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ENHANCING CARE OF YOUNG FEBRILE INFANTS IN HAWAI'I: A QUALITY IMPROVEMENT INITIATIVE TO REDUCE UNNECESSARY HOSPITALIZATIONS AND PROCEDURES

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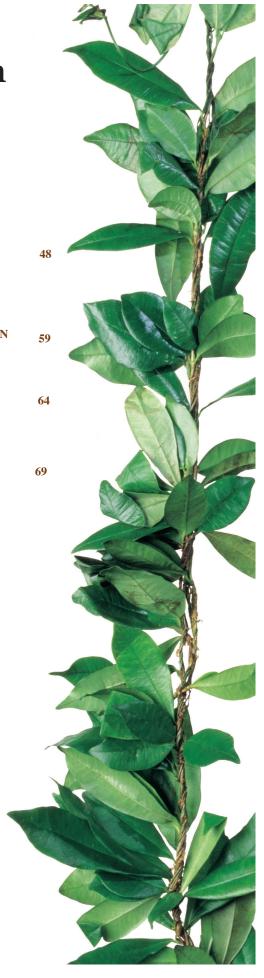
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INSIGHTS IN PUBLIC HEALTH

Weaving Indigenous Methodologies to Enact, Extend, and Innovate Best Practice Survey Measure Development

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A Special Mahalo

Please join us to express our heartfelt appreciation and to bid a fond farewell to

Dr. S. Kalani Brady, Co-Editor

and

Drake Chinen, Journal Production Editor

These fine gentlemen have been the lifeblood of the Hawai'i Journal of Health & Social Welfare shepherding it through the transition from all print to mainly digital, and through various name changes. They have been a guiding presence for decades and are now moving into retirement. We wish them all the best and are happy to announce that Dr. Brady will be continuing on as Editor Emeritus. Thank you is not enough.

Mahalo,

Tonya Lowery St. John and Francie Julien-Chinn, Co-Editors



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Enhancing Care of Young Febrile Infants in Hawai'i: A Quality Improvement Initiative to Reduce Unnecessary Hospitalizations and Procedures

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Abstract

Young infants under the age of 60 days are at high risk of invasive bacterial infection. Historically, several different criteria were developed to risk stratify this population and guide management yet since then epidemiology of invasive bacterial infection has changed. In 2021, the American Academy of Pediatrics released a clinical practice guideline on the evaluation and management of well-appearing infants aged 8 to 60 days with fever, with subcategories 8-21 days, 22-28 days, and 29-60 days. At the only pediatric hospital in the state of Hawai'i, practices for evaluation and management of infants 22-60 days differed from the published clinical practice guidelines. In 2022, a local quality improvement initiative was implemented in connection to a larger national quality improvement initiative to align the institution's practice with the guidelines, thereby decreasing unnecessary hospitalizations, procedures, and medications. After implementation, the admission rate for infants 22 to 60 days decreased significantly from 19% to 2% (P=.010). Lumbar puncture rates decreased for infants 22 to 60 days from 39 out of 47 (83%) to 12 out of 59 (20%) (P<.0001). There was a significant decrease in the number of infants 29 to 60 days with normal inflammatory markers and normal urinalysis who received antibiotics 74% to 20% (P<.0001). There was no increase in delayed diagnosis of invasive bacterial infection (P=NS). Within one implementation, there was significant change in clinical practice with adherence to the clinical practice guideline, resulting in fewer unnecessary hospitalizations, antibiotic administration, and lumbar punctures.

Abbreviations

AAP - American Academy of Pediatrics

CPG - clinical practice guideline

CSF - cerebrospinal fluid

EHR - electronic health record

IBI - invasive bacterial infections

KMCWC – Kapiʻolani Medical Center for Women and Children

PED - pediatric emergency department

PEM – pediatric emergency medicine

PHM – pediatric hospitalist medicine

POC – pediatric outpatient care

QI - quality improvement

REVISE II – Reducing Excessive Variability in Infant Sepsis Evaluation II

UTI - urinary tract infection

INTRODUCTION

Young infants under the age of 60 days are at high risk of invasive bacterial infection (IBI) which include bacteremia and meningitis. ^{1,2} Historically, several criteria were developed to risk stratify this population. ³⁻⁵ However, over the past 30 years since these criteria were published, there have been multiple changes affecting their applicability including changing epidemiology of organisms responsible for IBI, more recent investigations documenting the decreasing risk for IBI with increasing infant age, development of a new biomarker called procalcitonin for systemic inflammatory response, and investigations demonstrating that time to detection of most pathogenic bacteria in blood and cerebrospinal fluid (CSF) cultures is within 24 hours. ⁶⁻⁸

In August 2021, the American Academy of Pediatrics (AAP) released a clinical practice guideline (CPG) on the evaluation and management of well-appearing infants aged 8 to 60 days with fever. 9 Infants were stratified into 3 subgroups, ages 8 to 21 days, 22 to 28 days, and 20 to 60 days, based on their risk for IBI. Inflammatory markers (C-reactive protein, white blood cell count, absolute neutrophil count, and procalcitonin), urinalysis, and CSF fluid analysis were utilized to guide management. The new guidelines represented a departure from the historic criteria in that there was more potential for decreased hospitalization and decreased lumbar punctures in the older sub-groups of infants. Given the risks of hospitalization, outpatient management with good follow-up is preferred when deemed safe. Iatrogenic consequences and psychosocial impacts of hospitalization for both the infant and caregivers include exposure to nosocomial infections, intravenous catheter infiltration, disturbed sleep, disruption to the family unit, stress, and missed work for parents and caregivers. 10-14 Ad-

Table 1. Comparison of KMCWC Historic Practice and 2021 AAP CPG Recommendations for the Evaluation and Management of Well-Appearing Febrile Young Infants

KMCWC historic practice criteria	2021 AAP CPG
Admit infants ≤28 days	Admit infants ≤21 days Potential for no admission in qualifying infants 22 to 28 days
Admit infants 29-60 days old with positive urinalysis	Admit infants ≤28 days old with positive urinalysis Potential for no admission for qualifying infants 29 to 60 days
Lumbar puncture in all febrile infants < 60 days old	Lumbar puncture in febrile infants ≤21 days old Potential for no lumbar puncture in qualifying infants 22 to 60 days
Infants 29 to 60 days discharged from the PED receive antibiotics	Potential for no antibiotics in qualifying infants 29 to 60 days

ditionally, from a resource utilization standpoint, avoiding unnecessary admissions can prevent over-crowding and save cost to the system $^{15-17}$

The Kapi'olani Medical Center for Women and Children (KMCWC) is an urban, university-affiliated tertiary care center and the only children's hospital in Hawai'i. The emergency department is staffed by fellowship-trained Pediatric Emergency Medicine (PEM) physicians and is the only dedicated pediatric emergency department (PED) in the state, treating more than 45 000 patients annually. The majority of children hospitalized at KMCWC are cared for by the Pediatric Hospitalist Medicine (PHM) service. Practice at the institution therefore has the potential to affect the majority of Hawai'i's pediatric patients.

