

Hawai‘i Journal of Medicine & Public Health

A Journal of Pacific Medicine & Public Health

October 2017, Volume 76, No. 10, ISSN 2165-8218

NEUROLOGICAL COMPLICATIONS IN A POLYNESIAN TRAVELER WITH DENGUE

275

Maegan L.M. Doi MD; Sydney Y. Tatsuno MD, FACP; Gurdev Singh MD, FRCS, FACP; Eric M. Tatsuno BS; and Marjorie M. Mau MD, MS, MACP

KEY FACTORS IN OBSTETRIC DELIVERY DECISION-MAKING AMONG ASIAN AND PACIFIC ISLANDER WOMEN BY ENGLISH PROFICIENCY

279

Chevelle M.A. Davis BA; Mary Guo MPH; Jill Miyamura PhD; Ann Chang MD; Denise C. Nelson-Hurwitz PhD; and Tetine Sentell PhD

MEDICAL SCHOOL HOTLINE

287

John A. Burns School of Medicine Receives Continued Full Accreditation by the Liaison Committee on Medical Education (LCME) for the Maximum Accreditation Period of Eight Years

Kathleen Kihmm Connolly PhD; Patricia Lanoie Blanchette MD, MPH; and Jerris Robert Hedges MD, MS, MMM

INSIGHTS IN PUBLIC HEALTH

290

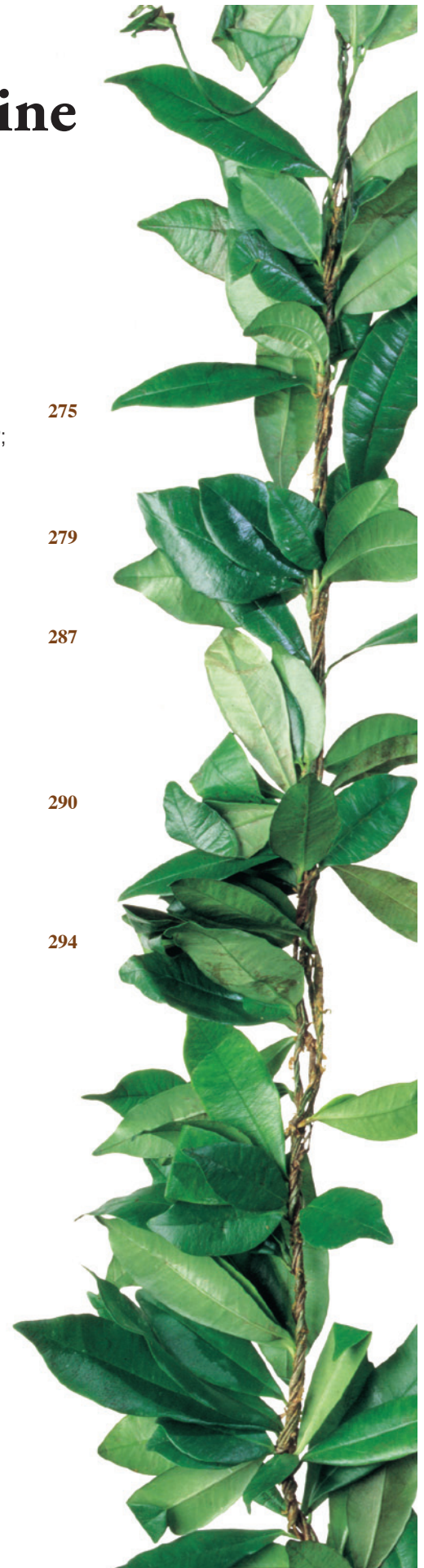
Project Laulima: Expanding Hawai‘i’s System of Care to Better Serve Children and Youth with Co-occurring Mental Health Needs and Intellectual/Developmental Disabilities and their Families

Pratima Kumar Musburger JD, MPH; and Lesley Slavin PhD

THE WEATHERVANE

294

Russell T. Stodd MD



Hawai'i Journal of Medicine & Public Health

A Journal of Pacific Medicine & Public Health
ISSN 2165-8218 (Print), ISSN 2165-8242 (Online)

The Journal's aim is to provide new scientific information in a scholarly manner, with a focus on the unique, multicultural, and environmental aspects of the Hawaiian Islands and Pacific Rim region.

Published by University Health Partners of Hawai'i (UHP Hawai'i) [formerly University Clinical, Education & Research Associates, UCERA]
Hawai'i Journal of Medicine & Public Health
677 Ala Moana Blvd., Suite 1016B, Honolulu, Hawai'i 96813
<http://www.hjmph.org>; Email: info@hjmph.org

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

Editors:

S. Kalani Brady MD, MPH
Michael J. Meagher MD

Editor Emeritus:

Norman Goldstein MD

Associate Editors:

Lance K. Ching PhD, MPH
Tonya Lowery St. John PhD, MPH
Ranjani R. Starr MPH

Copy Editor:

Alfred D. Morris MD

Senior Editors:

Joel Brown MD
Ben Young MD

Junior Editors:

Joshua Holmes MPH
Tricia Mabellos DrPH
Ghazaleh Moayedi DO

Contributing Editors:

Kathleen Kihmm Connolly PhD
Donald Hayes MD, MPH
Satoru Izutsu PhD
Carolyn Ma PharmD
Tetine L. Sentell PhD
Russell T. Stodd MD
Carl-Wilhelm Vogel MD, PhD

Layout Editor & Production Manager:

Drake Chinen

Editorial Board:

Benjamin W. Berg MD, Patricia Lanoie Blanchette MD,
S. Kalani Brady MD, John Breinich MLS,
Lance K. Ching PhD, John J. Chen PhD,
Donald Hayes MD, Satoru Izutsu PhD,
Kawika Liu MD, Tonya Lowery St. John PhD,
Carolyn Ma PharmD, Michael J. Meagher MD,
Alfred D. Morris MD, Tetine L. Sentell PhD,
Myron E. Shirasu MD, Ranjani R. Starr MPH,
Russell T. Stodd MD, Frank L. Tabrah MD,
Carl-Wilhelm Vogel MD

Statistical Consulting:

Biostatistics & Data Management Core,
John A. Burns School of Medicine,
University of Hawai'i (<http://biostat.jabsom.hawaii.edu>)

Advertising Representative

Roth Communications
2040 Alewa Drive, Honolulu, HI 96817
Phone (808) 595-4124

The Hawai'i Journal of Medicine & Public Health (ISSN 2165-8218) is a monthly peer-reviewed journal published by University Health Partners of Hawai'i (UHP Hawai'i). The Journal cannot be held responsible for opinions expressed in papers, discussion, communications, or advertisements. The right is reserved to reject material submitted for editorial or advertising columns. Print subscriptions are available for an annual fee of \$220; single copy \$20 includes postage; contact the Hawai'i Journal of Medicine & Public Health for foreign subscriptions. Full text articles available on PubMed Central. ©Copyright 2017 by University Health Partners of Hawai'i (UHP Hawai'i).



D. Varez

Over 50 Years of Dedication to Hawai'i's Physicians

The Board of Directors at Physicians Exchange of Honolulu invite you to experience the only service designed by and for Physicians in Hawai'i.

President:

Vince Yamashiroya, M.D.

Vice President:

Stephen Oishi, M.D.

Secretary:

Kimberly Koide Iwao, Esq.

Treasurer:

Richard Philpott, Esq.

Directors:

Cynthia Goto, M.D.
Robert Marvit, M.D.
Myron Shirasu, M.D.
Garret T. Yoshimi
David Young, M.D.

Executive Director:

Rose Hamura

- Professional 24 Hour Live Answering Service
- Relaying of secured messages to cell phones
- Calls Confirmed, Documented and Stored for 7 Years
- HIPAA Compliant
- Affordable Rates
- Paperless Messaging
- Receptionist Services
- Subsidiary of Honolulu County Medical Society
- Discount for Hawai'i Medical Association members

"Discover the difference of a professional answering service. Call today for more information."

Physicians Exchange of Honolulu, Inc.
1360 S. Beretania Street, #301
Honolulu, HI 96814

(808) 524-2575

Neurological Complications in a Polynesian Traveler with Dengue

Maegan L.M. Doi MD; Sydney Y. Tatsuno MD, FACP; Gurdev Singh MD, FRCS, FACP; Eric M. Tatsuno BS; and Marjorie M. Mau MD, MS, MACP

Abstract

In recent times, there has been an increased focus on mosquito-borne *Flaviviruses*, in particular dengue and Zika. With the reappearance of dengue in Hawai'i and the mainland United States (US), clinicians should be aware of both the common presentations of dengue, as well as other less common complications associated with the disease. Dengue can result in neurologic disorders such as encephalopathy, encephalitis, immune-mediated syndromes, neuromuscular dysfunction, and neuro-ophthalmologic disorders. We present an interesting case of dengue that initially presented with classic symptoms (arthropathy, biphasic fever, and rash) and subsequently developed into a neurologic movement disorder with muscle tightening and twitching of the face, chest, and extremities. We review and update the epidemiology, biology, the clinical presentations including the neurologic complications associated with dengue, as well as their management and areas of future study in this field.

Keywords

Dengue Virus, Dengue Fever, Flavivirus, Neuromuscular Complications of Dengue, Dengue in Hawai'i

Acronyms

Dengue Virus (DENV), Dengue Virus Serotypes (DENV -1, DENV -2, DENV -3, DENV -4), Non-Structural Protein 1 (NS1), Dengue - Reactive Immunoglobulin M (DENV - IgM) and Dengue - Reactive DENV Immunoglobulin G (DENV - IgG), World Health Organization (WHO), Medical Officer (MO), Status Post (S/P), White Blood Cell Count (WBC), Hemoglobin (Hgb), aspartate aminotransferase (AST), alanine transaminase (ALT), gamma glutamyl transferase (GGT), ribonucleic acid (RNA), Thyroid Stimulating Hormone (TSH), Complete Blood Count (CBC)

Introduction

Dengue is conservatively estimated to infect 50 million individuals throughout 100 countries on an annual basis, and appears to be increasing.¹ Some estimate 390 million new infections per year worldwide of which 96 million are symptomatic.² In 2015-2016, there was a dengue outbreak in Hawai'i with a reported 264 cases.

Dengue fever is caused by a *Flavivirus* and is transmitted to humans by mosquitoes. In Hawai'i, two species of mosquitoes, *Aedes aegypti* (*A. aegypti*) and *Aedes albopictus* (*A. albopictus*), are the known vectors responsible for transmission of the dengue virus.³ There are four dengue virus (DENV) serotypes (DENV - 1, DENV - 2, DENV - 3, DENV - 4), and infection from one serotype will provide lifelong immunity to that specific serotype; however, only partial and short-term immunity will be present to the other three serotypes.⁴ Laboratory testing is available through a rapid diagnostic test that identifies the non-structural protein 1 (NS1) viral antigen during the febrile phase, or DENV - reactive immunoglobulin M (IgM) and DENV - reactive immunoglobulin G (IgG) antibodies during the critical and recovery phases.^{1,4,5}

The febrile, critical, and recovery phases are three distinct phases associated with dengue fever infection. The symptoms present during the febrile phase are: high fever ($\geq 38.5^{\circ}\text{C}$), headache, vomiting, myalgia, joint pain, and in certain cases, macular rash. Additionally, mild hemorrhagic conditions such as petechiae and bruising, and a palpable liver are also present. During the critical phase, which can present between days four and seven following infection, a systemic vascular leak syndrome will present with the following symptoms: elevated hemoconcentration, hypoproteinemia, pleural effusions, ascites, persistent vomiting, severe abdominal pain, tender hepatomegaly, serosal effusions, mucosal bleeding, and lethargy or restlessness. The recovery phase is usually associated with rapid improvement in the patient's condition as the vascular permeability spontaneously improves to normal. Some patients may skip the critical phase and move from the febrile phase to the recovery phase. According to the World Health Organization (WHO), this is the classical form of dengue, also referred to as just dengue.¹ Severe dengue occurs when the patient experiences symptoms related to the critical phase. Most cases of dengue, however, are asymptomatic. It is believed that subsequent infections, either concurrent or divergent will increase the likelihood that the patient contracts severe dengue.⁴

Dengue and severe dengue have the potential to cause neurological complications, including dengue encephalopathy (caused by metabolic disorders or liver failure), encephalitis (caused by direct viral invasion), immune mediated syndromes, neuromuscular dysfunction (eg, Guillain-Barre) and neuro-ophthalmologic disorders with some overlap among the categories.⁶ We present a case of a 39-year-old Hawai'i resident who contracted dengue while on an ocean voyage in French Polynesia. She initially presented with the classical symptoms of dengue but subsequently developed neurological complications including twitching of her face, chest, and extremities and was diagnosed by her neurologist to have a neurological movement disorder. Considering the resurgence of dengue, clinicians in Hawai'i and the mainland US should be aware of the common classical presentations of dengue as well as the underreported neurological complications associated with this disease.

