing educa-

In 2002, the National Newborn Screening and Genetics Resource Center sponsored a review team to assess the Guam Newborn Screening Pro-

gram and identify specific newborn screening needs within the territory (National Newborn Screening and Genetics Resource Center, 2002).

They found that, although personnel in the Guam Department of Public Health and Social Services (DPHSS) were passionate and enthusiastic, they

required additional training and staff to successfully administer the Newborn Screening Program. Guam also needed access to clinical geneticists and

metabolic specialists for medical management of infants diagnosed through newborn screening. The review team recommended dedicating a full-time

staff member to the Newborn Screening Program,

tional opportunities for parents and professionals, and developing a formal genetics plan for the territory.

Four years later, the Western States Genetic Services Collaborative (WSGSC) sponsored a second review team to evaluate progress made in addressing the newborn screening needs identified in 2002. The WSGSC also expanded the needs assessment to include issues related to clinical genetic services. Results from this assessment were used to: 1) develop a comprehensive plan for genetics and newborn screening in Guam; 2) help focus programmatic efforts; and 3) maximize the use of existing resources to address high priority issues.

The 2006 needs assessment was com-

pleted with 88 key informants, including twelve parents of children or adults with genetic disorders and 76 health care professionals. The data was used to identify specific needs related to clinical genetic services, newborn screening, and genetics education. This publication will focus on the findings from the parent focus groups.

## **METHODS**

### **Design**

Two semi-structured focus groups were held with twelve parents of children or adults with genetic disorders. Focus group questions centered on experiences surrounding: 1) diagnosis of their child's genetic condition, 2) treatment, 3) education about the diagnosis, and 4) telemedicine. Several questions were also asked about specific needs regarding genetic resources and specialty services.

Focus groups were conducted by a researcher trained in focus group facilitation. A second researcher recorded the discussion and documented nonverbal events.

### **Participants**

Participants were parents of children or adults with genetic disorders. The first focus group included seven parents of children or adults with hemophilia recruited through the Guam Hemophilia Support Group. The second focus group included five parents of children with genetic conditions recruited by Guam DPHSS social workers from primary care clinics sponsored by the DPHSS. Incentives worth \$25 were provided to all participants as compensation. Written informed consent was collected from each participant prior to the session. The majority of the participants were English-

speaking (83.3%) Chamorro (58.3%) females (83.3%) between the ages of 18 and 35 (50.0%). Most had graduated from high school (91.7%) and had some college experience (50.0%) (Table 1).

### **Analysis**

Transcripts of participants' responses were analyzed using the long-table analysis method described by Krueger and Casey (2000). This method provided a general methodology for systematically comparing the qualitative data collected from the focus groups. It involves grouping similar ideas or statements into categories and then identifying and labeling the overarching themes of each categorical group. Themes embedded within the newly organized data were identified, and identified themes were compared. Similarities and differences between the two focus groups were noted. A second

researcher reviewed the data and themes and, at the completion of the analysis process, the themes and conclusions were electronically sent to three parents who participated in the Guam focus groups to ensure that the needs identified were accurate and representative of the focus group discussions.

### **RESULTS**

Four major themes were noted within the responses of the focus group participants. Each theme represented a value or need that was consistently emphasized. The four themes were then expanded into more specific needs (Table 2).

#### **Increase Access to Specialty Services**

All of the participants (N=12) stated that specialty services, such as cardiology, genetics, and hematology, are not easily available to indi-

viduals on Guam. Each family mentioned that they have had to travel off-island to Hawai'i, the U.S. mainland, or Asia at least once to receive care from specialists. The participants also believed that medical services were more thorough in Hawai'i and on the U.S. mainland.

The biggest concern of participants was the level of medical care their children received. Currently, to be seen by pediatric subspecialists, families must leave Guam for Hawai'i, the U.S. mainland, or Asia. However, the participants explained that, for non-emergent consults, a child can wait between two to three years for insurance companies to process off-island travel requests. Many participants commented that the services, specialists, and treatments accessed by families living in Hawai'i or on the U.S. mainland should be easily accessible to families living on Guam. As one

mother stated, "We're U.S. citizens, but we're being treated like we're living in a third world country!"

Another woman explained that she moved to Las Vegas to ensure that her son with hemophilia received proper care, but recently moved back to Guam because she had no family or family support in Nevada. She pointed out that "we shouldn't have to move...just to make sure our children get simple medical care."

When the researchers presented the scenario of a geneticist and genetic counselor from Hawai'i staffing in-person genetics clinics in Guam, the families were understandably enthusiastic. Parents would like a geneticist and genetic counselor to visit Guam at least twice a year. The families were also very interested in the use of telemedicine for specialty care. They explained that the technology would allow them increased access to spe-

cialty services without the expense and hassle associated with off-island travel. Two parents had participated in a telemedicine session in the past, and they encouraged its revival. The families would like telemedicine to be used for routine care and emergency situations.

### **Improve Genetics Education for Healthcare Providers and Families**

When asked about the medical services available in Guam, parents had mixed reactions. Many thought that the Guam physicians are reluctant to listen and are not open to information raised by parents. One mother said she has to “pick and choose” her child’s physicians from among “the few doctors who will listen to me, and who will try to understand my child’s condition.” The mother of a

girl with Beckwith-Weidemann syndrome explained:

We become the experts in our child’s condition. We’re the ones searching the internet for information and new research...but when I bring the information to my doctors, they won’t listen...We’ve finally found a pediatrician who will listen to what we say. He’ll work with us.

The participants wanted written information to be provided to doctors and nurses. The woman caring for her daughter with Beckwith-Weidemann syndrome showed us a huge packet of articles she carries with her to aid her in describing her daugh-

ter's disorder to new physicians. Families from the Hemophilia Support Group were especially nervous about emergency room staff. One parent mentioned that she and her son had to wait six to eight hours before receiving treatment at the local hospital emergency room, and when they finally received care, she had to help the physicians figure out how to mix the medication.

Parents also wanted increased education for themselves. The majority obtain information about their child's condition from the internet, from off-island specialists, and from the DPHSS staff. However, parents stated that the information they receive is often minimal or incomplete. For example, none of the parents from the Hemophilia Support Group had received genetic counseling about recurrence risks. Parents from the second focus group said it was often overwhelming to search

through the numerous internet sites in an attempt to answer medical questions. Many felt that increased access to medical specialists would directly increase parent knowledge of their child's condition.