Prior to the release and widespread practice adoption of the 2021 AAP CPG at KMCWC, well-appearing young infants with fever were evaluated based on historic criteria. In general, febrile infants ≤28 days were hospitalized, infants 29 to 60 days with positive urinalysis were hospitalized, all infants <60 days underwent a lumbar puncture, and infants 29 to 60 days discharged from the PED received antibiotics. These practices differed from recommendations of the 2021 AAP CPG and are presented in contrast in Table 1. Potential root causes are outlined in a fishbone diagram in Figure 1.

A quality improvement (QI) initiative was undertaken to align the institution's practice with the 2021 AAP CPG and decrease clinical variation in the care of well-appearing young febrile infants aged 22 to 60 days.

Methods

In May 2022, key stakeholders from the institution's PEM, PHM, Pediatric Outpatient Care (POC) department, local primary care community pediatricians, hospital administration and nursing worked collaboratively to develop and implement a QI initiative with the goal of reducing unnecessary investigations and hospitalizations. The local project was allowed to join the already ongoing national multicenter 103 hospital collaborative QI project sponsored by the AAP Value in Inpatient Pediatrics Network titled Reducing Excessive Variability in Infant Sepsis Evaluation II (REVISE II). ¹⁹ REVISE II primary aims were 90% adherence to obtaining appropriate lumbar puncture, appropriate dis-

charge from the emergency department, and appropriate avoidance of antibiotics for infants 29-60 days, and appropriate discharge for hospitalized infants 8-60 days. REVISE II balancing measures were appropriate evaluation in infants 8-21 days and 22-60 days, return visits to the emergency department, readmissions to the hospital, and delayed diagnosis of bacteremia and/or bacterial meningitis. The local project utilized elements of the REVISE II interventional bundle, specifically the educational webinars, electronic health record (EHR) "query data pull," documentation and patient instruction templates, project database to create run charts, and Maintenance of Certification credits. Within 1 year of implementation, the overlapping sitespecific aims were to reduce lumbar punctures in appropriately evaluated infants 29 to 60 days by 50% and reduce admission in appropriately evaluated infants 22 to 60 days by 25%. A designee of the Institutional Official of Hawai'i Pacific Health determined the project was not research subject to review by an Institutional Review Board (HPHRI Study Number 2022-047).

Behavior change was encouraged utilizing the REVISE II deimplementation frameworks previously described including intentional unlearning, substitution, engaging key stakeholders, encouraging buy-in, and providing audit and feedback.²⁰ The adopted hypothesis was that implementation of a clinical pathway that leveraged standardized and timely assessment, selective use of diagnostic testing, and optimized patient follow up would enable adherence to the AAP CPG, improve outcomes, cost effectiveness, and patient experience.

Site-specific interventions were as follows. The original 38-page AAP CPG was distilled by 1 author (CO) into a single page algorithm as seen in Figure 2, outlining the recommended evaluation and management for the 3 age groups. Local adaptions for a more conservative, expeditious, and simplified approach were made to make the algorithm locally applicable and consensus driven. The AAP CPG had various pathways depending on the availability of the inflammatory marker procalcitonin and results of a bagged urinalysis. The local algorithm differed from the AAP CPG by recommending inflammatory markers at 8 to 21 days, eliminating the option for bag urinalysis due to concern for prolonging PED visits, always including C-reactive protein and temperature >38.5C as primary inflamma-

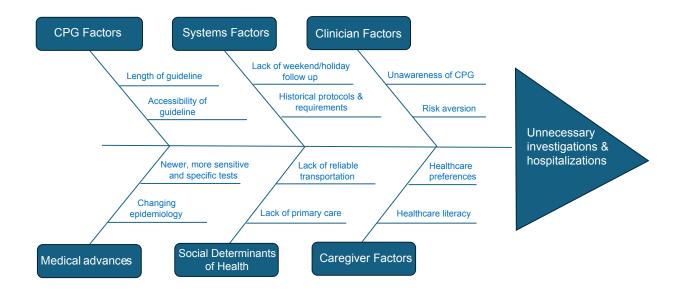


Figure 1. Fishbone Diagram of Potential Pre-Implementation Root Causes Leading to Unnecessary Investigations and Hospitalizations in Well-Appearing Young Febrile Infants

tory markers due to concern for limited procalcitonin availability, and including infants with bronchiolitis.

The flowchart was physically posted in the PED physician work areas. The AAP CPG and local flowchart were presented to various stakeholders at the PED and PHM division meetings, and at the hospital's Quality Council, Standard of Excellence, and Department of Pediatrics meetings. An institutional emergency department guideline outlining the AAP CPG recommended evaluation was created. A locally created educational webinar reviewing the AAP CPG and outlining the implementation plan was presented to the regional accountable care organization. Finally, an official letter was sent to all pediatric providers on the institution's medical staff that included CPG implementation plans, the created flowchart, and a link to the AAP CPG. Providers were advised that more infants may be discharged from the PED and require next day follow-up in their offices. Additionally, given that patients might require outpatient follow-up when primary care community pediatrician offices were closed, arrangements for follow-up to avoid a revisit to the PED were made through the POC clinic.

Data Collection

One year of retrospective pre-implementation data from May 2021 to April 2022 was collected to establish a baseline for the quality measures. Quality outcome measures were metrics that reflect impact of the intervention on the patient and balancing measures were unintended consequences of the intervention. Following pathway implementation, a monthly retrospective audit was conducted from May 2022 to April 2023 to assess both compliance with and performance of this QI initiative. Utilizing program-

ming from the REVISE II EHR "data query pull," a report was generated identifying infants 8 to 60 days with fever who presented to the KMCWC PED.¹⁹ A manual chart review was then conducted. Infants were excluded if they did not have a temperature ≥38.0C measured in the ED or at home, presented with ill appearance, gestational age <37 weeks, chronic medical condition, focus of bacterial infection, high suspicion for HSV, antibiotic administration in past 48 hours, and vaccination in the past 48 hours.