Case Presentation

A 39 year-old woman serving as a crew member on a traditional voyaging canoe presented to the on-board medical officer (MO) with a two-day history of nausea, diarrhea, and shaking chills. The previously healthy crew member came aboard the canoe in Pape'ete, Tahiti 14-days prior to her illness. The MO treated her empirically with ciprofloxacin for presumed traveler's diarrhea.

On Day Three she reported continued malaise and fatigue but declined any further medication. She was monitored frequently with temperature checks and on Day Four of her illness she was found to have a temperature of 99.8°F at 10 AM and re-checked at 1 PM with a temperature of 102.4°F and new symptoms of significant joint pain and muscle aches of both hands. She was treated with ibuprofen and her nausea and symptoms subsided to the point that she was feeling well enough to participate in voyaging land activities (celebrations, cultural protocols, etc). Day Five of the illness was notable for the voyaging canoe as it set sail for a 620 nautical mile open-ocean sail. After the canoe set sail, the crew member reported recurrence of her nausea, malaise, fatigue, and intermittent low grade fevers. On Days Five and Six of the patient's illness, she was unable to take oral hydration adequately with worsening malaise, weakness, and fatigue and was placed in "sick bay" to be monitored by the on-board MO. On Day Seven, the patient's status continued to decline, as her condition was marked by dehydration for two days while on open-ocean sailing, temperatures ranging from 99.4-100.0 °F with mild tachycardia (90s bpm), blood pressure 100/60 mmHg, and signs of dry mucus membranes and poor skin turgor. A presumptive diagnosis of acute dengue fever exacerbated by dehydration was made by the MO and supportive treatment including intravenous fluids were administered. As a result of the supportive treatment, the patient's vital signs responded well with a blood pressure of 120/82 mmHg and her low grade fever was responsive to acetaminophen. On Days Seven and Eight, the patient's clinical course improved and then relapsed throughout the 48 hour period despite supportive care on-board by the MO. At the end of Day Eight, the voyaging canoe captain in consultation with the MO decided to activate a medical evacuation plan for the patient to allow appropriate clinical management and stabilization. The patient, accompanied by the MO, was evacuated to Mitiaro Island then flown to Rarotonga Island, New Zealand and taken directly to an urgent care clinic. The Rarotonga physician agreed with the MO's presumptive diagnosis of acute dengue fever and laboratory tests were obtained. The patient was placed in home quarantine pending results, and on Day Nine the patient noticed a rash of diffuse erythematous macular lesions over her back, neck, abdomen, and palms.

The patient's past medical history was significant only for Grave's disease, status post (S/P) 131-I ablation more than 1 year ago and stable on replacement doses of levothyroxine. The rest of the patient's medical records as well as her social and family history were unremarkable.

Laboratory tests performed at the Rarotonga urgent care clinic facility revealed a low white blood cell count (WBC) 2.5×10^9 cells/liter (normal 4.0-14.5 $\times 10^9$ cells/liter), elevated hemoglobin (Hgb) 16.6 g/dL (normal 11.5-15.5 g/dL), low platelets 68×10^9 cells/liter (normal 150-400 $\times 10^9$ cells/liter) with a neutropenia of 0.6×10^9 on differential. Liver function tests were elevated 2-3X the upper limit of normal with aspartate aminotransferase (AST) 103 units per liter (U/L) (normal female <32 U/L), alanine transaminase (ALT) 63 U/L (normal

female <31 U/L); gamma glutamyl transferase (GGT) 82 U/L (normal female 7-32 U/L) and total bilirubin 20 micromol/L (normal <19 micromol/L). Blood samples were sent for a viral ribonucleic acid (RNA) antigen "quick test" for dengue antigen and IgM antibodies. Both tests were reported as "positive" within 24 hours and samples were sent to a reference laboratory for confirmation. The patient was placed on home restrictions while in Rarotonga and subsequently flown back to Hawai'i on Day Nine of the onset of her illness. A second blood test was obtained 11 days post-acute dengue fever illness by the patient's primary care provider in Hawai'i. The serology was sent to a certified reference laboratory (Focus Diagnostics) and revealed elevated titers of dengue IgM 9.77 (normal <0.90) and dengue IgG 2.3 (normal <0.90).

Approximately two weeks after the onset of her symptoms the patient reported the development of new involuntary "muscle tightening and twitching" of face, chest, and extremities. A laboratory work up was completed and the results were normal including a normal thyroid stimulating hormone (TSH) and the patient was referred to a neurologist for consultation. The patient was seen by the neurologist who made a presumptive diagnosis of mild neuromuscular complications of dengue disease. The neurologist did not recommend any specific treatment intervention but recommended continued observation instead. Additional laboratory tests including a complete blood count (CBC) with differential, sedimentation rate and creatine phosphokinase were ordered and were normal. The patient did not undergo any imaging tests, and her neurological symptoms eventually resolved without specific therapy over the next six months.

Discussion

We present a case of classic dengue, which presented initially with the common manifestations of dengue including arthropathy, biphasic fever, and rash. Serological testing for dengue was positive. However, 14 days after she presented with her initial symptoms she started to experience neurological complications including muscle tightening and twitching of her face, chest, and extremities. She was evaluated by a neurologist who confirmed a neurological movement disorder.

The exact extent of neurological complications associated with dengue are not known but are rarely reported,⁷ some estimating it at 1%.⁶ Many of the reports are in the international journals and some of the major textbooks and references do not even make mention of the neurological complications of dengue. Considering the recent outbreak of dengue fever in Hawai'i in 2015-2016 and the increase in global travel, clinicians need to be aware of not only the more classic presentation of dengue, including fever, retro orbital headache, and body aches, the so called "break bone fever," but also some of the neurological presentations.

Neurological complications of dengue disease can be categorized into dengue encephalopathy, encephalitis caused by direct viral invasion, immune mediated syndromes, neuromuscular dysfunction for example Guillain Barré and neuro-ophthalmo-

logical disorders. Furthermore, there may be some overlap, and some of the neurological manifestations may not fit neatly into any one particular category.⁶

Acute encephalopathy manifests itself with diminished level of consciousness and is the most common reported neurological disorder associated with dengue.⁸ It may be caused by hypotension, anoxia, metabolic disorders including hyponatremia, cerebral hemorrhage, edema and acute liver or renal failure, and the cerebrospinal fluid analysis is normal. Encephalitis is secondary to the direct central nervous system invasion of the virus and may present similar to encephalopathy including altered mental status and seizures, however, the cerebrospinal fluid analysis is abnormal. Immune mediated syndromes include post dengue acute transverse myelitis with urinary retention and lower extremity numbness, which can arise one to two weeks after the onset of symptoms. Neuro-ophthalmological complications usually involve the posterior segment and include visual disturbance secondary to retinal vasculopathy and optic neuropathy.⁶ A case of dengue with papilledema has been reported.⁹

Neuromuscular complications of dengue as reported in this case are relatively rare. They are only sporadic cases being reported worldwide. Cases of Guillain Barré¹⁰ including Miller-Fisher syndrome have been reported along with other forms of motor weakness¹¹ including rhabdomyolysis¹² and hypokalemic periodic paralysis.¹³ Abducens nerve palsy¹⁴ as well as opsoclonus myoclonus syndrome have been reported.¹⁵ Strokes, especially hemorrhagic stroke symptoms have been reported because of the coagulopathy associated with dengue fever.¹⁶ More recently in 2016 a case of a rhombencephalitis associated with dengue fever was reported,¹⁷ two cases of thalamic and basal ganglia involvement associated with dengue were also reported.⁷

Clinicians confronted with patients that have had febrile episodes with neurological complications, especially if they have traveled to an endemic area should have dengue in the differential diagnosis. Also included in the differential diagnosis should be malaria, measles, meningococemia, typhoid and paratyphoid fever, leptospirosis, the viral hemorrhagic fevers, and Chikungunya.⁴ The Zika virus which is in the same genus as the dengue virus, the Flaviviruses, has been reported to cause similar neurological complications including an outbreak of Guillain – Barré in French Polynesia.¹⁸ More alarmingly for Hawai'i, the same mosquitoes species that spread dengue are also responsible for the spread of Zika.

Given the rapid spread of these arthropod borne illnesses including dengue, Zika, and Chikungunya worldwide, novel public health approaches outside of the traditional vector control is needed. A dengue vaccine produced by Sanofi-Pasteur labeled CYD-TDV is the most promising but does have some potential concerns.^{19,20} Research involving bacteria called *Wolbachia* has found that the dengue virus cannot replicate in mosquitoes infected with this bacteria and infected mosquitoes produce offspring that do not transmit the dengue virus to humans.²¹ Currently, there are no effective antivirals. Considering the looming arbovirus pandemics, including dengue and Zika, a one-bug-one-drug approach appears inadequate and research should be geared to broad-spectrum antiviral drugs instead.²² A recent report summarizes the need for an integrated multi-pronged approach.²³

Conclusion

There has recently been a significant worldwide spread of diseases due to the mosquito-borne Flaviviruses, in particular Dengue and Zika. Patients may present with important, and less commonly reported, complications of these diseases. The neurological complications associated with dengue are rare and many of the case reports on the neurological complications associated with dengue are published in international journals. Due to the recent resurgence of dengue in Hawai'i and the increase in international travel, it is pertinent for all health care providers in the State to be familiar with both the common presentations of dengue and the unique manifestations, such as the neurological complications. For this reason we described a case of dengue virus infection with neurological complications, reviewed the clinical presentations, epidemiology, biology, management, and recommended areas for future investigation.

Conflict of Interest

None of the authors identify a conflict of interest.

Acknowledgement

Dr. Mau was supported under NIH grant: NIMHD, P20 MD 000173.

Authors' Affiliation:

- University of Hawai'i, John A. Burns School of Medicine, Honolulu, HI

Correspondence to:

Sydney Y. Tatsuno MD; Email: sydtatsuno@gmail.com

References

1. Simmons CP, Farrar JJ, Nguyen VV, Wills B. Dengue. *N Eng J Med*. 2012; 366:1423-1432.
2. Bhatt S, Gething P, et al. The global distribution and burden of dengue. *Nature*. 2013;496:504-507.
3. Winchester J, Kapan D. History of Aedes Mosquitoes in Hawaii. *Journal of the American Mosquito Control Association*. 2013;29:154-163.
4. Medecins Sans Frontieres. *Clinical guidelines diagnosis and treatment manual*. 2016; 213-219. Retrieved from: http://refbooks.msf.org/msf_docs/en/clinical_guide/cg_en.pdf.
5. Centers for Disease Control. Laboratory guidelines and diagnostic testing for dengue fever. Retrieved from: <https://www.cdc.gov/dengue/clinlab/lab/laboratory.html>.
6. Carod-Artal FJ, Wichmann O, Farrar J, Gascon J. Neurological complication of dengue virus infection. *Lancet Neuro*. 2013;12:906-919.
7. Liyanage, G, Adhikari L, et al. Two case reports on thalamic and basal ganglia involvement in children with dengue fever. *Case Reports in Infectious Disease*. 2016;1368:1-3.
8. Verma R, Sahu R, Holla V. Neurological manifestations of dengue infection: A review. *J Neurol Sci*. 2014;346:26-34.
9. Tahir M, Gupta E, et al. Dengue fever with papilledema: a case of dengue-3 virus in central nervous system. *Journal of Clinical Virology*. 2006;37:65-67.
10. Gupta P, Jain V, Chatterjee S, Agarwal AK. Acute inflammatory motor axonopathy associated with dengue fever. *JACM*. 2009;10:58-59.
11. Misra UK, Kalita, J. Spectrum of neurological manifestations of dengue in India. *Dengue Bulletin*. 2006;30:107-113.
12. Lim M, Goh HK. Rhabdomyolysis following dengue virus infection. *Singapore Med J*. 2005;46:645-646.
13. Gutch M, Agarwal A, Amar A. Hypokalemic quadriplegia: An unusual manifestation of dengue fever. *J Nat Sci Biol Med*. 2012;3:81-83.
14. Shivanthan MC, Ratnayake EC, Wijesiriwardena BC, Somaratna KC, Gamagedara LK. Paralytic squint due to abducens nerve palsy: A rare consequence of dengue fever. *BMC Infect Dis*. 2012;12:156.
15. Verma R, Sharma P, Garg RK, Atam V, Singh MK, Mehrotra HS. Neurological complications of dengue fever: Experience from a tertiary center of north India. *Ann Indian Acad Neurol*. 2011;14:272-278.
16. Kumar J, Kumar A, Gupta S, Jain D. Dengue haemorrhagic fever: an unusual cause of intracranial haemorrhage. *J Neurol/Neurosurg Psychiatry*. 2007;78:253.
17. Verma R, Bharti K, Mehta, M, Bansod A. Rhombencephalitis associated with dengue fever. *Journal of Clinical Virology*. 2016;78:99-101.
18. Cao-Lormeau VM, Blake A, et al. Guillain-Barre syndrome outbreak associated with Zika virus infection in French Polynesia: a case control study. *Lancet*. 2016;387:1531-1539.
19. Hadinegoro SR, Arredondo-Garcia JL, Capeding MR, Deseda C, Chotpitayasunondh T, Dietze R, Muhammad Ismail HI, Reynales H, Limkittikul K, Rivera-Medina DM, et al. Efficacy and long-term safety of dengue virus vaccine in the regions of endemic disease. *N Eng J Med*. 2015;373:1195-1206.
20. Simmons CP. A candidate dengue vaccine walks a tightrope. *N Eng J Med*. 2015;373:1263-1264.
21. O'Neill S. How a tiny bacterium called Wolbachia could defeat dengue. *Scientific American*. 2015.
22. Fauci AS, Morens DM. Zika virus in the Americas-Yet another arbovirus threat. *N Eng J Med*. 2016;374:601-604.
23. Pang T, Mak T, Gubler D. Prevention and control of dengue-the light at the end of the tunnel. *Lancet*. Retrieved from: [http://dx.doi.org/10.1016/S1473-3099\(16\)30471-6](http://dx.doi.org/10.1016/S1473-3099(16)30471-6).