### **Create a Guam-Based Family Support Group**

Many of the participants emphasized the need for a Guam-based family support group. The parents believed that this group would allow for an exchange of knowledge and information while also providing support and encouragement. One young mother described herself as feeling "completely alone" when trying to simultaneously navigate through the medical system and deal with the physical disabilities of her child. She said that, had she been a part of a group of parents with similar experiences, she would have felt stronger and less

isolated.

The benefits of organizing and maintaining a strong parent support group were obvious after listening to the experiences of the participants from the Guam Hemophilia Support Group. The families

said that the support group not only provides information and support, but members also routinely share Factor, a substance used to treat individuals with hemophilia. The parents explained that shortages of Factor VIII and Factor IX are common within the territory and, because Factor is essential to keeping their sons healthy, the Hemophilia Support Group has created an informal network of “Factor-sharing.” This system is so reliable that the local hospital will often call members of the Hemophilia Support Group when their supply of Factor expires or runs low. The Hemophilia Support Group has also empowered its members to be-

come self-advocates. As one mother said, “The public health staff has helped the parents a lot, but now we have to start advocating for ourselves... and we are stronger as a united group!”

**Improve Insurance Coverage for People with Special Needs**

Guam parents had many complaints about insurance coverage in Guam. Several said that private insurance companies will not cover services and treatments for children with special needs. A mother in the Hemophilia Support Group explained that, with private insurance, it is difficult to get coverage for her son’s Factor. However, the Medically Indigent Program (MIP), a locally funded public insurance program, will cover medical expenses, including Factor, up to \$50,000. As a result, many families rely on MIP to ensure coverage of health care costs. At the same time, families are cogni-

zant of the fact that the program is a huge financial burden on the government of Guam. Families are aware of the strain they place on the system but feel trapped because they have no other alternative methods of coverage.

Finally, families worry about insurance coverage as their children transition into adulthood. One mother of an 18 year old son with hemophilia said that, because the private insurance companies will not cover her son's necessary medical expenses, he must remain on MIP. However, to continue to qualify for MIP, her son cannot work full-time. She described this as a "waste" and wondered about his "quality of life."

## DISCUSSION

Although the needs assessment focused on issues surrounding newborn screening and ge-

netic services, the participating families identified needs that were much broader in scope including parent support, accessibility of services, and affordability of health care. It is not surprising that families caring for children with special needs

would be more concerned with issues of support and access to care than with newborn screening and genetics. The WSGSC is best positioned to address the needs associated with genetic services, genetics education, and reimbursement for genetics and newborn screening and does not have the resources to address the larger health care issues of children with special health needs.

However, the strategies and recommendations suggested by the WSGSC can be used as a model for improving other specialty services and public health programs in Guam that affect children with special health needs. Specific strategies and rec-

ommendations for genetic services and newborn screening can be found in Table 3.

### **Access to Genetic Services**

Because Guam lacks pediatric specialists including cardiologists, neurologists, and geneticists, parents explained that they must travel to Asia, Hawai'i, or the U.S. mainland to ensure their children receive the services they require. However, the travel costs are often prohibitive, and insurance companies will not always reimburse these expenses. To increase access to genetic services, families suggested that outreach clinics be held in Guam twice a year, and telemedicine be incorporated into health care.

In 2007, the WSGSC responded to the needs identified by the families by sponsoring a week-long genetics outreach clinic staffed by a ge-

netics team from Hawai'i. Twenty-five patients were evaluated, and the geneticist determined that all referrals to the outreach clinic were appropriate for genetic consultations. However, when the genetic tests recommended by the clinical geneticist were ordered, it was discovered that genetic testing is not a covered benefit of any Guam insurance company. This includes simple genetic tests, such as a chromosome analysis, that are routinely ordered and reimbursed in the United States. Genetic testing is an essential tool for clinical geneticists and, without its use, accurate diagnoses can not be made. Due to this obstacle, additional outreach clinics planned by the WSGSC were postponed, and efforts were redirected to improving

insurance reimbursement for genetic testing, newborn screening, and clinical genetic services. To date, one private insurance company has agreed

to add diagnostic testing for positive newborn screening results to their benefits package. Discussions remain ongoing with representatives from this and other insurance companies. The Hawai'i-based clinical geneticist remains available on an as-needed basis for phone consultations with Guam primary care physicians, and a second genetics outreach clinic to Guam is currently being planned for January 2010.

The WSGSC is also evaluating methods of utilizing telemedicine to provide genetic services to Guam. Several pilot projects have studied the use of telemedicine in providing genetic services to rural communities (Abrams and Geier, 2006; Stalker et al., 2006; Lea et al., 2005). All showed high levels of patient satisfaction, improved waiting times, and increased access, suggesting that telemedicine can be used successfully to provide clinical

services to underserved populations. The WSGSC is currently working with telemedicine sites in Guam, as well with the Hawai'i State Telehealth Access Network (STAN), to determine how to best utilize telemedicine for the provision of genetic services.

### **Genetics Education**

Educational opportunities are limited in

Guam due to its lack of subspecialists and geographic isolation. Many of the families felt that they and their providers have very little information about genetic conditions and have few opportunities to increase their awareness of genetics. With growing attention being placed on the genetics of common diseases, genome-wide association studies, and direct-to-consumer genetic testing, it will be increasingly important for both health care pro-

viders and consumers to have some knowledge of genetics. To increase the number of educational opportunities available to Guam professionals and families, the WSGSC recommends that visiting specialists participate in at least one educational event. The WSGSC will also work with Guam Memorial Hospital to organize educational opportunities via videoconferencing, and to ensure that alternative methods of continuing education, such as CD-ROMs, Internet sites, and online conferences, are available. Finally, the WSGSC has developed a list of electronic genetic resources for families and professionals and has made this list available on its website.

believed this support group would reduce feelings of isolation and would encourage an exchange of information and knowledge. Caregivers of individuals with chronic conditions often experience high levels of stress, and the need for peer support is frequently recognized (Douma et al., 2006). Although many methods of family support exist, participation in a support group has been shown to significantly increase family functioning and decrease levels of stress (Chien et al., 2005). Having a parent-driven support group on Guam would help families of children with special needs share their experiences, and would provide the structure necessary for successful parent advocacy.