Quality Outcome Measures

Outcome measure 1 evaluated the rate of hospital admissions, subcategorized by age, 22 to 28 days with normal inflammatory markers and normal CSF fluid analysis and 29 to 60 days with normal inflammatory markers. Infants who met these normal criteria in their age group were eligible for outpatient management. Outcome measure 2 evaluated the rate of lumbar punctures in infants 22 to 28 days with normal inflammatory markers and normal urinalysis and 29 to 60 days with normal inflammatory markers. Infants who met the normal criteria were eligible to not have a lumbar puncture. Outcome measure 3 evaluated the infants 29 to 60 days with positive urinalysis and normal inflammatory markers who were hospitalized. Infants who met these criteria were eligible for outpatient management. Outcome measure 4 evaluated infants 29 to 60 days with normal urinalysis and normal inflammatory markers who received antibiotics before discharge from the emergency room. Infants who met these normal criteria were eligible to not receive antibiotics prior to discharge from the emergency room.

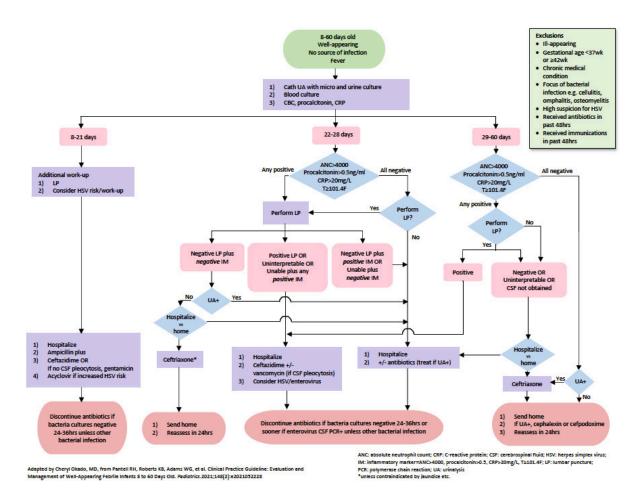


Figure 2. Local Adaptations to AAP CPG Algorithm Flowchart for Evaluation and Management of Well-Appearing Young Febrile Infants

Quality Balancing Measures

Balancing measure 1 evaluated infants 22 to 28 days with normal inflammatory markers, urinalysis and CSF, and 29 to 60 days with normal inflammatory markers discharged from the PED who returned to the PED within 7 days for any reason. Balancing measure 2 evaluated the infants 22 to 60 days without lumbar puncture or without antibiotics who were discharged from the PED or hospital and readmitted within 7 days with bacteremia or meningitis. See **Table 2** for summary of quality measures.

Analysis

Demographic data of patients were summarized by descriptive statistics. Frequencies and percentages of these variables were compared between pre- and post-implementation groups using the chi-square test or Fisher's exact test. Statistical Process Control (SPC) charts were created to monitor the monthly rates of hospital admissions and lumbar punctures pre- and post- implementation, followed by a statistical analysis using the Fisher's exact test to compare the differences between the two periods. All statistical analyses were performed using SAS software version 9.4

(SAS Institute Inc., Cary, NC). A two-tailed *P*-value <.05 was considered to be statistically significant.

Results

There were no significant differences in the populations pre- and post-implementation with respect to age, sex, race, and ethnicity. As in **Table 3**, both pre- and post-implementation, about three-quarters of patients were aged 29-60 days, evenly distributed between male and female sex, 34-44% Native Hawaiian or Pacific Islander, 31-34% Asian, and over 90% non-Hispanic or Latino.

Quality Outcome Measures

Table 4 summarizes the results for quality outcome measures. For outcome measure 1, infants 22 to 28 days with normal inflammatory markers and CSF analysis that were eligible for outpatient management, 0 of 3 infants in the pre-implementation phase and 1 of 2 infants in the postimplementation phase were discharged home (P=.40). For infants 29 to 60 days with normal inflammatory markers, hospitalizations decreased significantly from 5 of 40 (13%) in the pre-implementation period to 0 of 50 (0%) in the post-implementation period (P=.015). The combined hospi

Table 2. Local Quality Improvement Initiative for Well-Appearing Febrile Young Infants Outcome and Balancing Measures Descriptions

Quality Outcome Measure	22 to 28 days	29 to 60 days
1. Admission to hospital	Eligible for no admission if: Normal inflammatory markers Normal CSF	Eligible for no admission if: Normal inflammatory markers
2. Lumbar puncture	Eligible for no lumbar puncture if: Normal inflammatory markers Normal urinalysis	Eligible for no lumbar puncture if: Normal inflammatory markers
3. Admission to hospital for UTI	N/A	Eligible for no admission if: Normal inflammatory markers Positive urinalysis
4. Antibiotics before PED discharge	N/A	Eligible for no antibiotics if: Normal inflammatory markers Normal urinalysis
Quality Balancing Measure	22 to 28 days	29 to 60 days
1. Return to PED within 7 days	Normal inflammatory markersNormal urinalysisNormal CSF	Normal inflammatory markers
2. Bacteremia or meningitis	No lumbar punctureNo antibioticsDischarged home	No lumbar punctureNo antibioticsDischarged home

Table 3. Demographic Characteristics of Well-Appearing Young Febrile Infants Pre- and Post-Implementation of Local Quality Improvement Initiative

Demographic		mentation 120	Post-imple n=	P-value			
Age group	n	%	n	%			
0-21	15	13%	28	20%			
22-28	14	12%	12	8%	.24		
29-60	91	76%	103	72%			
Sex							
Female	63	53%	66	46%	.31		
Male	57	48%	77	54%	.31		
Race							
Black	2	2%	4	3%			
Asian	37	31%	49	34%			
Native Hawaiian or Pacific Islander	53	44%	48	34%	.27		
White	26	22%	33	23%	.27		
Other	1	1%	2	1%			
Unknown	1	1%	7	5%			
Ethnicity							
Hispanic or Latino	7	6%	7	5%			
Non-Hispanic or Latino	110	92%	134	94%	.80		
Unknown	3	3%	2	1%			

tal admission rate run chart for infants 22 to 60 days is in Figure 3 and decreased significantly from 8 of 43 (19%) to 1 of 52 (2%) (P=.010).