Key Factors in Obstetric Delivery Decision-Making among Asian and Pacific Islander Women by English Proficiency

Chevelle M.A. Davis BA; Mary Guo MPH; Jill Miyamura PhD; Ann Chang MD; Denise C. Nelson-Hurwitz PhD; and Tetine Sentell PhD

Abstract

Childbirth is the most common reason women are hospitalized in the United States. Understanding (1) how expectant mothers gather information to decide where to give birth, and (2) who helps make that decision, provides critical health communication and decision-making insights. Diverse Asian American and Pacific Islander (AA/PI) perspectives on such topics are understudied, particularly among those with limited English proficiency (LEP). LEP is defined as having a limited ability to read, write, speak, or understand English. To address this research gap, we interviewed 400 women (18+ years) with a recent live birth on O'ahu, Hawai'i. Participants completed a 1-hour, in-person interview in English (n=291), Tagalog (n=42), Chinese (n=36), or Marshallese (n=31). Women were asked (1) what information was most important in deciding where to deliver and why; and (2) who participated in the decision-making and why. Responses were compared by LEP (n=71; 18%) vs English-proficient (n=329; 82%) in qualitative and quantitative analyses. Both LEP and English-proficient participants reported their obstetrician as the most important source of health information. Significantly more LEP participants valued advice from family or acquaintances as important sources of information compared to English-proficient participants. The top three health decision-makers for both those with LEP and English-proficient participants were themselves, their obstetrician, and their spouse, which did not differ significantly by language proficiency. These findings provide insights into health information sources and decision-making across diverse AA/PI populations, including those with LEP, and can help direct health interventions such as disseminating patient education and healthcare quality information.

Keywords

limited English proficiency, Asian American/Pacific Islander, decision-making, obstetric

Introduction

Childbirth is the most common reason why women are hospitalized in the United States (U.S.).¹ Hospital labor and delivery units account for 98.8% of births.² Childbirth is one of the most expensive areas in health care and a critical target for quality improvement.³ Understanding how expectant mothers gather information to decide where to give birth and who is involved in that decision provides insights into health communication and health decision-making patterns in a critical health care area. Diverse perspectives on these topics are needed as women from different backgrounds, cultures, and locations may have distinct pathways to health information and preferences for health decision-making.

Asian Americans and Pacific Islanders (AA/PI), which include many heterogeneous cultures, are two of the fastest growing population groups in the United States.⁴⁻⁵ Approximately 34% of the combined U.S. AA/PI population had limited English proficiency (LEP) in 2012 vs 9% of the total U.S. population.⁶

LEP is defined by the Department of Health and Human Services as "individuals who do not speak English as their primary language and who have a limited ability to read, write, speak, or understand English."⁷ LEP is associated with poorer health outcomes across diverse racial/ethnic groups.^{6,8}

Despite their large and growing numbers, AA/PI perspectives on health communication and health care decision-making are significantly understudied, particularly among those with LEP. Better insight into how to make health information understandable and culturally relevant is critical to an accessible, high-quality health system that engages diverse individuals in health decisions. This is particularly important as some evidence suggests that AA/PI receive poorer quality health care in some health domains.^{9,10} LEP is specifically associated with poorer quality health outcomes in childbirth, including obstetric trauma, which can lead to anal incontinence and potential lifelong discomfort.¹¹⁻¹⁵

Evidence on non-AA/PI LEP populations suggests that those with LEP may acquire health information differently from those who are English proficient (EP).^{16,17} For example, Spanish-speaking Hispanic mothers noted fewer educational sources about breastfeeding compared to English-speaking Hispanic mothers.¹⁶ Those with LEP might make decisions in the U.S. health care environment differently than those with EP and have different factors of value in those decisions.¹⁸ For instance, in the hospital setting, patients with LEP report feeling particularly powerless and have a strong preference for family involvement.¹⁸

The goal of this research was to understand who and what factors AA/PI populations by LEP valued when making decisions around obstetric delivery. Hawai'i is an excellent location to conduct this work. Over 57% of Hawai'i's total population is Asian American⁵ and over 25% is Native Hawaiian or Pacific Islander.¹⁹ Furthermore, approximately 25% of households in Hawai'i speak a language other than English at home of which approximately 55% speak English "very well."²⁰ A recent analysis of deliveries in major hospitals in Hawai'i found that approximately 10% of women giving birth had a language preference other than English recorded in the hospital's administrative data.²¹

Methods

Sample

Four hundred women (18+ years) who delivered a baby in the previous two years were interviewed on O'ahu, Hawai'i between

July 2013 and January 2015. First-time mothers as well as those with more than one baby were eligible for participation. Exclusion criteria were severe vision impairment and lack of ability to provide informed consent.

Recruitment

Recruitment occurred across various locations to ensure a diverse representation across AA/PI linguistic and racial/ethnic groups. Following methods used in previous studies of new mothers in Hawai'i,²⁶ community-based recruitment activities included Baby Expos and Craigslist, bus advertisements, farmers' markets, and local festivals. The targeted racial/ethnic/linguistic combination recruitment was 50 participants to ensure that no racial/ethnic group dominated recruitment allowing us to achieve a diverse sample with relevance to Hawai'i. Approximately 12% of women screened were not eligible. Of screened women, 6% ultimately did not participate. Participants received a \$30 gift card to a local drug store as an incentive.

Interviews

Interviews were conducted in-person for about 1-hour in English, Tagalog, Chinese, and Marshallese between July 2013 and January 2015. The study focused on three non-English languages determined to have both local and national relevance. (To include all relevant languages was not practically feasible.) Two Chinese dialects (Mandarin and Cantonese) were included, as Chinese is the third most common non-English language spoken in the U.S. after Spanish and 9.5% of Hawai'i's Chinese population is LEP.^{20, 22} Filipinos are a large and growing Asian American population with over 1.5 million Tagalog speakers in the U.S.²²⁻²³ and Tagalog speakers comprise 17.7% of the Filipino population in Hawai'i.²⁰ We included Marshallese, a language from the Republic of the Marshall Islands, because the growing population of these individuals in the U.S. has significant health disparities and a unique immigration status.²⁴ They are also extremely understudied and of high policy relevance in Hawai'i.²⁴ Bilingual research assistants (one for each language) translated all interview materials including informed consent, following standard, back-translation methods to ensure reliable instruments.²⁵ Tablet computers were used to record all interviews for qualitative analyses and interviews were administered through the tablet computers using the *iSurvey* tool (Wellington, NZ).

Variables

RACE/ETHNICITY

Racial/ethnic groups were Chinese, Filipino, Japanese, Native Hawaiian, White, Marshallese, Other Asian (ie, Thai, Korean), Other Pacific Islander (ie, Chuukese, Samoan), and "Other" race/ethnicity (ie, Hispanic, black). Racial/ethnic information was self-reported using established methods for the multiethnic and multiracial population of Hawai'i.²⁷

LEP

Participants who interviewed in a language other than English

were asked to report their degree of spoken English proficiency across four levels. Following standard procedures, any rating of less than the highest level (corresponding to "very well") was considered to have *Limited English Proficiency (LEP)*.²⁸ Not all participants who interviewed in another language self-reported LEP.

PARITY

Women were asked if the baby was their first baby or their first baby in Hawai'i. Those who responded "no" were considered to already have experience giving birth in Hawai'i.

SOURCES OF HEALTH INFORMATION

Sources of health information were compiled by several questions. First, participants were asked the importance of sixteen sources of health information they used in choosing the hospital where they delivered. These sources were based on previous literature and pilot interviews. They included: discussion with obstetrician; hospital tour; discussion with birth attendant; advice from family; my experience; discussion with other providers; advice from friends; social media; hospital internet research; hospital print materials; blog internet research; other internet research; advice from acquaintances; chat; hospital advertisements; and print media. Responses that mattered "a lot" were compared to those that mattered "somewhat," "a little," "not at all," or "not applicable." Participants were also asked if there were any other sources that were not mentioned. Following this, participants were asked the following open ended questions: "What was your most important source of health information?" and "Why was this your most important source of health information?"

PARTICIPANTS IN THE DECISION-MAKING PROCESS

Participants in the decision-making process were compiled by several questions. First, participants were asked the importance of nine individuals in their decision for the hospital where they delivered. These individuals were also based on previous literature and pilot interviews included: self, obstetrician, spouse, birth attendant, other health care provider, parents, friends, family, and acquaintances. Responses that mattered "a lot" were compared to those that mattered "somewhat," "a little," "not at all", or "not applicable." Participants were also asked if there were any others not listed who participated in the decision about where to deliver. Following this list, participants were asked the following open-ended questions: "Who was the most important person who helped you decide where to have your baby?" and "Why was this person the most important to you?"

QUALITATIVE ANALYSES

Relevant responses from the open-ended questions about quality information sources and decision-making participants were transcribed. Themes regarding who were the most important decision-making participants, and why, were identified using the framework approach²⁹ by two independent raters. The framework approach is a commonly-used, qualitative method

that allows coders to enter with strong expectations of themes based on previous literature and research experience, while also leaving flexibility for emerging themes. We use open-ended responses as illustrative quotes in the text to provide insights into the richness of responses generally. Quotes are not intended to represent the perspective of an entire group or to signify specific consensus across participants.

QUANTITATIVE ANALYSES

Demographics, sources, the decision context, and participants were first compared descriptively (ie, Chi-Square tests for categorical variables) by English proficiency status. For outcomes that varied significantly by LEP in bivariate analyses, we ran multivariable logistic models and controlled for race/ethnicity (compared to Whites), educational attainment (less than high school, high school, vs college degree or higher) and continuous age. All quantitative analyses were performed in STATA 12.0 (College Station, TX). Significance was set as $P < .05$. We also ran sensitivity analyses including a variable for parity in all models. The study was approved by the Institutional Review Board (IRB) of the University of Hawai'i.

Results

Study Demographics

Demographic characteristics of the study sample are displayed in Table 1. Interviews were conducted in the following languages: English ($n=291$), Tagalog ($n=42$), Chinese ($n=36$), and Marshallese ($n=31$). Overall, 17.8% ($n=71$) of women had LEP; those with LEP were Chinese (45.1%), Filipino (23.9%) and Marshallese (31.0%). All other races/ethnicities were English-proficient. A significantly greater proportion of LEP participants self-reported lower levels of education ($P < .01$) and low health literacy than those who were EP (35.2% vs 21.3%; $P = .01$), although linguistic groups did not differ significantly by age group ($P = .65$). Over 80% of women were either first-time mothers or recently had their first baby in Hawai'i. Fewer of those with LEP were delivering for the first time in Hawai'i (66.2% vs 86.6%; $P < .01$).

Sources of Information

OVERALL

The sources of information that "mattered a lot" to mothers were: discussion with obstetrician (OB) (72.4%); advice from family (49.6%); hospital tour (47.4%); personal experience (44.8%); and advice of friends (38.7%). Sources under 15% were hospital advertisements (13.9%), print media (10.9%), and social media (7.7%) (Table 2).

LEP vs EP

Among both linguistic groups, the obstetrician was considered the most salient source of information for the decision about where to give birth by nearly the same proportion of LEP and EP participants. Qualitative results from LEP and EP revealed it was a common theme of experience and expertise. A woman with LEP said it was "because he has been a doctor for so long."

This was echoed by an EP woman who stated that her obstetrician was the most important source of information "because she has been delivering babies for years and she herself has twins."