The WSGSC recommends that Family

### **Family Support Group**

Several participating families identified the need for a family support group in Guam. Parents

Voices work with family leaders in Guam to organize a Family Voices chapter within the territory. Family Voices is a national organization of families

**Table1: Participant Characteristics (n=12)**

Category	N (%)
<b>Gender:</b>	
Female	10 (83.3)
Male	2 (16.7)
<b>Age:</b>	
18-25	3 (25.0)
26-30	3 (25.0)
31-35	0 (0.0)
36-40	1 (8.3)
41-45	3 (25.0)
46-50	1 (8.3)
Over 50	1 (8.3)
<b>Number of children:</b>	
0	2 (16.7)
1-2	3 (25.0)
3-4	3 (25.0)
5-6	4 (33.3)
<b>Ethnic background:</b>	
Chamorro	7 (58.3)
Filipino	4 (33.3)
Ponapeian	1 (8.3)
<b>Language most used:</b>	
English	10 (83.3)
Ilocano	1 (8.3)
Tagalog	1 (8.3)
<b>Education level:</b>	
Did not graduate high school	1 (8.3)
High school graduate	5 (41.7)
Some college	5 (41.7)
College graduate	1 (8.3)

**Table 2: Needs Described by the Focus Group Participants**

Themes
<ol style="list-style-type: none"> <li>1. Increase access to specialty services               <ul style="list-style-type: none"> <li>Hold in-person genetics clinics in Guam at least twice a year</li> <li>Establish telemedicine consultation for routine follow-up and emergent care</li> </ul> </li> <li>2. Improve genetics education for healthcare providers and families               <ul style="list-style-type: none"> <li>Increase communication between physicians and families</li> </ul> </li> <li>3. Create a Guam-based family support group               <ul style="list-style-type: none"> <li>Increase support systems for parents and encourage self-advocacy</li> </ul> </li> <li>4. Improve insurance coverage for people with special needs</li> </ol>

**Table 3: Recommendations and Strategies to Address the Needs Identified by Guam Families**

Recommendations and Strategies
<ol style="list-style-type: none"><li>1. Organize week-long semi-annual genetics outreach clinics. The WSGSC will sponsor semi-annual genetics outreach clinics staffed by Hawai'i providers.</li><li>2. Initiate telemedicine consults for genetics. The WSGSC will work with the Hawai'i State Telehealth Access Network and DPHSS staff to develop a telemedicine program for genetics patients.</li><li>3. Encourage visiting specialists to provide at least one educational event for families and health care providers.</li><li>4. Explore alternative methods of education. The WSGSC will work with Guam Memorial Hospital to increase awareness of alternative methods of genetics education.</li><li>5. Develop a Guam chapter of Family Voices. The WSGSC will identify a potential family leader in Guam and connect him/her to representatives from other state Family Voices. Together, they will organize a Guam Family Voices chapter.</li><li>6. Guam needs a local leader to advocate for reimbursement of genetic services and testing.</li><li>7. The WSGSC will continue discussions with Guam insurance companies to increase coverage for genetic services and testing.</li></ol>

## Domestic Violence in Hawaii: preliminary report from the Hawaii Domestic Violence Fatality Review

Marlene Lee, RN, BSN\*, Susan Fujii, RN, BSN\*, Lori Kamemoto, MD, MPH\*†, Loretta Fuddy, MSW, MPH\*

### Abstract

Domestic violence, also known as intimate partner violence, affects families from every social and educational background. Tragically, domestic violence can lead to homicide, leaving in its wake broken lives and emotional trauma amongst the survivors. The formation of Hawaii's Domestic Violence Fatality Review (DVFR) was legislated in 2006 and the multidisciplinary team began reviewing cases in 2007. DVFR's goal is to learn as much as possible about the circumstances surrounding the domestic violence fatality incident and to develop preventive measures. This article covers the background and organization of this new DVFR, and preliminary findings based on a review of 17 out of 23 cases occurring in 2000-2002.

### Background

Domestic violence (DV) or intimate partner violence occurs between two people who are in a close relationship, which may include current or former spouses, or dating partners. Non-intimate familial relationships (such as siblings, parents, and children) and non-related individuals residing in the same place are also included in this definition. Domestic violence can consist of actual physical harm, bodily injury or assault; threat of imminent physical harm, bodily injury or assault;

extreme psychological abuse; or malicious property damage between family or household members.

The average annual rate of domestic violence homicides over the ten year period 1996 to 2005 was 0.7 per 100,000 residents in the State of Hawaii<sup>1</sup>. The rate per 100,000 residents of domestic violence murders per county during the ten-year period from 1996 to 2005 was: Honolulu 6.5; Hawaii County 2.2; Maui County 0.7 and Kauai County 0.5.<sup>1</sup>

In response to these statistics, Hawaii criminal justice professionals and community advocates concerned about domestic violence attended a 2002 national conference on instituting a Domestic Violence Fatality Review program (DVFR). This group of concerned citizens was joined by the Department of Health (DOH), Department of Human Services and the military in 2004. Through this collaboration, assistance from national experts, and persistent legislative actions, DVFR legislation was passed in 2006. This legislation authorized the DOH Family Health Services Division's Maternal and Child Health Branch (MCHB) as the lead agency to implement the DVFR program.<sup>2</sup>

### Methods

The purpose of the DVFR is to gather information

towards reducing the incidence of domestic violence fatalities through a systematic, multidisciplinary retrospective review process. This program is based on the public health model of prevention. The review is used to analyze events which led up to the domestic violence fatality and the responses of community organizations and systems to identify possible system changes and make recommendations for the prevention of future fatalities. Future recommendations may include changes and improvement in policies, organizational practices, interagency services and linkages, trainings, community based education, and strengthening individual knowledge and skills towards improving both the community response to domestic violence, as well as prevention of domestic violence itself.

The DVFR core team includes representatives from the following organizations: DOH Family Health Services Division, Department of Human Services, Prosecuting Attorney's Office, Emergency Medical Services, Medical Examiner's Office, Domestic Violence Advocate Organizations, Law Enforcement/Police, and the Judiciary. Each organization brings information from their records related to the homicide being reviewed. Additional consultants include representatives from the Medical Field, DOH Vital Statistics, and Legal Organizations. Ad hoc members who may be able to assist in the review of certain cases are also included at the discretion of the core team's recommendation. All information disclosed at the review is confidential, and the statute provides protection and immunity from liability for any participant in the reviews. Due to legal considerations, cases are not reviewed until the related homicide has completed

the criminal and judicial process.

The criteria for case reviews is determined by the DVFR team consistent with the 2006 legislation, and may include both homicides and suicides relating to domestic violence. Other related deaths secondary to the domestic violence fatality may also be reviewed on a case-by-case basis such as deaths of neighbors, friends, children, police officers, and other emergency workers.

Through the DVFR process which began in 2007, each domestic violence related homicide undergoes extensive review by the multidisciplinary team. As of July 2008, 17 out of 23 cases occurring in 2000-2002 have been reviewed.