For outcome measure 2, the number of infants 22-28 days with normal inflammatory markers who received a lumbar puncture was 4 of 5 (80%) pre-implementation, and 2 of 4 (50%) post-implementation (P=.52). Infants 29 to

Table 4. Outcome Measures Results Pre- and Post- Implementation of Local Quality Improvement Initiative for Well-Appearing Febrile Young Infants

Age	Outcome 1 ^a Hospital Admissions		P-value	Outcome 2 ^b Lumbar Punctures		P-value	Outcome 3 ^c Outpatient UTI		P-value	Outcome 4 ^d Antibiotics		P-value
	Pre-	Post-		Pre-	Post-		Pre-	Post-		Pre-	Post-	
22 to 28 days	3 of 3 (67%)	1 of 2 (50%)	.40	4 of 5	2 of 4	.52	N/A	N/A	N/A	N/A	N/A	N/A
29 to 60 days	5 of 40 (13%)	0 of 50 (0%)	.015	35 of 42 (83%)	10 of 55 (18%)	<.001	0 of 1 (0%)	0 of 3 (0%)	N/A	25 of 43 (74%)	10 of 49 (20%)	<.001
22 to 60 days	8 of 43 (19%)	1 of 52 (2%)	.010	39 of 47 (83%)	12 of 59 (20%)	<.001	N/A	N/A	N/A	N/A	N/A	N/A

Footnote: Workup is as outlined in local adaptations to AAP CPG Algorithm Flowchart in Figure 2.

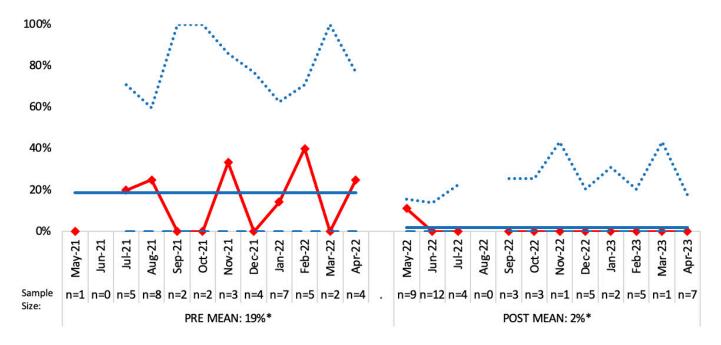
^a Hospital admissions in ages 22 to 28 days and 29-60 days with normal age-appropriate workup.

^b Lumbar punctures in ages 22-28 days with normal inflammatory markers and normal urinalysis and in ages 29 to 60 days with normal inflammatory markers.

^c Hospital admissions in 29 to 60 days with positive urinalysis and normal inflammatory markers.

^d Antibiotics given prior to discharge from PED in ages 29 to 60 days with normal inflammatory markers and normal urinalysis.





* Rate of Hospital Admissions significantly decreased after implementation (19% vs. 2%, P=.010).

Figure 3. Rate of Hospital Admissions in Well-Appearing Young Febrile Infants Ages 22 to 60 Days Pre- and Post-Implementation of Local Quality Improvement Initiative

60 days with normal inflammatory markers who received a lumbar puncture decreased significantly from 35 of 42 (83%) to 10 of 55 (18%) (*P*<.001). When combined, as seen in **Figure 4**, lumbar punctures decreased for infants 22 to 60 days from 39 of 47 (83%) to 12 of 59 (20%) (*P*<.001).

For outcome measure 3, there was an inadequate number of patients 29 to 60 days with normal inflammatory markers and positive urinalysis to analyze statistically. There was 1 in the pre-implementation phase and 3 in the post-implementation phase; none were admitted.

For outcome measure 4, there was a significant decrease in infants 29 to 60 days with normal inflammatory markers and normal urinalysis who received antibiotics from 25 of 34 (74%) pre-implementation to 10 of 49 (20%) post-implementation (P<.001).

Balancing Measures

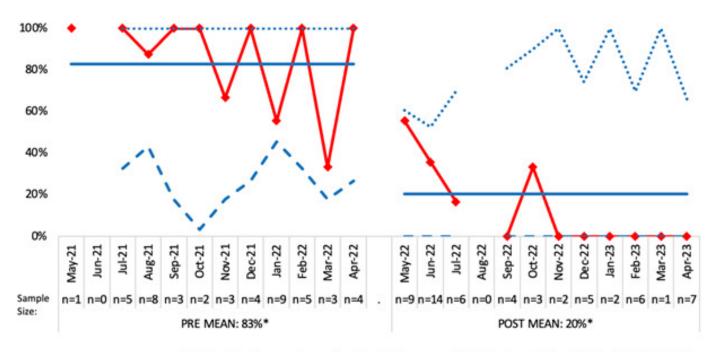
For return rates to the emergency department within 7 days for any reason, pre-implementation 7 of 35 (20%) and post-implementation 9 of 54 (17%) appropriately evaluated and discharged infants 22-60 days returned to the PED. There was no statistically significant change (P=.78).

Regarding delayed diagnoses of bacteremia or meningitis in infants managed in accordance with the guideline, in 22 to 60 days infants, there were 5 total cases of IBI. There was 1 bacteremia/UTI and 1 meningitis in the pre-implementation period versus 1 bacteremia, 1 bacteremia/UTI,

and 1 meningitis post-implementation (*P*>.99). All of these were treated in a timely fashion.

Discussion

The largest change in the care of young febrile infants locally was in the rate of lumbar punctures performed in the 29 to 60 days age group from 83% to 18%. This is in keeping with REVISE II results where the primary aim of appropriately not obtaining a lumbar puncture had the highest adherence at 92.4%.¹⁹ Lumbar punctures are painful procedures for infants, anxiety provoking for parents, and a frequent basis for unnecessary hospitalizations. Obtaining CSF in young infants is challenging as only 45% to 66% of lumbar punctures are successful on the first attempt and rates of unsuccessful or traumatic lumbar puncture in this age group have been reported to be as high as 18.6% to 23%.²¹⁻²³ Traumatic or unsuccessful lumbar punctures increase hospitalization rate 3 times compared to normal lumbar punctures.²¹ Furthermore, even when CSF is successfully obtained, false positives can cloud clinical decision making. When combining the CSF results of 3 separate studies of young febrile infants, only 53 of 497(10.7%) positive bacterial cultures were pathogens.²⁴⁻²⁶ Consequently, the elimination of a lumbar puncture is of direct benefit to the infant as well as with respect to workflow and resource utilization.



* Rate of lumbar punctures significantly decreased after implementation (83% vs. 20%, P<.001).