There were also some important differences across linguistic groups. LEP participants were significantly more likely than EP participants to endorse advice from family (69.0% vs 45.4%; $P < .01$), acquaintances (38.0% vs 14.9%; $P < .01$), or through chat/casual conversations (34.8% vs 14.3%; $P < .01$). Considering why receiving advice from family was important, one woman with LEP said, "I was too shy to ask questions, but I needed help." Similarly, the importance of receiving information by those who were close to her can be seen from a quote by a woman with LEP who said she valued information from friends because they "have experience and can talk to me in Chinese."

Significantly more mothers with English proficiency highly valued information from the hospital tour (51.2% vs 29.0%; $P < .01$) compared to those with LEP, and they were also significantly more likely to say "other" sources of information mattered a lot (17.6% vs 5.9%; $P = .02$) compared to those with LEP. The value of the hospital tour can be seen in this quote from an EP woman: "It encompassed what to expect when you are going to deliver the baby at this hospital and it showcased the hospital setting and patient accommodations."

MULTIVARIABLE MODELS

LEP retained statistical significance in logistic models where family (adjusted odds ratio (aOR):2.07; 95% CI: 1.02-4.18), acquaintances (aOR:2.61; 95% CI: 1.23-5.54); and "other" information sources (aOR:0.24; 95% CI: 0.07-0.87) were outcomes, adjusting for race/ethnicity, education, and age (Table 3). Chinese, Filipinos, Native Hawaiians, Marshallese, and other Pacific Islanders were significantly more likely than Whites to include family as a very important information source. Chinese, Native Hawaiians, and other Pacific Islanders were significantly more likely to include acquaintances.

Individuals Influencing the Decision-Making Process

OVERALL

The individuals who "mattered a lot" in participants' decision-making process were: the self (92.2%), OB (70.9%), and the spouse (67.8%). Individuals with the lowest endorsement were: others (4.3%) and acquaintances (10.8%) (Table 2).

LEP vs NON-LEP

Among both linguistic groups, participants considered themselves to be the most salient person in making decisions. A desire to make her own decision was a common theme among respondents as was their own trust in their knowledge, experiences, and preferences. As a woman with LEP said, she was the most important person in the decision-making process "because I have already experienced giving birth in this hospital." The OB was the next most influential person across the study sample, with a significantly higher number of those with LEP endorsing the OB as a participant compared to those with EP (81.4%

vs 68.7%; $P = .03$). Experience and expertise of the OB was noted by one of the participants. A woman with LEP stated, her obstetrician was the most important because “OB is specialized in pregnancy and delivering babies.” The importance of spouses was also high but did not vary significantly across groups. Joint decision-making between the spouse and the participant was important and a valued concern for several participants across both groups. As an EP participant said, her spouse was very important “because it was a decision we made together. And we wanted a birthing experience where it was between him and I and not necessarily between me and the OBGYN. It was something we wanted together.” A woman with LEP said her spouse was the most important because “I trust him the most and he must also be part of the decision-making; we need to both agree.”

MULTIVARIABLE MODELS

LEP retained statistical significance only in the logistic model where birth attendant was the outcome (aOR: 3.18; 95% CI: 1.36-7.39), controlling for race/ethnicity, education, and age (Table 4). Important differences were seen by race/ethnicity. For example, Filipino, Japanese, Marshallese, and other Pacific Islanders were significantly more likely than Whites to include their OBs in their decision. Filipino, Marshallese, and other Pacific Islanders were significantly more likely than Whites to include their parents and other family members. Those who were older were significantly less likely to include their parents in the decision.

SENSITIVITY ANALYSES

In the sensitivity analyses, the addition of the parity variable did not significantly impact any major study findings and the data are thus not shown.

Table 1. Demographic Data of Mothers by Language of Interview (N=400)				
	English Proficient	Limited English Proficiency	P-value	Total
n	n (%)	n (%)		n (%)
Total	329	71		400
Race/Ethnicity				
Chinese	23 (7.0)	32 (45.1)	<.01	55 (13.8)
Filipino	73 (21.3)	17 (23.9)		90 (21.8)
Japanese	56 (16.4)	0		56 (13.5)
Other Asian	12 (2.7)	0		12 (2.3)
Native Hawaiian	52 (15.8)	0		52 (13.0)
Marshallese	31 (9.4)	22 (31.0)		53 (13.3)
Other Pacific Islander/Chuukese	18 (5.2)	0		18 (4.8)
White	54 (16.4)	0		54 (13.5)
Don't Know/Other/Hispanic	10 (5.8)	0		10 (4.8)
Education				
Less than High School	20 (6.1)	21 (29.6)	<.01	41 (10.3)
High School	147 (44.7)	28 (39.4)		175 (43.8)
College Degree or More	162 (49.2)	22 (31.0)		184 (46.0)
Self-reported low health literacy^a	70 (21.3)	25 (35.2)	.01	95 (23.8)
Mother's Age Group				
18-24	87 (26.4)	16 (22.5)	.65	103 (25.8)
25-34	184 (55.9)	44 (62.0)		228 (57.0)
35+	58 (17.6)	11 (15.5)		69 (17.3)
First Baby/First Baby in Hawai'i	285 (86.6)	47 (66.2)	<.01	332 (83.0)
Born in U.S.	225 (68.4)	2 (2.8)	<.01	227 (56.8)
Born in Hawai'i	156 (47.4)	1 (1.4)	<.01	157 (39.3)

^aOne response was missing for this variable among the English proficient so n=328 for that group for this variable.

Table 2. Percent of Mothers Endorsing that These Source of Information and Potential Decision-Makers “Mattered a Lot” to Their Decision Where to Deliver, by English-Proficiency.

	English Proficient n (%)	Limited English Proficiency n (%)	P-value	Total n (%)	Valid responses
Source of Information					
Discuss Obstetrician	239 (72.9)	50 (70.4)	.68	289 (72.4)	399
Advice Family*	149 (45.4)	49 (69.0)	<.01	198 (49.6)	399
Tour*	168 (51.2)	20 (29.0)	<.01	188 (47.4)	397
My Experience	151 (46.0)	27 (39.1)	.29	178 (44.8)	397
Advice Friends	121 (37.0)	33 (46.5)	.14	154 (38.7)	398
Hospital Internet Research	102 (31.0)	15 (21.7)	.12	117 (29.5)	397
Hospital Print Materials	80 (24.5)	20 (29.0)	.43	100 (25.3)	396
Discuss with Other Providers	84 (25.7)	16 (22.5)	.58	100 (25.1)	398
Discuss Birth Attendant	73 (22.3)	16 (22.5)	.97	89 (22.4)	398
Advice Acquaintances*	49 (14.9)	27 (38.0)	<.01	76 (19.1)	399
Blog Internet Research	62 (18.9)	13 (18.8)	.99	75 (18.9)	397
Chat*	47 (14.3)	24 (34.8)	<.01	71 (17.9)	397
Other Info Source	54 (17.6)	4 (5.9)	.02	58 (15.5)	375
Other Internet Research	48 (14.7)	12 (17.4)	.57	60 (15.2)	396
Hospital Advertisements	41 (12.5)	14 (20.3)	.09	55 (13.9)	397
Print Media	36 (11.0)	7 (10.1)	.83	43 (10.9)	395
Social Media	25 (7.7)	5 (7.3)	.92	30 (7.7)	397
Decision-Makers					
Self	305 (92.7)	63 (90.0)	0.44	368 (92.2)	399
Obstetrician*	226 (68.7)	57 (81.4)	0.03	283 (70.9)	399
Spouse	221 (67.2)	49 (71.0)	0.54	270 (67.8)	398
Parents*	88 (26.8)	35 (50.0)	<0.01	123 (30.8)	399
Friends	74 (22.5)	24 (33.8)	0.04	98 (24.5)	398
Family*	67 (20.4)	27 (38.6)	<0.01	94 (23.6)	399
Birth Attendant*	63 (19.3)	25 (36.8)	<0.01	88 (22.3)	395
Other Health Care Provider	64 (19.6)	16 (23.5)	0.47	80 (20.3)	394
Acquaintances	30 (9.1)	13 (18.6)	0.43	43 (10.8)	399
Others*	12 (3.9)	4 (6.1)	0.02	16 (4.3)	375

*indicates statistical significance, $P < .05$.

Table 3. Multivariable Logistic Models for Information Sources that “Mattered a Lot” in Deciding Where to Deliver for Outcomes Significant in Descriptive Comparisons.

	Tour OR (95% CI)	Family OR (95% CI)	Acquaintances OR (95% CI)	Chat OR (95% CI)	Other Sources OR (95% CI)
LEP	0.53 (0.26-1.09)	2.07 (1.02-4.18)*	2.61 (1.23-5.54)*	2.24 (0.98-5.12)	0.24 (0.07-0.87)
Race/ethnicity					
Chinese	0.64 (0.26-1.56)	3.02 (1.16-7.83)*	3.88 (1.09-13.85)*	5.05 (1.65-15.48)*	1.28 (0.43-3.84)
Filipino	1.12 (0.54-2.32)	4.35 (1.98-9.58)*	2.73 (0.86-8.72)	0.99 (0.33-2.99)	0.71 (0.29-1.71)
Japanese	0.55 (0.25-1.21)	1.71 (0.72-4.09)	0.70 (0.15-3.32)	0.58 (0.15-2.19)	0.57 (0.22-1.48)
Other Asian	1.91 (0.45-8.10)	1.26 (0.29-5.48)	Omitted ^a	0.66 (0.07-6.13)	0.25 (0.03-2.14)
Native Hawaiian	0.56 (0.25-1.27)	4.91 (2.07-11.66)*	4.06 (1.21- 13.59)*	2.62 (0.87-7.91)	0.57 (0.20-1.63)
Marshallese	1.31 (0.51-3.39)	3.60 (1.35-9.60)*	1.29 (0.31-5.31)	1.49 (0.37-6.00)	Omitted ^a
Other Pacific Islander	2.57 (0.80-8.24)	6.37 (1.82-22.26)*	5.79 (1.34-25.12)*	3.73 (0.84-16.44)	0.31 (0.03-2.75)
White	ref	ref	ref	ref	ref
Other	1.93 (0.47-7.99)	1.75 (0.41-7.45)	1.35 (0.13-13.88)	1.26 (0.13-12.25)	0.50 (0.05-4.53)
Education					
<High School	0.17 (0.06-0.48)*	1.44 (0.53-3.90)	1.58 (0.51-4.92)	0.31 (0.07-1.30)	0.60 (0.06-5.61)
High School	0.42 (0.25-0.72)*	1.40 (0.82-2.38)	1.13 (0.57-2.24)	0.59 (0.28-1.21)	0.50 (0.24-1.05)
College Degree+	ref	ref	ref	ref	ref
Age	1.03 (0.99-1.07)	0.96 (0.92- 1.00)	1.01 (0.96-1.06)	1.01 (0.96-1.07)	1.03 (0.96- 1.09)

^aEveryone in this group picked one response (either all 0s or all 1s) so they were dropped from the model.

*indicates statistical significance, $P < .05$.

Table 4. Multivariable Logistic Models for Who “Mattered a Lot” in Decision-Making for Outcomes Significant in Descriptive Comparisons.

	Obstetrician OR (95% CI)	Birth Attendant OR (95% CI)	Parents OR (95% CI)	Family OR (95% CI)	Other OR (95% CI)
LEP	1.91 (0.85-4.30)	3.18 (1.36-7.39)*	1.83 (0.86-3.93)	1.47 (0.69-3.15)	5.93 (0.86-40.79)
Race/ethnicity					
Chinese	1.72 (0.70-4.24)	0.17 (0.04-0.70)*	1.82 (0.54- 6.06)	2.01 (0.44-9.11)	0.075 (0.01-0.83)*
Filipino	3.32 (1.58-6.99)*	1.26 (0.51-3.11)*	4.04 (1.52-10.73)*	6.54 (1.85-23.15)*	0.15 (0.03-0.92)*
Japanese	3.61 (1.58-8.21)*	0.69 (0.24-2.03)	0.71 (0.19-2.71)	1.02 (0.20-5.33)	0.30 (0.05-1.69)
Other Asian	1.10 (0.31-3.88)	0.47 (0.05-4.10)	Omitted ^a	Omitted ^a	1.04 (0.11-10.13)
Native Hawaiian	2.13 (0.96-4.76)	0.53 (0.16-1.73)	2.78 (0.96-8.04)	4.39 (1.14-16.87)	0.34 (0.06-1.92)
Marshallese	4.08 (1.44-11.60) *	5.82 (2.00- 16.97)*	13.05 (4.11-41.45)*	11.94 (3.02-47.28)*	0.08 (0.004- 1.34)
Other Pacific Islander	8.07 (1.63-39.98) *	3.30 (0.94-11.60)	6.91 (1.87-25.53)*	5.90 (1.23-28.32)*	Omitted ^a
White	--	--	--	--	--
Other	1.47 (0.36-5.97)	2.07 (0.43-9.96)	2.78 (0.54- 14.22)	5.95 (0.97- 36.51)	Omitted ^a
Education					
<High School	0.93 (0.30-2.84)	0.84 (0.27-2.62)	1.77 (0.62-5.06)	3.40 (1.18-9.75)	Omitted ^a
High School	1.17 (0.66-2.07)	1.17 (0.59-2.34)	1.12 (0.59- 2.09)	1.55 (0.78-3.09)	2.45 (0.68-8.80)
College Degree+	--	--	--	--	--
Age	1.00 (0.95-1.05)	1.02 (0.96-1.07)	0.94 (0.89-0.99)*	1.00 (0.95-1.05)	1.12 (1.01-1.24)*

^aEveryone in this group picked one response (either all 0s or all 1s) so they were dropped from the model.