#### **DVFR Preliminary Findings, 2000-2002**

On review of the 17 DV related homicide cases, one case involved two homicides of an intimate partner DV victim and her family member who tried to intervene, therefore these 17 cases resulted in 18 homicides (Table 1). The homicide victim was not necessarily the DV victim in all cases, and the homicide perpetrator was the DV victim in one case. There is a wide age range in domestic violence victims and perpetrators and homicide victims and perpetrators, with most in the 26 to 45 year old age group (Table 2). The majority (82%) of DV victims were female, and the majority of DV perpetrators (82%) were male, however it should be noted that three of the DV perpetrators were female (Table 3). 78% of the DV associated homicide victims were female and 76% of the homicide perpetrators were male (Table 3).

<b>Table 1: Domestic Violence Homicide Victims, 2000-2002*</b>	
	<b>Homicide Victim</b>
Domestic Violence (DV) Victim	15
DV Perpetrator killed by DV Victim	1
Family Member of DV Victim	2
Total	18

\*there are 18 victims as one case involved two homicide victims

<b>Table 2: Domestic Violence and Homicide Victims and Perpetrators by Age, 2000-2002</b>				
<b>Age Group</b>	<b>DV Victim</b>	<b>DV Perpetrator</b>	<b>Homi- cide Victim</b>	<b>Homicide Perpe- trator</b>
18-25 years old	1	0	1	0
26-35 years old	4	5	4	5
36-45 years old	7	7	6	7
46-55 years old	3	3	3	3
56 years old and older	2	2	4	2
Total	17	17	18	17

Eleven homicides were committed using a knife or other sharp object, three cases involved the use of unregistered guns, one involved a registered gun of questionable ownership, and one perpetrator used his service gun. One victim was killed with a blunt object. The cause of death in one case was severe neglect. Three of the 18 victims were killed using multiple weapons.

Of the seventeen DV perpetrators, five perpetrators committed suicide shortly after the homicide.

Fifteen DV victims (83%) died at the hand of their intimate partners. One DV victim killed her husband, the DV perpetrator. 11% of DV homicide victims were family members who tried to intervene when the DV victim was being attacked. One DV victim survived her injuries, however the perpetrator killed her mother who tried to intervene, and another perpetrator killed his mother-in-law who tried to intervene.

Of these 17 DV cases, five (29%) of the DV vic-

ims had accessed services within the domestic violence system prior to the fatality. Four had filed for a temporary restraining order, with one of these victims receiving services at a victim's shelter. One victim had received law enforcement services in the past, but refused to be treated for her injuries. One victim was pregnant and was killed shortly after a prenatal visit with her physician.

Seven (41%) of these perpetrators were known to the DV system and had gone through past criminal proceedings. Four of these seven perpetrators had been ordered to attend batterer's intervention programs, with two completing the program.

Eleven DV couples were married to each other and of these couples, three were living together and there was no evidence that the DV victim had voiced wanting to leave the relationship; five were living together, but the DV victim had voiced wanting to leave; two were separated, and one had filed for divorce. Of the six unmarried couples, three remained in a relationship, but the DV victim

had voiced wanting to leave; and three had broken off the relationship.

Twelve homicide perpetrators were charged with murder. Seven perpetrators pleaded guilty and are serving prison time, four perpetrators were found guilty and are serving time as well, and one was acquitted by reason of insanity. Five perpetrators committed suicide in conjunction with the murder, and therefore did not enter the criminal justice system.

Risk factors were identified for the perpetrators and victims through the DVFR review process from documentation prior to the incident, as well as post-homicide evaluations (Table 4). 59% of the homicide perpetrators lost their jobs prior to the incident. 41% of homicide perpetrators had documented mental health issues including depression, bipolar disorder, schizophrenia, and drug induced psychosis. 41% of homicide perpetrators were known to the court system for other than domestic violence including assault, criminal property damage, drinking under the influence, gambling, bankruptcy, divorce, theft, child support,

<b>Risk Factor</b>	<b>DV Victim</b>	<b>DV Perpetrator</b>	<b>Homicide Victim</b>	<b>Homicide Perpetrator</b>
Substance Abuse	7	11	7	11
Child Abuse and Neglect	0	3	0	3
Documented Mental Health Issues	1	6	0	7
Known to Courts other than for DV	1	7	1	7
Job Loss prior to incident	5	10	5	10
Pregnant	1	0	1	0

\*perpetrators and victims may have had more than one risk

impersonating a law enforcement officer, and guardianship petition. Substance abuse was present in 65% of the homicide perpetrators and 39% of the homicide victims. Substance abuse included methamphetamine, marijuana and alcohol abuse, with the majority involving methamphetamine.

Of these seventeen cases, a total of thirty-four children were affected by the DV homicide incident. Their ages were 0-5 years (35.3%); 6-10 years (26.5%); and 11-17 years (38.2%). Eight of these children were documented to have received counseling after the event.

## **Discussion**

Approximately 25 states conduct some form of Domestic Violence Fatality Review. According to the National Domestic Violence Fatality Review Initiative, 30% of all female murder victims are killed by their intimate partners, whereas only 7% of male victims are killed by their intimate partners.<sup>3</sup>

Although the number of Hawaii DV fatalities reviewed thus far is small, comparisons to national statistics reveal that Hawaii follows most of the national trends. Nationally, about 80.3% of DV perpetrators are male, compared to 82% in Hawaii.<sup>3</sup> The national age range of DV victims and perpetrators is consistent with Hawaii cases.<sup>3</sup> Domestic violence does occur among the elderly, and can affect all age groups.

In Hawaii, there is a predominant use of knives or sharp objects in 11 of the 17 cases, and firearms are used less often. However, of the five cases in which a firearm was used, three were unregistered guns and one was of questionable ownership, supporting stricter gun laws in Hawaii.

Of these 17 cases, at least one partner of seven couples (41%) were known to the DV system prior to the incident, through either the court, social services or law enforcement. Of the seven DV perpetrators who were known to the court system, 57% were ordered to attend batterer's intervention but only half of them completed the program. 26% of the DV victims had some contact with DV services in the community.

When a DV victim tries to leave their relationship, this is a dangerous time for her or him. Our review reveals that approximately 82% of these DV victims had voiced wanting to leave the relationship, were in the process of leaving, or had already left the relationship at the time of the homicide.

For the homicide perpetrators, job loss occurred in 59%, 41% had documented mental health issues, 41% were known to the court system for other than domestic violence, and 65% had documented substance abuse issues, the majority involving methamphetamine. Approximately 29% of the DV cases reviewed so far involved murder-suicides committed by men. Social and counseling services to support families going through job loss, experiencing substance abuse

problems, and criminals are needed to prevent the stressors and risk factors leading to domestic violence.