Figure 4. Rate of Lumbar Punctures in Well-Appearing Young Febrile Infants Ages 22 to 60 Days Pre- and Post-Implementation of Local Quality Improvement Initiative

Because of the small number of infants in the 22 to 28 days age group, only 5 infants with normal blood, urine, and CSF analyses were eligible for home discharge. There was insufficient statistical power to conduct any meaningful analysis. However, the REVISE II study had 2250 infants in this age group. While the analysis for potential increase in home discharge for eligible infants has yet to be reported, there was a significant increase post-implementation in discussions with parents about the harms and benefits of hospitalizations from 1.9% to 17.9%. ¹⁹

With respect to balancing measures, there were no increased PED visits post-implementation. As there was a marked decrease in lumbar punctures and hospitalizations, it was critical to monitor delays in the detection and timely treatment of IBIs. While there was no increase in the delayed detection of IBIs post-implementation, a delayed detection case is very uncommon, and the local study did not have statistical power to address this without participating in a national collaborative. The REVISE II study which included 6549 infants in the pre- and 11159 infants in the post-intervention periods had a similar rate of delayed IBI detection; pre- and post-intervention 0.4% v 0.3%, P=.74.19

By implementing established methods of behavior change the clinical care of febrile young infants at the institution was improved. Strengths of this QI initiative were interventions that were simple to implement that addressed capability, opportunity, and motivation by distilling the information, educating key stakeholders, and decreasing bar-

riers to behavior change. A key strength of this study was its association with a national quality improvement project that provided legitimacy and additional tools to assist with implementation, audit and feedback and stakeholder engagement.

A limitation of this implementation work is that it cannot be excluded that the PEM physicians would have changed their clinical behavior on their own. The AAP CPG was released in 2021, and the interventions were implemented 9 months later. Clinical behavior may have changed eventually, however the dramatic rate of change, especially in the decreased number of lumbar punctures demonstrated in Figure 4 run chart, speaks to the likely acceleration of clinical behavior change affected by the interventions. Additionally, during the implementation phase the institution's urgent care permanently closed due to lack of staffing. Therefore, patients requiring next day follow-up on Sundays or holidays were instructed to return to the emergency department for re-evaluation, and this may have affected clinician behavior. Clinicians may have been inclined to perform additional investigation or consider hospitalization given the lack of scheduled follow-up the following day.

While the primary goal was to implement recommendations of the first AAP CPG on fever management in young infants, another outcome was that local practice variance from national practice decreased. For the national network, the baseline frequency of lumbar punctures in keeping with

the AAP CPG was 78.5% whereas for the local institution it was 17%. With the advent of a nationally recognized guideline and participation in a multicenter collaborative, a rapid and dramatic change was implemented that currently resembles the clinical approach to febrile infants throughout the country. A post-implementation frequency for lumbar puncture performance of 80% was achieved over the entire year but was 92% for the last 10 months of the year.

In addition to developing a method to "safely do less" for infants in Hawai'i, there were a number of mutual benefits the local study had with the national collaborative. ²⁷ The local contribution of patients comprised 10% of the Western region in the national study and while this institution was 1 of 103 hospitals, it provided 1.5% of the data. The local ethnic make-up also adds to the generalizability of the study. Importantly, the statistical power of the larger study allowed the ability to address balancing measures, without which there would be lingering concerns about the safety of the approach. In summary, a local team collaborating with a national network represents a model with documented and potential benefits that is worthy of ongoing support.

Conclusions

A method to "safely do less" for infants in Hawai'i was developed by the implementation of a locally applicable clin-

ical algorithm based on the AAP CPG that leveraged standardized and timely assessment, selective use of diagnostic testing, and optimized patient follow up. Patient clinical outcomes, overall patient experience, and cost to the system were improved. The initiative has fostered a culture of collaboration and continuous improvement across the institution by supporting practice change and future steps include adapting the algorithm to make it applicable to other emergency departments that care for this patient population in the state.

Conflicts of Interests and Disclosures

Cheryl Okado was the REVISE II site lead for KMCWC. Robert Pantell is the first author of the AAP CPG.

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DRESS Syndrome - Rare but Potentially Fatal Drug Reaction

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Abstract

Drug rash with eosinophilia and systemic symptoms (DRESS) syndrome is a rare phenomenon. Review of the literature revealed 2425 DRESS syndrome case reports and only 175 case reports secondary to allopurinol, with this being the first published report of DRESS Syndrome in the state of Hawai'i. This case report describes a Han-Chinese patient diagnosed with DRESS syndrome secondary to allopurinol use, which has been reported to be a high-risk group for allopurinol-related drug reactions. Given Hawaii's unique patient population, compromised of a large Chinese and mixed-race population, it is important to maintain a higher level of suspicion when prescribing allopurinol.

Abbreviations and acronyms

CMV = cytomegalovirus

DHS = drug hypersensitivity syndrome

DIHS = drug-induced hypersensitivity syndrome

DRESS = drug rash with eosinophilia and systemic symptoms

EBV = Epstein-Barr virus

ED = emergency department

HHV = human herpesvirus

PCP = primary care physician

QD = once a day

Introduction

Drug hypersensitivity syndrome (DHS), also known as drug rash with eosinophilia and systemic symptoms (DRESS) syndrome, and drug-induced hypersensitivity syndrome (DIHS) was first encountered during treatment with anticonvulsant drugs in 1936, which remain the predominant cause. The term 'DRESS syndrome' and its diagnostic criteria was proposed in 1996 by Bocquet et al to encompass the association with over 50 drugs. This syndrome is characterized by rash, fever, lymphadenopathy, and single or multiple internal organ involvement. Prompt recognition of this syndrome is crucial given its high associated mortality (10%), as the mainstay of treatment is discontinuation of the offending agent.

DRESS syndrome is a rare but serious delayed T-cell mediated hypersensitivity reaction in response to certain drugs. Most frequently implicated are aromatic anticonvulsants, antidepressants, sulfonamides and sulfones, nonsteroidal anti-inflammatory drugs, antibiotics, and allopuri-

nol.⁴ It has a reported prevalence of 2.8 per 100000 adults and is estimated to occur in every 1000 to 10000 drug exposures.^{4,5} However, it is thought to be underdiagnosed and underreported due to its broad clinical presentation. Common differential diagnoses include Stevens-Johnson syndrome, toxic epidermal necrolysis, and Kawasaki Disease.⁶ With proper knowledge of DRESS syndrome, that usually occurs 2-8 weeks following exposure to an offending agent, the differential can be narrowed.^{7,8}

The RegiSCAR criteria is a widely used scoring system for the diagnosis of DRESS syndrome, which includes acute rash, fever >38°C, involvement of at least 1 internal organ, and blood count abnormalities.⁹ Fever ≥38.5°C is found in 96-100% of cases and usually preceded by cutaneous eruptions, which occur in 85-100% of cases. Eosinophilia occurs in 82-95% of cases.^{7,8} Lymphadenopathies are described in 80% of cases. Among internal organ involvement, the liver is the most commonly involved, in 50-84% of cases, and can range from transient elevation of liver enzymes to hepatic failure, which is the primary cause of death in DRESS syndrome.^{7,10} The substantial mortality (10%) makes early identification essential to halt disease progression and prevent long-term complications. Suggested treatment is prompt discontinuation of the potential culprit drug, supportive care, and immunosuppressive therapy.7

Case Report

A 76-year-old Chinese male with a past medical history significant for diabetes mellitus type II, essential hypertension, stage 4 chronic kidney disease, hyperlipidemia, and coronary artery disease status-post coronary artery bypass graft surgery was seen on 10/03/23 by his primary care physician (PCP) for a regular check-up. His chief complaint at that time was right knee pain of 1 week duration. Arthrocentesis revealed intracellular and extracellular negatively birefringent crystals, consistent with uric acid. The serum uric acid level was 13.4 mg/dL (normal range: 3.4–7.0 mg/dL). The patient was started on 100 mg of allopurinol once a day (QD) on 10/17/23.