*indicates statistical significance, $P < .05$.

Discussion

To fill an important literature gap with particular relevance for Hawai'i, this study determined what information sources were valuable to women when choosing a hospital to give birth and who helped with making such decisions. Given the lack of research on LEP women from diverse AA/PI racial/ethnic groups, these findings give insight into the sources of information women in these groups value, as well as who they trust and rely on to help make health care decisions around obstetric delivery.

Similarities were seen in some decision factors, including the fact that many LEP and EP participants endorsed their obstetrician as the most important source of health care information and as a critical health decision-maker. Follow-up research could determine how LEP and EP participants find their obstetrician. However, there were other important areas of variation by LEP. For example, LEP participants appeared to place more value on information they received through word of mouth from family members, friends and acquaintances while EP participants placed more value on information they received from hospital tours. These findings suggest that resources such as a hospital tour may not be available across diverse languages.

In other important findings, advice from acquaintances was also more common among those with LEP compared to those who were EP (38.0% vs 14.9%), as was information from casual conversations (chat) with acquaintances (34.8% vs 14.3%) (Table 2). Those with LEP may trust information from a personal relationship more, especially if written materials may not be available in their language or not easily understood/culturally relevant. Additionally, many Pacific Islander cultures have strong oral histories, which may also help explain this finding.³⁰

Many LEP and EP participants valued themselves, their obstetrician and their spouse/partner as important decision-making participants. Much like sources of information, LEP respondents valued individuals such as parents, friends, other family members (eg, sister, cousins, and in-laws) and acquaintances. LEP participants also highly valued their OB in the decision making.

Our findings suggest that those with LEP rely heavily on their social networks of families and communities. As immigrants may have smaller social networks in Hawai'i than those who were born or raised here, these tight knit social networks may provide critical social support, but have less access to a wide variety of diverse health information or perspectives.

The focus of our study was LEP vs EP, which is significantly understudied. However important differences were also found by race/ethnicity. In particular, we highlight the critical importance of the family and the social network to health information flow in many Asian and Pacific Islander populations.

Limitations

This study has many strengths, including rich data from hard to sample, understudied populations around a topic of vital national and local relevance but also has several limitations. It was conducted only in Hawai'i, and for practicality and relevance, specifically focused on only three of 60+ AA/PI languages. Therefore, it is not fully representative of all people with LEP in AA/PI racial/ethnic groups and may not be relevant to AA/PI in other locations. The study focused on LEP, rather than language of preference and variation may be seen in access and preferences across particular languages (Tagalog, Chinese, and Marshallese). Our sampling frame may have introduced potential bias due to the violation of independence assumption. We also only interviewed individuals able to provide informed consent in the languages of focus in this study. Not all women delivering in Hawai'i meet these criteria and we are thus not representative of all such women. Finally, responses were reported after birth occurred and recall could have been influenced by the passage of time.

Conclusions

Little research exists on how AA/PI populations, especially by LEP, make health care decisions, specifically decisions related to childbirth. Understanding women's decision-making influences when selecting a hospital for birth can help design and target useful interventions to improve the birthing experience. Patterns identified in this study around health decision-making and health communication are also likely relevant across a variety of health outcomes.

Conflict of Interest

None of the authors identify any conflict of interest.

Acknowledgements

This project was supported by Agency for Healthcare Research and Quality (AHRQ) grant R21 HS021903. The authors thank Melinda Nascimbeni, Charmaine Milla, and Nancy Chen for generous assistance with thematic coding and Venus Bermudo and Anita Kabua for their hard work completing interviews.

Authors' Affiliations:

- Office of Public Health Studies at the University of Hawai'i at Manoa, Honolulu, HI (CMAD, MG, DCN-H, TLS)
- Hawai'i Health Information Corporation, Honolulu, HI (JM)
- John A. Burns School of Medicine, University of Hawai'i at Manoa, Honolulu, HI (AC)


Correspondence to:

Chevelle M.A. Davis BA; Email: cmadavis@hawaii.edu

References


- Pfuntner A, Wier L, Stocks C. Most Frequent Conditions in U.S. Hospitals, 2010. *AHRQ*. 2013. <http://www.hcup-us.ahrq.gov/reports/statbriefs/sb148.pdf>. Accessed October 23, 2014.
- Dekker R. How many women give birth in hospitals and birth centers today? American Association of Birth Centers. 2013. <http://www.birthcenters.org/?page=NBCSII>. Accessed November 21, 2014.
- Center for Healthcare Quality & Payment Reform. How to Save \$5 Billion in Healthcare Spending for Employers and Taxpayers. Center for Healthcare Quality & Payment Reform. <http://chqpr.org/blog/index.php/2013/01/how-to-save-5-billion-in-healthcare-spending-for-employers-and-taxpayers/>. Published January 2013. Accessed December 16, 2016.
- Hixson L, Helper B, Ouk Kim M. The Native Hawaiian and Other Pacific Islander Population. United States Census Bureau. 2012. <http://www.census.gov/prod/cen2010/briefs/c2010br-12.pdf>. Accessed December 16, 2016.
- Asian Pacific American Legal Center. A Community of Contrasts: Asian American in the United States: 2011. Asian Pacific American Legal Center. 2011. https://www.advancingjustice.org/pdf/Community_of_Contrast.pdf. Accessed April 22, 2015.
- AAPCHO. Limited English Proficiency (LEP) of AA&NHOPIs. AAPCHO. http://www.aapcho.org/resources_db/lep_factsheet/. AAPCHO. Published May 2014. Accessed December 29, 2016.
- United States Department of Health and Human Services. Limited English Proficiency. United States Department of Health and Human Services. <http://www.hhs.gov/ocr/civilrights/resources/specialtopics/lep/>. Accessed November 21, 2014.
- Sentell T, Braun K. Low Health Literacy, Limited English Proficiency, and Health Status in Asians, Latinos, and Other Racial/Ethnic Groups in California. *J Health Commun*. 2012;17(3):82–99. doi:10.1080/10810730.2012.712621.
- Sentell T, Chang A, Cheng Y, Miyamura J. Maternal quality and safety outcomes for Asians and Pacific Islanders in Hawaii: an observational study from five years of statewide data. *BMC Pregnancy Childbirth*. 2014;14(1):298. doi:10.1186/1471-2393-14-298.
- Hughes DL. Findings from The Commonwealth Fund 2001 Health Care Quality Survey. The Commonwealth Fund. 2002. http://www.commonwealthfund.org/-/media/files/publications/other/2002/mar/quality-of-health-care-for-asian-americans--a-fact-sheet/hughes_factsheetasam.pdf. Accessed December 20, 2016.
- Russo CA, Andrews RM, Barrett M. Racial and Ethnic Disparities in Hospital Patient Safety Events, 2005 Statistical Brief #53. <http://www.ncbi.nlm.nih.gov/books/NBK56034/>. Accessed May 14, 2014.
- Bek KM, Laurberg S. Risks of anal incontinence from subsequent vaginal delivery after a complete obstetric anal sphincter tear. *Obstet Gynecol Surv*. 1992;99(9):724–6. <https://www.ncbi.nlm.nih.gov/pubmed/1420009>. Accessed May 14, 2014.
- Haadem K, Ohrlander S, Lingman G. Long-term ailments due to anal sphincter rupture caused by delivery – a hidden problem. *Eur J Obstet Gynecol Reprod Biol*. 1988;27(1):27–32. <https://www.ncbi.nlm.nih.gov/pubmed/3338606>. Accessed May 14, 2014.
- Haadem K, Dahlstrom JA, Ling L, Ohrlander S. Anal sphincter function after delivery rupture. *Obstet Gynecol*. 1987;70(1):53–6. <https://www.ncbi.nlm.nih.gov/pubmed/329918>. Accessed May 14, 2014.
- University of Manitoba. Term: Obstetrical Trauma: Vaginal Delivery, without Instrumentation. University of Manitoba. 2007. <http://mchp-appserv.cpe.umanitoba.ca/viewDefinition.php?definitionID=103190>. Accessed April 22, 2014.
- St Fleur R, Petrova A. Knowledge and perception of breastfeeding practices in Hispanic mothers in association with their preferred language for communication. *Breastfeed Med*. 2014; 9(5):261–5. doi:10.1089/bfm.2013.0145.
- Schömlerich VL, Ghorashi H, Denktas S, Groenewegen P. Caught in the middle? How women deal with conflicting pregnancy advice from health professionals and their social networks. *Midwifery*. 2016; 35:62–9. doi:10.1016/j.midw.2016.02.012.PMID:27060402.
- Garrett PW, Dickson HG, Whelan AK, Roberto-Forero. What do non-English-speaking patients value in acute care? Cultural competency from the patient's perspective: a qualitative study. *Ethn Health*. 2008;13(5):479–496. doi:10.1080/13557850802035236.
- Hawaii Department of Health. Gender, Age, Ethnicity, and Poverty by County – Population of Hawaii, Hawaii Health Survey (HHS) 2008. Hawaii Department of Health. <http://health.hawaii.gov/hhs/files/2013/05/hhs08t11.pdf>. Published July 2009. Accessed April 23, 2016.
- Department of Business, Economic Development & Tourism. Research & Economic Analysis Division. The Non-English Speaking Population in Hawaii. Data Report 2011. Department of Business, Economic Development & Tourism. Research & Economic Analysis Division. 2011. <http://files.hawaii.gov/dbedt/census/acs/Report/Data-Report-Non-English-Speaking-Profile-Hawaii.pdf>. Accessed April 23, 2016.
- Sentell T, Chang A, Ahn HJ, Miyamura J. Maternal language and adverse birth outcomes in a statewide analysis. *Women's Health*. 2016;56(3):257–280. doi:10.1080/03630242.2015.1088114.
- Ryan C. Language Use in the United States: 2011. American Community Survey Reports. United States Census Bureau. 2013. <https://www.census.gov/prod/2013pubs/acs-22.pdf>. Accessed February 10, 2016.
- Office of Hawaiian Affairs, Research Division, Demography. Native Hawaiian Health Fact Sheet 2015. Volume 1: Chronic Diseases. Office of Hawaiian Affairs, Research Division, Demography. 2015. <http://19of32x2y133s8o4xza0gf14.wpengine.netdna-cdn.com/wp-content/uploads/Volume-I-Chronic-Diseases-FINAL.pdf>. Accessed February 12, 2017.
- Rikson S, Alik W, Hixon A, Palafox N. The 'Compact Impact' in Hawaii: Focus on Health Care. *Hawaii Med J*. 2010;69(6):7–12. <https://www.ncbi.nlm.nih.gov/pubmed/20539994>. Accessed November 21, 2014.
- Dela Cruz FA, Padilla GV, Agustin EO. Adapting a Measure of Acculturation for Cross-Cultural Research. *J Transcult Nurs*. 2000;11:191–8. <https://www.ncbi.nlm.nih.gov/pubmed/11982107>. Accessed April 23, 2016.
- Albright CL, Steffen AD, Novotny R, et al. Baseline Results from Hawaii's Nā Mikimiki Project: A Physical Activity Intervention Tailored to Multiethnic Postpartum Women. *Women Health*. 2012;52(3):265–91, doi:10.1080/03630242.2012.662935.
- Kaneshiro B, Geling O, Gellert K, Millar L. The Challenges of Collecting Data on Race and Ethnicity in a Diverse, Multiethnic State. *Hawaii Med J*. 2011;70(8):168–171. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3158379/>. Accessed April 28, 2016.
- Agency for Healthcare Research and Quality. Chapter 4: Defining Language Need and Categories for Collection: Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement. Agency for Health Care Research and Quality. 2014. <http://www.ahrq.gov/research/findings/final-reports/iomraceport/relata4a.html>. Published September 2012. Accessed March 1, 2015.
- Smith J, Firth J. Qualitative Data Analysis: The Framework Approach. *Nurse Res*. 2011;18(2):52–62. doi:10.7748/nr2011.01.18.2.52.c8284.
- Young KGT. *Rethinking the Native Hawaiian Past*. New York, NY: Routledge Taylor & Francis Group; 1998.