Domestic violence affects not just the perpetrator and homicide victim, but adversely affects whole families. Two of the homicide victims were family members of the DV victim that attempted to intervene. Thirty-four children were affected by these 17 DV homicide cases, and only 23% were documented to have undergone counseling. Counseling services for affected children and families should be readily available and built into the DV system.

Given the relatively small number of Hawaii's DV homicide cases reviewed, these findings cannot be generalized to reflect strict population based conclusions. However, this data is useful in identifying trends and areas for improvement in the response to, and prevention of domestic violence. Ongoing statewide reviews continue to be worked on in all four of Hawaii's counties as well as the military.

### **Summary**

Despite the relatively small numbers of Hawaii's DV related homicides, even one death is too many and this violence affects entire families. The effects of trauma upon young children who witness the violence and/ or death are life-long. Family members or others who come to the rescue, subject themselves to serious injury and even death.

Although 41% of these DV homicide cases were

known to the DV system, tragically these fatalities still occurred. Increased awareness and intervention on the part of government agencies and community organizations is needed. Agencies, organizations and the community need to ask themselves serious questions regarding how to improve the awareness, reporting, and prevention of domestic violence. In the seven couples where at least one partner was known to the DV system, what failed these victims? Was s/he not taken seriously by organizations or those around her? Four of the seventeen DV victims had filed a temporary restraining order (TRO). How can TRO enforcement be improved? Of the 17 cases, only one victim received services at a domestic violence shelter. Are more safe shelters or shelters that include children needed to accommodate DV victims?

The majority of DV fatality cases involved couples who were not known to the DV system. What prevented these victims from accessing services? Was there a lack of knowledge of resources available? Were family, friends or law enforcement minimizing reports? Was there shame on the part of the victim or mental health issues that prevented her/him from reporting?

More information is needed to answer some of these questions and the Domestic Violence Fatality Review program will continue to evaluate this information. However, policy and procedural changes to assist in preventing domestic violence should be examined now by all involved, including lawmakers, the court system, law enforcement, domestic violence agencies and the

community at large. We require more public awareness and education at the social/medical services, and police and first responders level, as well as at the family and community response level. Domestic violence victims, children, and other family members and friends need to know that they can ask for help and will receive the attention warranted.

vices; Department of the Attorney General; Domestic Violence Action Center; Hawaii State Coalition Against Domestic Violence; the Judiciary, and the Department of Health

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Maternal & Child Health Branch, Family Health Services Division, Hawaii Department of Health

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## A Demographic Profile of Hispanics in Hawaii - Implications for Population Health?

Ann Pobutsky, PhD and Dmitry Krupitsky, PhD

The most prominent ethnic groups in Hawaiian history include not only the indigenous Native Hawaiians, but the *Haole* (Europeans and Americans), Chinese, Portuguese, Japanese, Koreans, Puerto Ricans and Filipinos arriving in Hawaii in successive waves of migration. In Hawaii, the phenomenon of new migrants from an area coming in along with established local communities from the same area is a common one for Asian groups (e.g. Filipinos and Chinese) and can present unique public health issues (for infectious diseases such as tuberculosis). In Hawaii the established 'local' Hispanic population is mainly comprised of Spanish, Mexican and Puerto Ricans and their descendants who have intermarried with

other ethnic groups including Portuguese, Native Hawaiian and especially Filipinos. A more recent wave of 'Hispanic/Latinos' are mainly new migrants from Mexico and/or Central/Latin America.

Some of the first Hispanics or Latino peoples in Hawaii were Mexican vaqueros or cowboys, brought to Hawaii to control cattle which had been introduced in the 1800's (Hawaii Hispanic News, 2008). The cowboys were called "*paniolo*" by Native Hawaiians, thought to be derived from 'español' or Spanish<sup>1</sup>. The main migration of Puerto Ricans to Hawaii occurred between 1901 and 1906, as one of several groups brought in to work on the plantations. Puerto Ricans were

<sup>1</sup> although this could also have been derived from the word 'pañuelo' which is Spanish for bandana, handkerchief, or scarf (personal communication, Enrico I. Neri).

a mix of Indian and Spanish, but also a mix of other ethnicities including Africans from the Guinea coast and other Europeans (Silva and Souza, 1996).

Like other ethnic groups in Hawaii, there was considerable intermarriage with other groups over time. In 1996, Silva and Souza estimated that there were 5,000 Puerto Ricans in Hawaii, or less than 1% of the total and also noted they while they were one of the smaller ethnic groups in Hawaii, their intermarriage with other groups was high. After arriving in Hawaii, the proportion of Puerto Ricans who were born outside Hawaii or the U.S. continent decreased greatly over time (Lind, 1955).

Historically, the Spanish were counted in U.S. decennial censuses prior to World War II and Puerto Ricans in Hawaii have been counted

as a separate ethnic group from 1910 when they constituted 2.5% of the population up until 1950 (see Table 1). The proportion of Puerto Ricans decreased from 1920 onward but by 2000, Puerto Ricans were again 2.5% of the population. Puerto Ricans constituted the main 'Hispanic' group in Hawaii until recently, and the Hispanic/Latino population is now estimated to be 7.8% of the population, or approximately 100,000 people, of which about one-third are Puerto Rican (Table 2). Lee and Edsmonston (2005) note that:

Hawaii's Hispanic population is distinctive from [U.S.] mainland Hispanics in several ways. In Hawaii, most Hispanics identify as 'other Hispanics' or Puerto Rican; few identify as Mexican. About one-third of married Hispanics in Hawaii reported more than one race, and more than one-tenth of married Hispanics in Hawaii reported themselves as Filipino or Hawaiian on the race question (*my emphasis*).

It is important to note that Hawaii has the distinction of having the largest proportion of its population reporting more than one race in the 2000 U.S. Census (Hobbs and Stoops, 2002). The three leading states with high inter-ethnic marriage rates are New Mexico, California, and Arizona, also have large Hispanic populations. The fourth leading state, Hawaii, does not have a large Hispanic population, but does have high intermarriage (Lee and Edmonston, 2005). The federally designated term 'Hispanic or Latino' used for statistical purposes in the US decennial Census and in health and other surveys is not comparable to conventionally used race/ethnic categories, since it can include people of different 'races'. Race and Hispanic origin are two separate concepts in the federal statistical system, whereby people who are Hispanic may be of any

'race' and people in each 'race' group may be either Hispanic or Not Hispanic (US Department of Commerce, 2008). As an example, in the 2005 Hawaii Behavioral Risk Factor Surveillance Survey, there were 491 people in the sampling frame of 6,395 who self-reported being 'Hispanic/Latino'. Of those reporting being 'Hispanic/Latino' in 2005, 24% were European-Americans, 23% were Filipino, 11.4% were Native Hawaiian, 3.5% were Japanese and 38.1% were other ethnic groups (including Mexicans, Puerto Ricans, Central Americans etc).