On 12/3/23, the patient was examined in emergency department number 1 (ED-1) for a pruritic generalized macular rash, accompanied by fatigue, of 10-day duration. He reported that the rash began on the extremities, then spread to the torso and face. He denied any swelling, fever, joint pain, discharge, insect bites, exposure to new chemicals, clothing, lotions, or other potential sources for his rash.

He was given one dose of dexamethasone and discharged home. Within 24 hours, he developed anorexia and generalized muscle weakness to the point of being unable to ambulate to the bathroom by himself. Two days after ED-1 visit, he was brought to his PCP by his wife. In his PCP's office, he was noted to have systemic maculopapular rashes including palms and soles, tachycardia, cervical lymphadenopathy, and an 8 lb weight loss since his last office visit two months prior. He appeared weak and dehydrated. He was sent directly to another ED (ED-2) from his PCP's office for further evaluation. Labs were significant for blood glucose level of 990 mg/dL (normal range: 70-99 mg/dL), 22000 white blood count cells/µL (normal range: 4000- 11000 cells/µL) with left shift, 36.5% eosinophils (normal range: 0.0-7.0%), reduced estimated glomerular filtration rate of 15 mL/min/1.73 m² (normal range: \geq 90 mL/min/1.73 m²) and mild elevation of alanine transaminase. Hyperglycemia was treated with insulin bolus and drip. Chest x-ray was unremarkable. The patient was admitted to an intesive care unit (ICU) for management of hyperosmolar hyperglycemic state and fluid resuscitation.

During admission the patient experienced fevers with a maximum of 39.9°C and elevation of liver function tests up to 250 IU/L (normal range: 0-40 IU/L). Dermatology was consulted. Additional history revealed the initiation of allopurinol 5 weeks prior to rash onset. DRESS syndrome secondary to allopurinol was suspected on hospital day 2. Allopurinol was discontinued at this time. Serologies for viruses associated with DRESS syndrome including Epstein-Barr virus (EBV), cytomegalovirus (CMV), human herpesvirus (HHV)-6, and HHV-7, as well as the a HLA-B*58:01 were obtained. EBV and CMV serologies were consistent with past infection and the patient was positive for the variant HLA-B*58:01 allele. HHV-6 and HHV-7 were negative.

Prednisone was started at 60 mg. Discontinuation of allopurinol and initiation of prednisone was followed by improvement of fever, rash, and liver function tests. The patient was discharged on hospital day 12 with a tapering dose of prednisone and Febuxostat 40 mg PO QD.

Upon follow-up with his PCP 3 days after discharge, the patient noted continued improvement of his rash in itchiness and appearance and endorsed skin peeling. He denied fatigue and reported he was able to ambulate on his own without assistance.

Discussion

This is a case of allopurinol induced DRESS syndrome with a delayed diagnosis due to this patient's 10-day history of symptoms prior to seeking medical treatment as well as an initial missed diagnosis. On admission, 5 weeks after starting allopurinol, this patient met the RegiSCAR criteria for DRESS Syndrome. The correct diagnosis, discontinuation of allopurinol, and initiation of treatment soon resulted in resolution of symptoms and improvement in labs.

The exact pathophysiology is unclear, but mechanisms that are thought to contribute to DRESS syndrome include a T-cell response to a drug or its metabolites after antigen presentation by the major histocompatability complex (MHC), herpes virus reactivation, and genetic susceptibility associated with specific HLA groups in some ethnic groups. Most notable in this case is the association of HLA-B*5801 with allopurinol hypersensitivity in the Han Chinese population. ¹¹ This is a case of allopurinol-induced DRESS syndrome in a HLA-B*5801 positive, Chinese male, with documented past-infection with EBV and CMV, both herpes family viruses. Additionally, the specific pathophysiology of allopurinol-induced DRESS syndrome is thought to be related to the accumulation of oxypurinol. Thus, this patient's renal insufficiency may have contributed to the development of DRESS syndrome.

Despite resolution of DRESS syndrome with withdrawal of the offending agent, development of autoimmune sequelae has been reported, particularly Grave's disease, autoimmune hemolytic anemia, lupus, alopecia areata, and type one diabetes. ¹² Thus, DRESS syndrome patients should be monitored for signs and symptoms of autoimmune disease in the months-to-years following recovery.

This patient's case highlights the importance of considering DRESS syndrome in patients who present with unexplained fever, cutaneous rash and characteristic lab findings in the weeks following intake of a triggering drug. Clinicians should familiarize themselves with the list of drugs associated with DRESS syndrome and maintain a high index of suspicion when prescribing them to patients, particularly of Chinese ethnicity. Patient education should be provided about the symptomatic presentation of DRESS syndrome when prescribing offending agents so that prompt medical treatment can be sought. A team-based care approach with inclusion of a pharmacist could be helpful in the continuum of care for raising awareness and reiterating potential presentations of DRESS syndrome associated with certain drugs.

Conclusion

DRESS syndrome is a rare drug-induced hypersensitivity reaction that can affect multiple organ systems and can be fatal if not recognized early. Due to its rarity and heterogenous clinical picture that mimics many other infectious or autoimmune conditions, diagnosis can be difficult. Thus, physicians should have a high index of suspicion for patients presenting with cutaneous and internal organ involvement after initiation of an offending drug, so as to not miss this critical diagnosis.

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Conflict of Interest and Disclosures

None of the authors identify any conflict of interest.