What matters most?






When it comes to your information management program, what matters most to you? We think you will agree, it's access: secure and compliant, yet fast and convenient for you. Access serves healthcare organizations throughout Hawaii.

The right choice for you? It's Access.
Call us today to arrange your FREE consultation and quote.



InformationProtected.com
808.673.3200

Access to, storage, management and destruction of both paper and digitally based information. Nationwide.

MEDICAL SCHOOL HOTLINE

John A. Burns School of Medicine Receives Continued Full Accreditation by the Liaison Committee on Medical Education (LCME) for the Maximum Accreditation Period of Eight Years

Kathleen Kihmm Connolly PhD; Patricia Lanoie Blanchette MD, MPH;
and Jerris Robert Hedges MD, MS, MMM

The Medical School Hotline is a monthly column from the University of Hawai'i John A. Burns School of Medicine and is edited by Satoru Izutsu PhD and Kathleen Kihmm Connolly PhD; HJMPH Contributing Editors. Dr. Izutsu is the vice-dean of the University of Hawai'i John A. Burns School of Medicine and has been the Medical School Hotline editor since 1993.

John A. Burns School of Medicine (JABSOM) has received the maximum eight year accreditation period from the LCME, demonstrating that the faculty, students, staff, and clinical partners who help deliver and support the infrastructure for medical education in Hawai'i continue to meet or exceed established national standards. The next survey visit will occur in the 2024-25 academic year.

“On behalf of the JABSOM ‘ohana, Dean Hedges wishes to express heartfelt gratitude to all who advance the missions of JABSOM throughout the year. The LCME accreditation process is rigorous and demanding. We all have much aloha for our school and those who have trained with JABSOM over the years; this accreditation visit highlighted a number of areas for which Hawai'i can take great pride in its medical school.”

During the LCME accreditation process, several areas of excellence were identified, these included the following:

- An enduring, well-integrated problem-based learning curriculum of excellence that fosters self-directed and life-long learning.
- A well-established culture of engagement between medical students and faculty in a nurturing and supportive learning environment throughout the duration of the medical education program, bolstered by student well-being programs.
- A mature, robust and comprehensive medical education program evaluative process.
- A community-based teaching model that has generated stable, supportive and sustainable partnerships with clinical affiliates and which places faculty and students in educationally-diverse clinical settings across the State.
- Health disparities expertise in multiple disciplines and missions.
- A revenue base that is well balanced and comprises diverse sources.

- A significant and ongoing contributor to the state workforce.
- A highly diverse student and faculty population, and a leader in women faculty numbers and leadership positions.¹

The process for preparing for the LCME site visit began two years ago and included an extensive effort from faculty, staff, students, and community participants. Activities included the completion of LCME's Data Collection Instrument (DCI), an Independent Student Analysis (ISA), an Institutional Self-study (IS) evaluation, and many hours of preparation for all the site visit participants.²

JABSOM's Site Visit

The actual site visit occurred over two and half days in late January 2017. JABSOM was evaluated by a strong and experienced LCME site visit team. The team consisted of a medical school dean, two representatives from the LCME, and two associate deans of faculty development and academic affairs. Throughout the visit, JABSOM faculty, staff, students, and community partners met with the site visit team to discuss, answer questions, and clarify data from the DCI, ISA, and IS. After each meeting, JABSOM participants in each session met separately in debrief meetings to discuss any further questions, issues, or concerns presented by the site visitors. The site visit team also took tours of the campus and affiliated hospitals. After the site visit, JABSOM received a draft of the final report for review. Comments or clarifications regarding the report were submitted to the site visit team for consideration prior to the team sending its report on to the LCME. On submission to the LCME, the final report was reviewed and an accreditation determination was made at the regularly scheduled LCME meeting (held in June 2017).

LCME accreditation requires documentation on 12 standards; a total of 93 supporting elements compose these 12 standards. Although JABSOM received the maximum accreditation period,

areas of concern (requiring attention in the coming year) were identified. Two of the 93 supporting elements were identified as representing “*satisfactory with the need for monitoring*” and five of the 93 supporting elements identified as “*unsatisfactory*.” Given the gestalt of these findings, three of the standards as a whole were assessed as “*compliant with the need for monitoring*” and one standard determined “*noncompliant*”. JABSOM having only one standard area of noncompliance is an accomplishment, having received the full accreditation term. Past accreditation statistics, between the years of 2004 and 2012, revealed that of the 143 schools that received full survey reports forty of the schools (28%) received severe action decisions, a situation where a medical education program is granted less than the maximum eight year term. Themes that were found associated with a severe action decision at other schools included the following:

- 1) A significant number of areas of noncompliance with accreditation standards
- 2) Noncompliance with standards related to comparability of instructional sites and to curriculum management
- 3) Chronic or recurrent noncompliance with accreditation standards
- 4) An insufficient or unclear response to the information requested in the DCI/self-study³

Strategic Planning and Continuous Quality Improvement

With a high number of schools receiving severe action decisions,³ coupled with the rapid advancement of science, technology and medical practice, the standards for medical education and the accreditation processes for medical schools worldwide has become more rigorous. As a result, the LCME has included, in 2016, an element in Standard 1 to assist medical schools in mitigating risk for noncompliance.

1.1 Strategic Planning and Continuous Quality Improvement (CQI)

A medical school engages in ongoing planning and continuous quality improvement processes that establish short and long-term programmatic goals, result in the achievement of measurable outcomes that are used to improve programmatic quality, and ensure effective monitoring of the medical education program’s compliance with accreditation standards.⁴

In addressing Element 1.1, the LCME has published recommendations for a system to carry out ongoing monitoring. Components include the following: a formal policy that provides a common vision and coordination process; personnel who monitor the process; involvement of those knowledgeable in program evaluation, curriculum, and IT support; and lastly, resources to collect, store, and report data.⁴ Additionally, it is recommended that a strong central management of the curriculum, such as a curriculum committee, act as the central authority in managing the curriculum as a whole.³ Specific medical school performance outcomes should determine the frequency of monitoring for

each standard and elements, however, general categories recommended by the LCME for ongoing monitoring include the following:

- Elements that include language that monitoring is required or involve a regularly-occurring process that may be “prone to slippage”⁵
- New elements or elements where LCME expectations have evolved
- Elements that include policies that must be congruent with current operations
- Elements that directly or indirectly affect the core operations of the school
- Standards/elements that were cited in the medical school’s previous full survey⁶

JABSOM’s LCME Compliance Committee

To address the need for CQI, JABSOM formed the LCME Compliance Committee (LCME-CC), which evolved from the planning group for the site visit. The LCME-CC was officially established as a standing committee by the JABSOM Bylaws in November 2016. As stated by the Bylaws, duties of the LCME-CC include the following:

- Review JABSOM compliance with current LCME standards, standards to be implemented at an identified future date, and standards applicable to the year of upcoming JABSOM accreditation visits.
- Maintain a dashboard that reflects the current status of compliance on all standards.
- Have access to and review all materials, documents, reports, program evaluation information, admissions data, fiscal data, and human resources data that would be placed in the LCME Data Collection Instrument, Course Report Forms, and the Institutional Self-Study.
- Provide regular (generally annual) reports and recommendations to the JABSOM Executive committee, Faculty Senate, Curriculum Committee, and the dean and the dean’s leadership team.
- Make recommendations to be considered for addition to the list of measurable objectives included within the school’s strategic plan.⁷

The LCME-CC meets monthly and acts as a liaison between the Dean and JABSOM’s Executive Committee and to those at JABSOM responsible for maintaining compliance to LCME standards and data collection. This committee will not only fulfill the requirement of Element 1.1, but will also assure that JABSOM maintains excellence up to the next site visit which is expected to occur in the 2024-25 academic year.

Importance of accreditation and the LCME

In conclusion, the importance of a medical school aligning with a national accrediting body cannot be stressed enough, not only to maintain and improve the quality of medical education, but to assure the public that medical education processes are

meeting expectations and are on par with established standards. The LCME consists of 19 voting members. Fifteen are medical educators, administrators, and practicing physicians.⁴ This organization serves as a private medical non-governmental self-regulating authority.⁸

The LCME has been accrediting medical schools in the US for approximately 75 years, having been established by the Association of American Medical Colleges (AAMC) and American Medical Association (AMA) in 1942. Historically, the establishment of the LCME was prompted by the shortage of physicians during World War II and the creation of accelerated medical programs to meet physician demand. The purpose of the LCME was to reduce duplication of processes by the AAMC and AMA and to ensure that standards and quality of medical education were being upheld nationally.⁹ The LCME is currently a world leader in medical education, having been approved and recognized by the World Federation for Medical Education as globally accepted standards in 2013.¹⁰

Non-accredited medical programs are available. However, conforming to national or international accreditation organizations ensures (both to the student and public) that the highest quality education is being delivered and that standards in medical education are being addressed in all areas of medical education. These include teaching and curriculum development, administration, faculty, finances, learning environment, facility resources, and student services. Into the future, LCME standards will continue to develop and evolve as new medical and educational knowledge and technology advance, and cultural norms shift. The LCME will continue to be at the forefront in medical school education both nationally and worldwide.

Authors' Affiliation:

John A. Burns School of Medicine, University of Hawai'i, Honolulu, HI

References

1. Blanchette P, Takanishi D, Connolly K. Medical School Hotline: Liaison Committee on Medical Education Accreditation, Part IX: Strengths and Challenges at the John A. Burns School of Medicine (JABSOM). *Hawaii J Med Public Health* [serial online]. November 2016;75(11):345-347. Available from: MEDLINE, Ipswich, MA. Accessed August 7, 2017.
2. Sakai D, Kasuya R, Hedges J, et al. Medical School Hotline: Liaison Committee on Medical Education Accreditation: Part I: The Accreditation Process. *Hawaii J Med Public Health* [serial online]. September 2015;74(9):311-314. Available from: MEDLINE, Ipswich, MA. Accessed August 7, 2017.
3. Hunt D, Migdal M, Waechter D, et al. The Variables That Lead to Severe Action Decisions by the Liaison Committee on Medical Education. *Academic Medicine: Journal Of The Association Of American Medical Colleges* [serial online]. January 2016;91(1):87-93. Available from: MEDLINE, Ipswich, MA. Accessed August 9, 2017.
4. Functions and Structures of a Medical School. Liaison Committee on Medical Education Website. http://lcme.org/wp-content/uploads/filebase/standards/2018-19_Functions-and-Structure_2017-08-02.docx. Published March 2017. Accessed August 14, 2017.
5. Barzansky B, Hunt D, Moineau G, et al. Continuous quality improvement in an accreditation system for undergraduate medical education. *Medical Teacher*. 2015;37(11):1032-1038.
6. Implementing a System for Monitoring Performance in LCME Accreditation Standards. Retrieved from http://lcme.org/wp-content/uploads/filebase/white_papers/CQI-Guidance-Documents-10-16.docx. Published October 19, 2016. Accessed August 14, 2017.
7. Verheyden C. Medical Accreditation in the United States: What For?. *Plastic And Reconstructive Surgery* [serial online]. December 2016;138(6):1367-1370. Available from: MEDLINE, Ipswich, MA. Accessed August 9, 2017.
8. Bylaws of the John A. Burns School of Medicine University of Hawai'i. John A. Burns School of Medicine Website. <http://jabsom.hawaii.edu/about-us/policies/>. Published November 4th, 2016. Accessed August 14, 2017.
9. Kassebaum D. Origin of the LCME, the AAMC-AMA partnership for accreditation. *Academic Medicine: Journal Of The Association Of American Medical Colleges* [serial online]. February 1992;67(2):85-87. Available from: MEDLINE, Ipswich, MA. Accessed August 10, 2017.
10. Process for Recognition of Medical School Accrediting Agencies Now Available. ECFMG Website. <http://www.ecfm.org/forms/process-recognition-february-2015.pdf>. Published February 13, 2015. Accessed August 14, 2017.

INSIGHTS IN PUBLIC HEALTH

Project Laulima: Expanding Hawai'i's System of Care to Better Serve Children and Youth with Co-occurring Mental Health Needs and Intellectual/Developmental Disabilities and their Families

Pratima Kumar Musburger JD, MPH; and Lesley Slavin PhD

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

Overview

Over the past two decades, Hawai'i's Child and Adolescent Mental Health Division (CAMHD), housed within the state's Department of Health, has made great progress in implementing a statewide systems of care framework. The system of care framework, with the child and family at the center of the care model, is evidenced through CAMHD's wide array of services for youth with diagnosed mental health needs; emphasis on home and community-based services; commitment to evidence-based practice; development of strong child and family teams; implementation of coordinated service planning; development of parent peer support services; and partnership with the University of Hawai'i on continuous performance assessment and program evaluation.¹

Although CAMHD has made major strides in the implementation of the system of care approach, the division has faced challenges in providing accessible, effective, and evidence-based services and supports to some groups of children and youth with complex, multi-agency needs. One specific population has been children and youth with co-occurring mental health needs and intellectual or developmental disabilities (MH-I/DD). To provide these children and youth with increased access to specialized services and supports, and to develop mechanisms for cross-system collaboration, CAMHD applied for and was awarded a Substance Abuse and Mental Health Services Administration (SAMHSA) System of Care Expansion grant in 2011. The grant-funded program, called Project Laulima, has implemented strategies at the family, community and state-levels to increase collaboration and coordination among child-serving agencies to better serve children and youth with MH-I/DD and their families. This paper will address the initiatives developed and implemented by Project Laulima from 2011-2017 to expand Hawai'i's system of care.