From 1980 to 2000 the proportion of the population that was Hispanic increased in every state except Hawaii (*my emphasis*)(Hobbs and Stoops, 2002). In 2006 the US Census Bureau estimated the population of Hispanic/Latinos in the U.S. to number more than 44 million people

(14.8%) and the Hispanic/Latino population in Hawaii to be almost 100,000 or 7.8% of the population (U.S. Census Bureau, 2008). And, while every state showed an increase in the number of Hispanics from 2000 to 2006, the population growth rate of Hispanics/Latinos in Hawaii is one of the lowest among the fifty states. The percent change in the Hispanic or Latino population from 2000 to 2006 was highest (50-60%) in many southern states, but lower in Hawaii (13.3%) (U.S. Census Bureau, 2008).

Data from the American Community Survey in 2006 show that of the total proportion of foreign born persons in Hawaii in 2006, only 4.2% were 'Hispanic or Latino' while fully 79% were Asian and 6% were Pacific Islanders. In Hawaii the proportion of foreign born persons in 2006 included 15,868 persons or 7.6% of Hawaii's for-

ign born population from 'Latin America'. Of these persons 50% were born in Latin America, 20% were born in South America, another 18.4% were born in Mexico, 6.4% were born in other Central American countries and 5.6% were born in the Caribbean.

An increase in the number of recent Hispanics/Latino migrants (or undocumented workers) in Hawaii may or may not present public health issues. Unlike migrants from Asia (i.e. China or the Philippines) or Micronesia, at this time there is no evidence that Mexican or other Hispanic migrants have presented the State of Hawaii with public health issues of concern such as communicable diseases (tuberculosis or Hansen's disease), or costly chronic diseases such as cancer or diabetes. Hispanics or Latinos are likely also underrepresented in any health as-

assessment surveys, so at this time it is prudent to only consider the 'Hispanic/Latino' population as another ethnic group of interest in Hawaii and to begin to include them, when possible, in disease surveillance efforts and reporting.

#### Authors affiliation

Community Health Division, Hawaii State Department of Health.

(808) 586-4485 or email:

[ann.m.pobutsky@doh.hawaii.gov](mailto:ann.m.pobutsky@doh.hawaii.gov)

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<b>Table 1: Population of Hispanics in Hawaii, and as a percentage of the total population, 1910-1950</b>					
	1910	1920	1930	1940	1950
<b>Total population</b>	191,909	255,912	368,336	423,330	499,794
<b>Hispanic or Latino (of any race) Total</b>	---	---	---	---	---
Puerto Rican	4,890 (2.5%)	5,602 (2.2%)	6,671 (1.8%)	8,296 (2.0)	9,551 (1.9%)
Spanish	1,990 (1.0%)	2,430 (0.9%)	1,219 (0.3%)	---	---
Mexican	---	---	---	---	---
Other Hispanic or Latino	---	---	---	---	---

<b>Table 2: Population of Hispanics in Hawaii, and as a percentage of the total population, 1960-2006</b>						
<b>Total population</b>	1960	1970	1980	1990	2000	2006 estimate
<b>Hispanic or Latino (of any race) Total</b>	632,772	768,561	964,691	1,108,229	1,211,537	1,285,498
Puerto Rican	---	---	71,263 (7.4%)	81,390 (7.3%)	87,699 (7.2%)	99,663 (7.8%)
Spanish	4,289 (0.7%)	3,490 (0.4%)	---	25,778 (2.3%)	30,005 (2.5%)	---
Mexican	---	---	---	---	---	---
Other Hispanic or Latino	---	---	---	14,637 (1.3%)	19,820 (1.6%)	---
---	---	---	---	41,245 (3.7%)	37,874 (3.2%)	---

# Dementia Protective Factors: A Discussion

Vanessa Cunanan

**Abstract.** The concept of brain reserve refers to the ability to tolerate the age-related changes and the disease-related pathology in the brain without developing clear clinical symptoms or signs. A considerable body of work has documented various factors such as education, work complexity, social network, and leisure activity that may contribute to this reserve allowing cognitive function to be maintained in old age. This paper is a brief review of published English language literature on this topic based on a Pub Med search on the key words, “education and prevention of dementia and Alzheimer’s Disease” from 1998 to present.

## INTRODUCTION

Dementia is an acquired syndrome that consists primarily of a decline in memory as well as at least one other area of cognition such as language, visual-spatial or executive function, and interferes with normal activities. It is characterized by a progressive decline in cognitive function beyond what might be expected of aging. The most common form of dementia among older people is Alzheimer’s disease (AD). AD is a progressive neurodegenerative disease characterized in the brain by abnormal clumps of protein (amyloid plaques) and bundles of twisted protein filaments (neurofibrillary tangles). AD is mostly age-related, with rates rising from approximately 10% at age 65 to about 35% at age 85. In the U.S. there are approximately 4.5 million who suffer

from AD while worldwide, it is estimated that 24.3 million people have AD. Researchers estimate that by 2050, 13.2 million Americans will have AD if current population trends continue and no preventive treatments become available. One of the fastest growing segments – approximately 4 million currently - of the U.S. population is those 85 years and older, it is also the group with the highest risk of AD. This trend is the same worldwide. One study showed that nearly half of all people aged 85 and older have some form of dementia. As the U.S. (and worldwide) population continue to age while advances in science and technology continue to increase life spans, the prevalence rates of aging diseases such as AD are expected to rise exponentially. The disease toll of AD includes a healthcare cost of greater than \$100 billion per year in the U.S.

alone. The magnitude of AD nationally is steadily increasing given the aging U.S. population, making AD an urgent research priority.

As AD and dementia have no known cure, the best strategy is prevention. While numerous studies have been conducted on different protective factors against AD and dementia, a considerable body of work has focused on various factors such as education, work complexity, social network, and leisure activity that may contribute to what is termed as “brain reserve,” that allows cognitive function to be maintained in old age. The concept of brain reserve refers to the ability of the brain to tolerate the pathology of age- and disease-related changes without obvious clinical evidence. The brain reserve hypothesis was initially proposed as number of neurons and synaptic density in the neocortex while the subsequent concept of cognitive reserve expanded the brain reserve hypothesis by stating that innate intelligence as well as aspects of life experience may supply reserve in the form of a set of skills or repertoires allowing some

people to cope with progressing dementia pathology better than others.” Finally, the term neural reserve has been proposed to more specifically refer to the redundancies within the neural system which may provide reserve at both cellular and subcellular levels as well as at their interconnections.’