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Climate Change and the Lāhainā Wildfires: Raising Global Awareness as Native Hawaiians

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Abstract

On August 8th, 2023, Lāhainā, the first capital of the Kingdom of Hawai'i, experienced one of the deadliest wildfires in US history in over a century. Through historical and cultural data, the role of westernization in Maui's regional climate change is investigated. Since the 1800s, Lāhainā has fallen victim to climate-change-driven human activity. Whaling altered the ocean's carbon sink, the sugar industry diverted water from Native Hawaiian farmlands and increased carbon dioxide emissions, the opportunistic invasive, more flammable grasses predisposed the land to fire, and tourism perpetuated these harmful environmental impacts. Combined with climate change on a global scale, these factors contributed to the destruction in Lāhainā and to the physical and mental toll on its people, especially the Native Hawaiians. This manuscript's primary focus is to discuss the impact on Native Hawaiians given the deep ancestral connection with the land and the ancestry of the authors. As Native Hawaiians, this article serves as a platform for the authors' personal experiences to advocate for climate change awareness as future physicians and to emphasize inclusion of Native Hawaiians in the rebuilding of Lāhainā.

Abbreviations

None

Glossary

Ahupua'a = land divisions from the mountain to the sea

'ai pono = healthy food

'āina = land

Ali'i = Hawaiian royalty

Aloha ' \bar{A} ina = love of land

'auwai = water channels

'eha = pain

Hāloanakalaukapalili = name of taro ancestor of all Hawai-

ian people

'Imi na 'auao = seek knowledge

 $K\bar{a}hea = call to action$

 $K\bar{a}ko$ 'o = support

Kanaka = Native Hawaiian

Kiaʻi = protect

Kuleana = responsibility

Kūpuna = ancestors

Lāhui = Native Hawaiian nation

Loʻi kalo = taro patches

Loko i'a = fish ponds

Mālama = nurture

Nānā i ke kumu = look to the source

Ola mau = perpetuate

Pono = balance

Introduction

"Ola ka 'āina, ola ke kānaka, ola ka lāhui. The health of the land, is the health of the people, is the health of the nation." - Noa Emmett Aluli, MD

Aloha 'āina' is the deep love that Hawaiians have for the land that can be genealogically traced in the creation story from every Hawaiian to *Hāloanakalaukapalili* (name of taro ancestor of all Hawaiian people). This sacred belief establishes the Native Hawaiian familial connection to the land. Any insult to the land causes great 'eha (pain) to the people. This article's primary focus is to explore the impact on Native Hawaiians based on the deep ancestral connection with the land and the Native Hawaiian ancestry of the authors

The article acknowledges all experiences brought about by climate change, however, the first author's ancestral roots in Maui and the first-hand accounts of Lāhainā before, during and immediately after the wildfires provide a profound insight into the effects of climate change to sacred land and its inhabitants.

A history of Lāhainā

Lāhainā or ka malu 'ulu o Lele is located in the West on the island of Maui, the second largest island in the Hawaiian archipelago. Lāhainā is watched over by the Kahalawai mountains, graced with the Ma'a'a wind and nourished by the Pa'ūpili rain. From the valleys of Kahoma, Kanahā and Kaua'ula flowed life-giving water into many 'auwai (water channels) that sustained the entire district. Lāhainā was known as the land of the chiefs and the capital of the Hawaiian Kingdom with 27 ahupua'a (land divisions from the mountain to the sea) created by the early Hawaiians to divide resources among everyone. Ahupua'a was a practice of peace with a collective understanding to share all bounties of land and ocean. Since the land was viewed as



Figure 1. Irrigation Pipes for Pioneer Co. Mill in Lāhainā Circa 1905 Diverting Water from Native Hawaiian Agriculture. Used with permission (Lahaina Restoration Foundation, 2023).⁹

an ancestor, it belonged to no one and was always kept in a state of *pono* (balance).

With Western contact, the land system of *ahupua'a* evolved into one allowing ownership of land,⁴ and Lāhainā became the epicenter of trade and industry starting with whaling. Despite targeting what seemed to be a small portion of the ocean's overall biomass, whaling altered the ocean's ability to store and sequester carbon⁵⁻⁷ sparking climate change in Lāhainā.

When sugar became more profitable than whaling, water was diverted away from 'auwai that supplied the loko i'a (fish ponds) and lo'i kalo (taro patches) of kuleana (responsibility) lands and supplied to sugar lands. ⁸ Kuleana lands are protected lands for Hawaiian farmers and their descendants. To sustain the growing sugarcane industry, foreign businessmen bought more lands in Lāhainā which only consumed more water (Figure 1). ⁹ By the 1940s, almost no viable lo'i kalo remained and the once-flourishing Mokuhinia loko i'a was filled to develop a baseball field (Figures 2-3)^{2,10,11} prompting the generations-long Native Hawaiian to fight for water rights.

The sugarcane industry in Lāhainā continued to operate from 1862-1999 with its dark smoke clouds billowing above town (**Figure 4**). ¹² A carbon emission level of 350 ppm and under is considered by most scientists to be the "safe operating space for humanity" to avoid irreversible climate change. ¹³ From 1958 to 1999, carbon emissions increased from 315.98 to 368.54 ppm, ¹⁴ highlighting the industry's negative impact on climate change. Resource diversion and

carbon emissions were overlooked in exchange for economic growth.

Tourism has now supplanted the sugar industry. In 2020, the Maui County Department of Water Supply's top water users were hotels and resorts with a remarkable consumption of $226\,000$ gallons/day, in contrast to the average use of 400 gallons/day by a single-family dwelling, equating to the water use of 565 single-family homes per hotel in Lāhainā.

Altered biodiversity contributed to the predisposition to fire. Lāhainā is considered a wildland-urban interface where wildland vegetation and houses are in proximity, increasing fire risk. 16,17 This environment is composed of invasive grasses commonly introduced for livestock forage or landscape décor. 18,19 With the decline in agriculture, plantation fields were abandoned, aggressive grasses grew and displaced native vegetation. Invasive grasses now cover 25% of Hawai'i's total land mass which poses a higher fire risk. 19,20 A 2018 book investigating fire ecology cited a Maui resident who said, "We don't even have to ask what the fuel type is if we know the location. Like, if it's at Lahainaluna School, I know it's in cane grass [*Arundo donax L*.] and that it's going to hit the big trees eventually." 21

To investigate the possible implications of climate-aware management of water and biodiversity, a 2019 Maui study conducted climate projections which showed that increased irrigation and conversion of grassland to native forests improved groundwater recharge and mitigated the climate change effects.²²

In addition to human-driven climate change, Lāhainā's leeward location made the area prone to drought. According to the US Drought Monitor, Lāhainā's drought conditions were rated severe with increased annual temperatures and decreased rainfall (Figure 5).²³ When combined with strong winds, devastating wildfires resulted.²⁴ Lāhainā's regional climate change combined with global climate change created the perfect storm (Figure 6).²⁵

The Fire, Aftermath and Resilient Response

The fire burned an estimated 2170 acres of land in Lāhainā. 26 There were 102 confirmed fatalities. 27 This made the Lāhainā wildfires one of the deadliest in US history. 27 The loss of life and 'āina (land) caused climate refugees with many still displaced to this day. Some refused shelter at a hotel and have chosen to stay within their community and the ancestral land. Others were too traumatized to leave their evacuation sites, fearing the sight of their burned homes or the possibility of being denied reentry. A young family shared their experience evacuating; they took separate cars to save both their vehicles. This family was fortunate to be reunited and to have survived. Many families who were separated were not reunited, or worse, did not survive.