System of Care Approach

First published in 1986, systems of care were defined as "a comprehensive spectrum of mental health and other necessary

services which are organized into a coordinated network to meet the multiple and changing needs of children and their families."² System of care values are centered upon family-driven and youth-guided care, cultural and linguistic competency, and home and community-based services.

The system of care approach provides an organizational framework and philosophy for system reform and can be adaptable to a variety of systems landscapes and responsive to diverse populations.³ The framework suggests that youth and families' needs should be looked at holistically and across life domains and areas of need (See Figure 1).⁴ While the system of care concept was originally conceptualized for children and youth with diagnosed mental health conditions, its application has been broadened to include children and youth with complex, co-occurring needs. Children and youth with co-occurring needs and their families often receive services and supports through myriad social service agencies and organizations, which further underlines the need for coordination and collaboration across systems.⁵

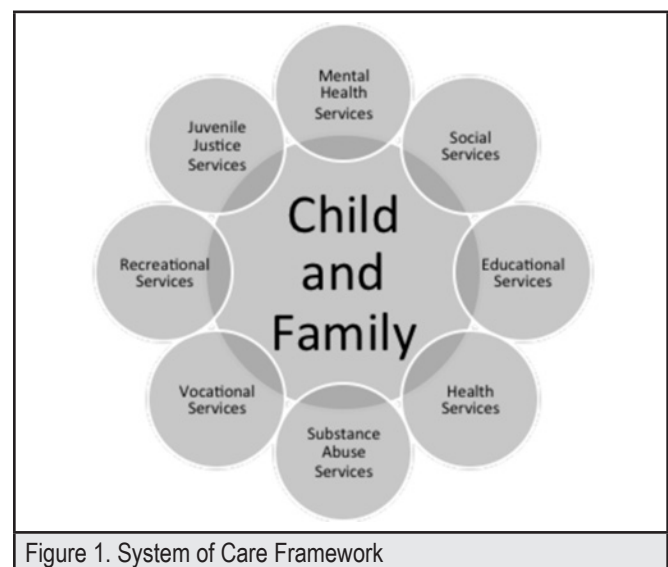


Figure 1. System of Care Framework

Critical Need to Better Serve Youth with Co-occurring MH-I/DD

The American Association on Intellectual and Developmental Disabilities defines an Intellectual Disability (“ID”) as a disability that originates before the age of 18 and is “characterized by significant limitations in both intellectual functioning and in adaptive behavior.” Adaptive behavior can be described as the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives.⁶ The literature suggests that children and adolescents with ID are vulnerable to developing co-occurring mental health conditions. Studies have shown that 30%-64% of children and adolescents with ID develop co-occurring mental health disorders, which is 2.8-4.5 times that of their peers in the general population, including higher rates of depression, anxiety, and psychosis. Furthermore, individuals with ID have been exposed to traumatic events or experiences including abuse, neglect, social disadvantage, challenging family circumstances, stigma, peer neglect, and peer exclusion in greater numbers than individuals without such disabilities.⁷

Estimating the number of children and youth with MH-I/DD in Hawai‘i has been challenging. They often do not appear in state data sets, because they are often ineligible for services through CAMHD or the Developmental Disabilities Division (DDD), despite having genuine needs to be addressed. Utilizing existing state and national data helps to better understand the number of children and youth in Hawai‘i with complex needs who require specialized care. The 2015 Hawai‘i Interagency Youth Performance Report provides some useful data from the Department of Education. The official annual child count for the 2014-2015 school year states that 19,081 children and youth were eligible to receive Special Education services due to some kind of disability. National data suggest that 30%-35% of these children and youth will have co-occurring behavioral or emotional challenges.⁸ In addition, data suggest that of individuals with ID, approximately 85% have mild ID, 10% have moderate ID, 3.5% have severe ID and 1.5% have profound ID.⁹ The estimates therefore suggest that there is a significant population of underserved children and youth in Hawai‘i with mild to moderate ID and co-occurring mental health needs.

Children and youth with ID and mild to moderate ID have historically fallen into a gap between child-serving state agencies. The DDD’s eligibility criteria are defined by statute and focus on individuals with moderate, severe, or profound impairments, thus leaving those with mild impairments ineligible. A child or youth with mild cognitive impairments and co-occurring mental health needs may in fact be eligible for CAMHD services; however, specialized services to meet their needs historically have not been available. Recent data from CAMHD’s 2015 Fact Book suggest that over 6% of CAMHD’s 2405 registered youth had a diagnosis of ID or Pervasive Developmental Disability, thus emphasizing the need for targeted services and supports within CAMHD, specifically designed for youth with co-occurring ID.

To develop innovative services, supports, and infrastructure to better meet the needs of children and youth with MH-I/DD

and their families, CAMHD applied for and was awarded a SAMHSA-funded System of Care Expansion Grant in 2011. The grant-funded program, called Project Laulima, focused on implementing multi-agency and multi-disciplinary strategies at the family, community, and system levels to expand Hawai‘i’s system of care. Eligibility criteria for the program specifically focused on youth with mental health needs and borderline intellectual functioning or mild to moderate ID, since youth within that specific population were often unable to receive specialized mental health services under either CAMHD or DDD.

Five Core Strategies for SOC Expansion at the Family, Community and State Levels

The key components of Project Laulima’s system of care expansion for children and youth with MH-I/DD was based upon Stroul and Friedman’s five “core strategy areas,” which are critical for expanding and sustaining systems of care.¹⁰ The five core strategy areas include: (1) implementing policy and regulatory changes and partnership changes, (2) developing or expanding services and supports based on the system of care philosophy and approach, (3) creating or improving financing strategies, (4) providing training, technical assistance, and workforce development, and (5) generating support through strategic communications. Table 1 highlights the specific initiatives undertaken by Project Laulima in each of the five core strategy areas.

Program Evaluation and Sustainability

Project Laulima’s program evaluation is ongoing and serves to inform both national and local efforts focused on serving children and youth with MH-I/DD and their families. Project Laulima was the first SAMHSA-funded, system of care grant to focus on this specific population; therefore, many states, communities and jurisdictions across the country are eager to understand which of Project Laulima’s services and infrastructure developments generated improved outcomes for children, youth, and families. In order to test and measure the effectiveness of its program initiatives, Project Laulima collected a variety of data to better understand the demographics of youth and families served through Project Laulima; youth and family satisfaction with services received; stakeholder satisfaction with capacity building efforts; whether CBI services improved outcomes of youth enrolled in CBI; and whether the program’s infrastructure-oriented initiatives promoted cross-system collaboration among stakeholders.

Preliminary analyses of the program’s infrastructure, services and process evaluation data helped to inform CAMHD leadership’s decision-making around which program initiatives will be sustained after federal funding is complete. It is anticipated that CAMHD and HISYNC will each sustain specific initiatives, with the former sustaining CBI and access to the PLC’s online training resources and the latter retaining the MET and the Solutions Hui processes, albeit with broader eligibility criteria. The TUFF training curriculum will continue to be implemented by Project Laulima’s partnering family-serving organizations.

Table 1. Core Strategies and Initiatives for Expanding Hawai'i's System of Care to Better Serve Children and Youth with MH-I/DD	
Core Strategy Area and Corresponding Level of SOC Expansion:	Specific Initiative(s) Implemented by Project Laulima within each Core Strategy Area
<p>Implementing Policy, Regulatory, and Partnership Changes.</p> <p>System changes directed at infusing and "institutionalizing" the system of care approach into the larger service system</p> <p>SOC Expansion Level: System</p>	<p>Worked to develop the Hawaii Interagency State Youth Network of Care ("HISYNC"), a committee comprised of all relevant child-serving agencies including: Department of Health (DOH), Department of Human Services (DHS), Department of Education (DOE) and Office of Youth Services (OYS). This included expanding the membership of the group, developing a Memorandum of Understanding (MOU) focused on goals and strategies for cross-system collaboration at the state and local levels, and developing a jointly-funded position for a HISYNC coordinator.</p> <p>Developed a Concurrent Resolution for the 2017 legislative session focused on supporting the collaborative work of the statewide HISYNC and developing regionally-based multi-agency committees across the state. The Concurrent Resolution was included as part of the Keiki Caucus' 2017 legislative package. The measure was not passed; however, and will be reintroduced during the 2018 legislative session.</p>
<p>Developing or Expanding Services and Supports Based on the System of Care Philosophy and Approach</p> <p>System changes to implement and sustain a broad array of home- and community-based services and supports that are individualized, coordinated, family driven, youth guided, and culturally and linguistically competent</p> <p>SOC Expansion Level: Family and Community</p>	<p>Developed and implemented a specialized home and community-based service, called Comprehensive Behavioral Intervention ("CBI"), a mental health treatment for youth with ID within the CAMHD system. CBI aims to enhance the family's capacity to sustain the youth in their current living environment and prevent the need for placement outside the home due to behavioral challenges. Between 3/2014 and 5/2017, over 75 CAMHD-eligible youth with co-occurring I/DD have been enrolled in the service.</p> <p>Implemented the "Solutions Hui," a family-driven, multi-agency teaming process designed to reduce or eliminate system barriers for youth with MH-I/DD and their families. The Solutions Hui outcomes included: helping families to locate services and supports and coordinating services among siloed agencies.</p> <p>Implemented a specialized consultation process, whereby parents, school officials or agency workers could contact Project Laulima staff members by telephone to help them identify needed services and resources for youth with MH-I/DD.</p> <p>Implemented the Multi-disciplinary Evaluation Team ("MET"), an evaluation and consultation service provided by a consortium of professionals across several disciplines including developmental pediatrics, child psychiatry, pediatric neurology, social work, physical therapy, occupational therapy and special education. Outcomes from the MET included diagnostic clarity, individualized treatment planning/recommendations and system improvements.</p>
<p>Creating or Improving Financing Strategies</p> <p>System changes to create or improve financing mechanisms and use funding sources more strategically to support system of care infrastructure and services.</p> <p>SOC Expansion Level: System</p>	<p>Added CBI to CAMHD's service array. Initially funded by the SAMHSA grant, the service is now partially-reimbursed by Medicaid.</p>
<p>Providing Training, Technical Assistance, and Workforce Development</p> <p>System changes to develop a skilled workforce to provide services and supports within a system of care framework</p> <p>SOC Expansion Level: Family, Community and System</p>	<p>Developed a multi-agency Professional Learning Community ("PLC") on MH-I/DD, comprised of 50 individuals across the state, to build expertise and develop statewide capacity. Participants in the PLC include individuals from the Department of Health, Department of Education, Office of Youth Services, and numerous provider agencies and family support organizations. Training resources and meeting facilitation for the PLC were provided by the Center for START Services, based out of the University of New Hampshire. The model developed by the Center for START Services has been identified as best practice by the National Academy of Sciences Institute of Medicine.</p> <p>Developed and implemented regional cross-system trainings, designed to enhance and support multi-agency collaboration and service coordination. Training curriculum developed in partnership with Dr. Jenny Wells from the University of Hawai'i, College of Education, Special Education Department. Several trainings were conducted across the state, including events on Hawai'i Island, Kaua'i, Maui and Moloka'i. Participants included professionals from child-serving agencies, including DOE, DOH, DHS, OYS, provider organizations and community and family organizations.</p> <p>Implemented the Team up For Families training across the state. The training is based on the Team up For Families Road Map, a step-by-step guide for families of youth with special needs, developed by Wendy Bessman. The training and accompanying guide helps families navigate the service system and helps youth-serving professionals better serve the families they work with. The training is supported by several of Project Laulima's partners, including the Community Children's Council Office, the Department of Education, Child and Family Service, and the Developmental Disabilities Council, which has included implementation of the training into its five year State Plan.</p> <p>Served on the planning committee for the Hawaii Institutes on Violence, Abuse and Trauma Summit to promote the inclusion of I/DD-related topics on the conference agenda. Encouraged Project Laulima partners to attend the I/DD-related sessions to build expertise of the state's child and youth-serving providers.</p> <p>Coordinated several single session training events with an array of experts in the field. Topics included Fetal Alcohol Spectrum Disorder (Dr. Georgiana Wilton), Adapting Mental Health Treatment for Youth with I/DD (Dr. Ruth Myers), Developing Clinical Education Teams (Dr. Joan Beasley), Bullying Prevention and Intervention (Dr. Dorothy Espelage), and Adaptive Leadership for Systems Change (Ellen B. Kagen).</p>

Table 1. Core Strategies and Initiatives for Expanding Hawai'i's System of Care to Better Serve Children and Youth with MH-I/DD Cont.	
Generating Support through Strategic Communications	Participated on the Special Parent Information Network (SPIN) conference committee to help identify session topics and speakers for SPIN's annual conference, focused on providing resources and sharing information to families with youth who have special needs.
Strategies to generate the support of high-level policy makers and key constituencies and stakeholders for SOC expansion.	Worked with Hawai'i Youth Services Network on the development of a culturally-relevant bullying prevention video entitled "Take a Stand, Lend a Hand" and accompanying Public Service Announcement (PSA) entitled "Stop the Hate." The video and PSA were designed to raise awareness and generate dialogue about issues of youth bullying. The PSA was awarded a bronze Pele Award in 2017.
SOC Expansion Level: Family, Community and System	Collaborated with the multi-agency Children's Mental Health Matters Campaign Committee to implement activities across the state during the Children's Mental Health Awareness month, including community resource fairs, sign waving activities, and film screening events.