This paper is a brief review of published English language literature on this topic based on a Pub Med search on the key words, “education and prevention of dementia and Alzheimer’s Disease” from 1998 to present. . Out of 164 studies identified through this means, only a few studies explored the role of education as a protective factor against dementia and Alzheimer’s disease, and are described in this review.

### Canadian Study of Health and Aging

The Canadian Study of Health and Aging was a large-scale cohort study based on a representative, nationwide sample of the Canadian population aged 65 years or older. The study included two phases. The first phase in 1991 included 6,434 subjects aged 65 years or older who were evaluated using a 2-phase

procedure including a screening interview using the Modified Mini-Mental State (3MS), followed by a clinical examination of those with a 3MS Examination score of below 78/100) and a random sample of those who screened negative (a score of 78 or above). The second examination five years later in 1996 followed 4,615 participants who were reassessed using a similar two phase approach. A total of 527 study participants out of the 4,615 were excluded from the analysis as they were evaluated to have cognitive impairment but no dementia. The analysis included 194 Alzheimer's disease cases and 3,894 normal controls with results showing statistical significance between increased risk of Alzheimer's disease and fewer years of education independent of increasing age, and apolipoprotein E  $\epsilon$ 4 allele.

### Psychosocial Network and Dementia

A study conducted in Germany's city of Frankfurt-on-Main and in the neighboring cities of Darmstadt, Offenbach and Bad Homburg explored possible etiological relevance to dementia and psychosocial network factors,

such as marital status, confidants and close relatives, sports activities, cultural activities, club membership; and education. 195 patients with dementia were recruited from 23 general practices, 108 of which were diagnosed with possible Alzheimer's disease, 59 with possible vascular dementia, and 28 with secondary or unclassified dementia. A total of 229 control subjects were recruited, 122 comprising the population controls and 107 dementia-free ambulatory patients.<sup>21</sup> Data were gathered in structured personal interviews and analyzed using logistic regression, to control for age, region, sex, dementia in parents, education and smoking. For cases, it was administered to the next-of-kin – mostly child (40%) or partner (22%)—and to the control subjects themselves. When patients were suffering from the first signs of dementia and no surrogates were available (n=37; 19% of the cases), they were asked to answer the questions themselves.<sup>21</sup> However, as mentioned in the study, the exclusion of these patients would not have fundamentally influenced the results. Odds ratios (OR) and 95% confidence intervals (CI) were calculated using logistic regression analysis. The odds ratio

for subjects with a university graduation compared with those who had elementary level/ no graduation was 0.4 (95% CI 0.2–1.1) for dementia generally (P for trend=0.02), 0.6 (95% CI 0.2–1.8) for cases with possible Alzheimer's disease (P for trend=0.24), and 0.2 (95% CI 0.1–1.0) for cases with possible vascular dementia (P for trend=0.04). Adjustment for the psychosocial network neutralized the otherwise protective effect of education for dementia of any type and for possible vascular dementia.<sup>21</sup>

### The HARMONY Study

The HARMONY Study, also known as the Study of Dementia in Swedish Twins comprise of members from the Swedish Twin Registry who were screened by telephone for cognitive impairment in 1998 to 2000 when they were aged 65 or older. As in most other studies on dementia, the study consisted of a 2-phase procedure involving screening followed by clinical evaluation, if impairment was suspected. The evaluation and assessment were reviewed by a diagnostic board to yield a clinical diagnosis.

The analyses involved 14,165 participants, 1,393

of whom were diagnosed as demented and 12,772 were non demented. Another 555 study participants were not included in the analyses due to ambiguous cognitive status. The study comprised of 3,395 individuals from monozygotic (MZ) twin pairs; 5,915 individuals from like-sex dizygotic (DZ) twin pairs; 4,592 individuals from unlike-sex DZ twin pairs; and 263 pairs of indeterminate zygosity. Sex distribution was 43.7% male and 56.3% female with average age at time of assessment being 73.70 (standard deviation=6.74, range 65 to 103). Educational attainment was assessed by Swedish Twin Registry questionnaires in 1963 (for those born before 1926) or 1973 (for those born later), with education level measured both as total years of education and as a dichotomous variable based on completion of any schooling past compulsory education. Results show a correlation in risk (hazard) for dementia onset as  $r=0.56$  for MZ pairs and  $r=0.24$  for DZ pairs. After adjusting for twin pair similarities and differences in educational level, the correlations increase slightly to 0.67 for MZs and 0.29 for DZs (95% CI=0.49, 0.69), indicating that some of the discordance for dementia onset is attributable to

discordance in the level of education, consistent with a causal effect of education on onset of dementia. Information about level of education was available for 2,354 MZ twin pairs. For 165 MZ pairs discordant for education who were born before 1926, the more educated twin reported greater participation in mentally stimulating leisure activities, OR=0.65 (95% CI=0.43, 0.99). For 108 MZ pairs for whom information on social class based on adult occupation was available, the more educated twin was more likely to achieve a professional or managerial position, OR=0.51 (95% CI=0.27, 0.98). Finally, there were 157 pairs where one of the twins had died before the telephone screening that began in 1998. In these cases, the more educated twin was more likely to survive longer, OR=0.46 (95% CI=0.32, 0.65). In the survival analyses, dementia onset was significantly associated with educational level ( $b=0.0434$ ,  $SE=0.0072$ ,  $P<0.0001$ ), with basic educational level being associated with higher risk. Survival curves show a significant effect of education on dementia onset that is not due to genetic or family environmental factors, consistent with the notion that education may serve as a delaying

factor.

### The Kungsholmen Project

The Kungsholmen Project was a population-based study conducted in the Kungsholmen area of central Stockholm, Sweden. The study explored risk and protective factors for AD and dementia from a lifetime perspective: at birth, during childhood, in adult life, and in old age. Beginning in 1987 with 1,810 participants, a 76% response rate of all inhabitants who were 75+ years old at that time, study participants were contacted every three years until the last follow-up in 2000. At each contact the subjects were interviewed by nurses who collected social and demographic data, measured functional disability, administered brief cognitive tests, took blood pressure, height and weight measurements, and blood samples. They were also clinically examined by physicians, the process being similar to the comprehensive physical, neurological, and psychiatric examination usually performed in clinical practice, but more structured and defined with scoring criteria. In addition, a proxy was used in the form of family interviews with a next-of-kin or

other close person to the participant. All diagnoses of dementia and dementia types were verified by specialists, and discordant diagnoses were reviewed by a senior physician. The study found that subjects with only 2–7 years of education had an increased risk for AD and dementia, but not for AD or dementia mortality.