Lessons Learned

Project Lailima did experience challenges in program implementation, which is not unusual when attempting to effectuate change within a large, statewide system. The barriers the program experienced often resulted from working within a less-than-nimble bureaucracy, in which change happens inconsistently across the breadth of the system and requires a significant expenditure of time and resources. Project Lailima was developed to specifically address gaps in services due to eligibility considerations; however, eligibility changes within a system require more time and consideration than a time-limited grant program can provide. What the program was able to do; however, was to start conversations with key stakeholders about where the system gaps exist and what child-serving agencies need to do to work collaboratively and expand boundaries. In addition, the program experienced challenges around uniform implementation of program initiatives across the state, as specific communities varied in their level of participation with the program. Although the program's specialized services and capacity building efforts and outreach activities varied in utilization across the state, the communities with which the program collaborated most closely will provide the data required to determine which program strategies were most successful, thereby helping to determine what strategies to expand and sustain in the future.

Conclusion

Developing, implementing, and sustaining systems of care is a complex process that necessitates simultaneous change at the family, community, and system-levels. Grant-funded programs provide the child-serving system with resources to help progress toward improved outcomes for children, youth, and families; however, systems transformation requires continuous, persistent, and sustained effort. It is hoped that the initiatives piloted by Hawai'i's Project Lailima can inform the development of new services, infrastructure, and capacity building initiatives both locally and nationally, and can serve as a model for states and communities that seek to provide a more comprehensive network of care for families of youth with complex needs.

Acknowledgements

The authors would like to sincerely thank the youth, families, service providers and administrators who supported the work of Project Lailima over the past five years. The authors would also like to thank Dr. Stanton Michels, CAMHD Administrator and Principle Investigator, for his guidance and leadership on this project. Mahalo to Nicole Bell, Ada Demleitner, Susan Emley, Natalia Lukey, Yolanda Rucker, Dr. Scott Keir, Dr. David Jackson, Dr. Daniel Ulrich and Dr. Scott Shimabukuro for their tremendous contributions to the program. Project Lailima is supported by Grant No. SM061226 under the direction of the Child, Adolescent and Family Branch, Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, United States Department of Health and Human Services.

Authors' Affiliation:

Hawai'i State Department of Health, Child and Adolescent Mental Health Division, Honolulu, HI

References

1. Stroul, B., Friedman, R. (2011), Effective Strategies for Expanding the System of Care Approach. A Report on the Study of Strategies for Expanding Systems of Care. Atlanta, GA, ICF Macro
2. Stroul, B., Blau, G. (2008), The System of Care Handbook, Baltimore, MD, Paul Brooks Publishing Co.
3. Stroul, B., Dodge, J., Goldman, S., Rider, F., & Friedman, R. (2015). Toolkit for Expanding the System of Care Approach. Washington, DC: Georgetown University Center for Child and Human Development, National Technical Assistance Center for Children's Mental Health.
4. Stroul, B., Blau, G. (2008), The System of Care Handbook, Baltimore, MD, Paul Brooks Publishing Co.
5. Stroul, B., Blau, G. (2008), The System of Care Handbook, Baltimore, MD, Paul Brooks Publishing Co.
6. Definition of Intellectual Disability, retrieved from <https://aidd.org/intellectual-disability/definition#WURzf-vyvV>
7. Ludi, E., Ballard, E., Greenbaum, R. Pao, M., Bridge, J., Reynolds, W., Horowitz, L. (2012), Suicide Risk in Youth with Intellectual Disability: The Challenges of Screening. Journal of Developmental and Behavioral Pediatrics, 33(5), 431-440
8. Information on Dual Diagnosis, retrieved from <http://thenadd.org/resources/information-on-dual-diagnosis-2/>
9. Boat, TF., Wu, J. (2015) Mental Disorders and Disabilities Among Low-Income Children. Committee to Evaluate the Supplemental Security Income Disability Program for Children with Mental Disorders. Washington DC, National Academies Press.
10. Stroul, B., Dodge, J., Goldman, S., Rider, F., & Friedman, R. (2015). Toolkit for Expanding the System of Care Approach. Washington, DC: Georgetown University Center for Child and Human Development, National Technical Assistance Center for Children's Mental Health.

THE WEATHERVANE

RUSSELL T. STODD MD; CONTRIBUTING EDITOR

THIS INFORMATION MAY CAUSE AN EARLY EXIT FROM THE PLAYING FIELD.

A new study published in the Journal of the American Medical Association is another attempt to emphasize the dangers of CTE (chronic traumatic encephalopathy) a progressive neurodegenerative disease caused by repeated head trauma. A total of 208 brains of former high school, college and semi-professional and pro players were donated for study. Sports neurologist Jeffrey Kutcher cautioned against drawing broad conclusions, noting that the study only included brains of those willing to participate or whose families donated their brains posthumously. Anne McKee, a neurologist at Boston University studied 111 former NFL players, including quarterback Ken Stabler, with the shocking finding that 110 showed symptoms of CTE. "The fact that we found it in 99% of individuals who donated their brain is a frightening statistic." The players averaged 15 years on the field. The study was a factor in the early retirement of John Urschel, an offensive lineman with the Baltimore Ravens. He is pursuing a doctorate in mathematics at MIT. Buffalo linebacker A.J. Tarpley is leaving at age 23 after a pair of concussions. "I am walking away from the game I love to preserve my future health." Even in Texas where football is basically religion, the Dallas Morning News sounded the alarm. "this new data gives a sense of urgency to our push for more study on concussions in all sports." Regardless of how the study was compiled, the detailed pathological descriptions bring more light on being able to diagnose CTE while the athlete is living. A trophy on the mantel or in the hallway won't compensate for a scrambled brain or premature death.

IT MUST BE CLEAN, BUT NOT TOO STERILE.

Hundreds of thousands of American men get vasectomies each year. The procedure costs about \$500 according to the American Urological Association, and is managed as an ambulatory procedure. Vasectomies are considered a permanent form of birth control (they can be revised) and some men want to freeze their sperm "to retain ownership" over contraception. Some more gregarious gents are opting for a fraternal environment, offered by surgeons like Shane Geib MD, in Tysons Corner, Virginia. Patients meet in the doctor's paneled office, are made comfortable with leather sofas, a cushy setting with big screen TVs. "We avoid having a sterile appearance to make it more like a club lounge," said urologist Paul Turek, with clinics in Beverly Hills and San Francisco. The patients become relaxed, and gowned, the surgeon breezes in with soft jazz playing. He takes about eight minutes to perform his task. The patient retires to a recovery room in bathrobe and slippers, may have a drink and a steak dinner before going home the same day. "I thought it was going to be painful, but it was more like a rubber band snap." Patients are told to rest for a few days with limited mobility before returning to regular activities. Sometimes friends will throw a "brosectomy" party, and three or more will have vasectomies together. One guy will say he may do it, others mention they are contemplating it, and then they have courage and energy to feed off one another. Perhaps enterprising urologists will soon be sending limos to pick up and deliver patients.

IT SOUNDS WHACKY, BUT IT'S ADULT ACNE.

For many, it's a cringe-inducing outbreak as videos proliferate on YouTube recording pimple-popping. Amy Wechsler, a dermatologist and psychiatrist in New York, says the satisfaction that comes from watching a pimple pop is almost universal. Pimples are ubiquitous. The majority of our population has or had pimples, so it is a shared desire to rid oneself of them. Dr. Sandra Lee, a dermatologist in southern California, calls herself Dr. Pimple Popper and has amassed 2.5 million subscribers on YouTube, 2.4 million Instagram followers and 38,000 on her Twitter club. The most popular video featuring a giant blackhead removed from an 85-year-old woman has been seen 29 million times since 2015. Dr. Lee's on line popularity has attracted patients to her Upland California, clinic from as far away as Saudi Arabia and South Africa. She was recently nominated for the Shorty Awards that honor best content creators and producers on social media. In the science, technology, engineering and mathematics category, she beat Elon Musk, but lost to Bill Nye, the Science Guy. Says Dr. Lee, "Some people feel like this is a joke. This is what I do. People are interested. This is real life."

IS YOUR FAMILY SAFE FROM THE ANTIVACCINE CABAL?

In the year 2000 doctors were celebrating the eradication of measles in the United States. Even newborns who could not be safely immunized were protected by the herd phenomenon. When a large portion of a population has been immunized there are few potential carriers to spread the disease, which shields everyone. A study published in JAMA Pediatrics shows how quickly the herd immunity can break. Researchers estimated that a 5% drop in measles vaccination in the United States could triple the number of cases annually among children 2 to 11. The alarming part of this report is how many parents are now skipping their children's vaccine, citing religious, philosophical, or personal objections. In Oregon the exemption rate for kindergarten was 6.4%; in Vermont 5.7% in Wisconsin, 5.4%. Andrew Wakefield a discredited British doctor, produced erroneous claims that fueled the anti-vaccine movement. He lost his license, but lame brain celebrities like Bill Maher, Jim Carrey, Robert De Niro, and Alicia Silverstone took up the cause. In 2014 the CDC reported 667 cases of measles in 27 states — a record since 2000. Patients should not view the vaccines with trepidation, but worry instead about the conspiracy theories and gossip in social media. Listen to your doctor.

ADDENDA

- Paradise South Dakota, was named by two residents named Adam and Eve.
- Kangaroos are lactose intolerant.
- "A lie can travel half way around the world before the facts have put their boots on." Mark Twain
- Whatever their other contributions to our society, lawyers would be an important source of protein.
- I'm not going to buy my kids an encyclopedia. Let them walk to school like I did.
- Casual sex is best, because you don't have to wear a tie.
- Before we got engaged I never farted. Now it's our second language.

ALOHA AND KEEP THE FAITH rts

(Editorial comment is strictly that of the writer.)

WRITING CONTEST



HAWAI'I JOURNAL OF MEDICINE & PUBLIC HEALTH

The Hawai'i Journal of Medicine & Public Health invites students and professionals at public health, medical, nursing, pharmacy, and dental schools or programs to enter in its **3rd Annual Writing Contest**.

Submissions must be original works related to the practice of medicine or public health, with a focus on Hawai'i or Pacific Rim region.

Eligibility:

Undergraduates, masters- and doctoral-level students, post-doctoral fellows, and residents.

Applicants must have an advisor who can attest to the individual's contributions and provide final approval.

DEADLINE 12/29/17

\$500 in cash prizes.
Winners will have their photographs and works featured in a future issue.

WWW.HJMPH.ORG/CONTEST

“For more than 35 years, MIEC has been a valued partner of the HMA and an invaluable resource for our members.”

Christopher Flanders
Executive Director of the
Hawaii Medical Association



MIEC has just announced \$11 Million in dividends* to be distributed to policyholders in 2017

MIEC continues to support policyholders and their communities!

MIEC has a dividend policy that is vastly superior to our competitors and we've never lost sight of the medical associations who back our policyholders. Our mission: provide our policyholders and local medical communities with the exemplary service and support they deserve.

Added value:

- No profit motive and low overhead
- Local Claims office in Honolulu
- Supports organized medicine in Hawaii

For more information or to apply:

- www.miec.com
- Call 800.227.4527
- Email questions to underwriting@miec.com

* On premiums at \$1/3 million limits. Future dividends cannot be guaranteed.

MIEC 6250 Claremont Avenue, Oakland, California 94618 • 800-227-4527 • www.miec.com

UCERA_ad_06.07.17

MIEC

Owned by the policyholders we protect.