#### Alzheimer's Disease Center Study

The study at 27 AD Centers in North America involved 2,051 participants age 65+ years who died and underwent autopsy. Many patients at ADCs were referred or self-referred for evaluation of possible dementia; some were recruited specifically to participate in research, including some as normal controls. At enrollment, all participants underwent clinical evaluation and neuropsychological testing which were followed over time with periodic clinical re-evaluation and cognitive testing. Permission for brain autopsy was sought. At the initial evaluation, date of birth and educational attainment were obtained from each subject or from an informant. Education was categorized for analysis as less than high school, high school graduate, or beyond high school. Cognitive

function was measured by the last Mini-Mental State Examination (MMSE) score recorded prior to death. All participants took the MMSE within 2 years before death while neuropathologic severity was quantified using Braak & Braak stage, neuritic plaque density, and Consortium to Establish a Registry for Alzheimer's disease and National Institute on Aging (NIA)/Reagan diagnostic classifications. Multivariate analyses modeled MMSE in relation to education and neuropathologic severity, adjusting for age at death, Lewy body pathology, and vascular dementia. The study found that higher education was associated with higher MMSE scores when AD neuropathology was absent or mild but with more advanced neuropathology, differences in MMSE scores among education levels were attenuated. They found no evidence of larger education-related differences in cognitive function when Alzheimer disease (AD) neuropathology was more advanced suggesting that higher Mini-Mental State Examination scores among more educated persons with mild or no AD may reflect better test-taking skills or cognitive reserve, but these advantages may ultimately be overwhelmed by AD

neuropathology.

### The NEST-DD Project

The paper on education and occupation as proxies for reserve in amnesic Mild Cognitive Impairment (aMCI) converters and AD used participants from the Network for Efficiency and Standardization of Dementia Diagnosis Project (NEST-DD Project). The aim of this study was to assess the impact of education and occupation on brain glucose metabolism (rCMRglc) measured with FDG-PET in aMCI and in a very large sample of subjects with probable AD (pAD). A total of 242 patients with possible AD (pAD) participated in the study; 72 with aMCI, and 144 healthy controls. All patients and a subgroup of control subjects (35 healthy subjects) underwent the extensive neuropsychological NEST-DD battery including tests evaluating global cognitive impairment, memory, speed of information processing and executive functioning, visuo-constructive abilities, word fluency, and language comprehension. Caregivers were administered the Lawton Instrumental Activities of Daily Living scale to describe patients' everyday functioning

while behavioral disorders and depression were assessed with the Neuropsychiatric Inventory and the Hamilton Depression Rating Scale. Glucose metabolism was measured by performing 18F-fluoro-deoxy-glucose (FDG)-PET scans with all subjects having only one FDG-PET scan at inclusion. The subdivision in aMCI converters or nonconverters was based on the clinical follow-up data. The mean educational level was  $9.2 \pm 4.2$  (range 4–20) in pAD,  $10.5 \pm 4.7$  (range 6–20) in aMCI converters,  $10.9 \pm 4.4$  (range 4–20) in aMCI nonconverters, and  $13.6 \pm 3.1$  (range 3–23) in the healthy controls group. The mean occupational level was  $3.7 \pm 1.2$  (range 1–6) in pAD,  $3.9 \pm 1.3$  (range 1–6) in aMCI converters,  $4 \pm 1.1$  (range 1–6) in aMCI nonconverters, and  $4.3 \pm 0.9$  (range 2–6) in the healthy controls group. Subjects were seen in follow-up at a mean of 14.3 months (range: 12–27, SD: 3.3). At clinical follow-up 21 (29.2%) aMCI progressed to pAD (aMCI converters) and 51 (70.8%) remained stable (aMCI nonconverters). The correlation analysis showed a significant relationship between higher education and lower rCMRglc, for a similar level

of neuropsychological impairment. A significant relationship was also present between higher occupation and lower rCMRglc in temporal and parietal cortex, bilaterally. A regression analysis was conducted, with education and occupation as independent variables, and regional cerebral metabolic activity (rCMRglc) as dependent variable, adjusting for demographic data, global cognitive status, and neuropsychological scores. Findings suggest that education and occupation may be proxies for brain functional reserve, reducing the severity and delaying the clinical expression of Alzheimer disease (AD) pathology, these represents an extension and an important advancement of previous functional neuroimaging studies, indicating that highly educated subjects can cope better than less educated subjects with the same level of AD changes in the brain, maybe by recruiting alternative, or redundant, neural networks to support cognitive function.

## **CONCLUSION**

It must be noted that 5 out of 6 studies reviewed in this brief literature review found varying degrees

of statistical associations between AD/dementia and education. The Canadian Study of Health and Aging found statistical significance between increased risk of Alzheimer's disease and fewer years of education. The HARMONY study shows a significant effect of education on dementia onset that is not due to genetic or family environmental factors, consistent with the notion that education may serve as a delaying factor.

The Kungsholmen Project observed that subjects with only 2–7 years of education had an increased risk for AD and dementia, but not for AD or dementia mortality. The study at the 27 AD Centers in North America found that higher education was associated with higher MMSE scores when AD neuropathology was absent or mild but with more advanced neuropathology, differences in MMSE scores among education levels were attenuated. They found no evidence of larger education-related differences in cognitive function when AD neuropathology was more advanced suggesting that higher Mini-Mental State Examination scores among more educated persons with mild or no AD may reflect better test-taking skills or cognitive reserve, but

these advantages may ultimately be overwhelmed by AD neuropathology. Finally, the NEST-DD Project findings suggest that education and occupation may be proxies for brain functional reserve, reducing the severity and delaying the clinical expression of Alzheimer disease (AD) pathology.

Even with an astounding body of research on the disease, there is still no medical test available that can conclusively diagnose AD before a microscopic tissue examination after death. There is no cure for AD and treatment options only alleviate symptoms. While the six studies discussed here may have limitations, it is encouraging to find that while there is no cure for the disease, there may be multiple ways to prevent its occurrence. This opens the field for more research on prevention strategies that perhaps involve a greater number of study subjects from different ethnicities; better follow-up involving prospective cohort studies; improvements on assessment tools; as well as enhanced study designs that adjust for possible sources of bias (e.g., recall bias).

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