Significant hazardous conditions remain. The ash in the air possibly contains cancer-causing chemicals like arsenic, lead, silica, and asbestos, and unsafe water containing volatile organic chemicals. ²⁸ A resident who returned to see what was left of her house sustained serious chemical burns

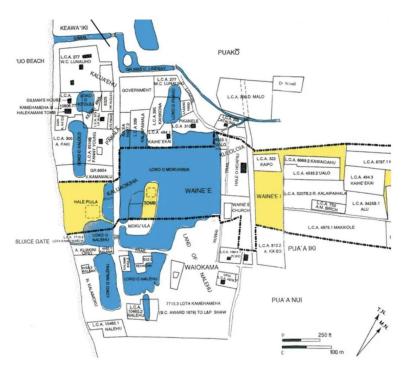


Figure 2. Historical Map of Mokuhinia Fish Pond and the Surrounding Areas in 1879. Labeled as "Loko o Mokuhinia," meaning fish pond of Mokuhinia. Mokuhinia was once a flourishing fish pond in Lāhainā until it was filled to develop a baseball field. Blue shading indicates bodies of water such as fish ponds, streams and canals. Yellow shading indicates landmarks of cultural significance (e.g. Hale Piula was the royal palace of King Kamehameha III, "tomb" is the mausoleum for relatives of Kamehameha, Keōpūolani, Liholiho, Kamāmalu and Nāhi'ena'ena) (Young, 2019).^{2,10}



Figure 3. Mokuhinia Replaced by a Baseball Field Pictured in 2023 Prior to and After Wildfires (Google, n.d.). 11

after discovering a leaking pipe. Lāhainā residents were also threatened by visitors who were attempting to purchase their land.²⁹ Yet, Lāhainā remains strong. The people who lost their homes created community Hawaiian-style hubs, coined "kanaka (Native Hawaiian) Costcos" (Figure 7).³⁰ The leaders of these gathering places were Native Hawaiian families with deep ties to the 'āina of Lāhainā. They were trusted to assess the needs of the community and ap-

propriately distribute resources. Although health care organizations were at the county's distribution centers, locals preferred to visit the hubs. A grassroots Native Hawaiian organization called Mauna/Maui Medic Healers Hui provided the author access to the hubs since they were entrusted by the hub leaders to provide both medical care and alternative medicine options. Families came for medical care, 'ai pono (healthy food), acupuncture, talk therapy, tra-



Figure 4. Pioneer Co. Mill in Lāhainā with Dark Smoke Clouds Circa 1900. Used with permission (Lahaina Restoration Foundation, 2023).¹²

ditional Hawaiian medicine, massage, singing princesses, face painting, and pet therapy. They watched the children play while some wept for the children who cannot. Witnessing the resiliency of Lāhainā will forever shape the authors as future physicians, solidifying our belief that patients have the determination to take their fate into their own hands.

The University of Hawai'i John A. Burns School of Medicine supports climate change awareness through a certificate of distinction in One Health, an elective program that integrates human, animal, and environmental health.³¹ Incorporating disaster-response, psychological first aid, and climate change health effects are warranted in the medical

school curriculum. Disaster response training can be integrated into the emergency medicine rotation, while psychological first aid can be added to the psychiatry rotation. Rural health programs should prioritize these areas given the limited infrastructure and resources, as seen in the flooding in Kauaʻi,³² the volcano eruptions on Hawaiʻi island,³³ and the fires on Maui. Medical schools should consider adding the health effects on climate change to their graduation objectives.³⁴

Conclusion

As Lāhainā continues to rebuild, it is important to look at the past to inform the future. Since western contact, Lāhainā has changed from a landscape of vast 'auwai to dry kuleana lands, from a system of ahupua'a to private ownership, and from a renowned land of the ali'i (Hawaiian royalty) to a tourist destination. It is imperative to reflect on Dr. Aluli's philosophy that the health of this 'āina is the health of our people. As Native Hawaiians, the authors are tasked with the kuleana of aloha 'āina and remains steadfast in the wisdom of our kūpuna (ancestors) which states to take care of the land so the land takes care of us.

The data, research, and history should be used to inform future policies on resource management. The *pono* that the 'āina once held to bring back the health of the lāhui (Native Hawaiian nation) needs to be restored. Climate change awareness among all health care providers is possible by bringing attention to the resolution passed by Indigenous physicians committing to climate justice.³⁵ 'Ahahui o nā Kauka, the Association of Native Hawaiian Physicians, echoed this resolution in a statement rooted in Native Hawaiian values: to nānā i ke kumu (look to the source) of

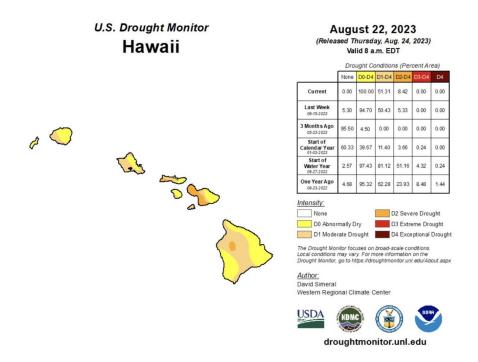


Figure 5. Hawai'i Drought Map August 2023 (U.S. Drought Monitor, n.d.).²³

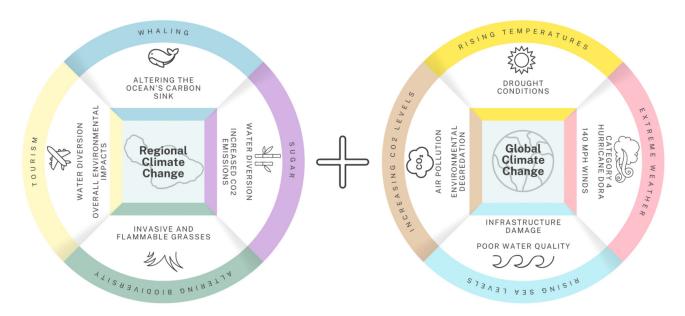


Figure 6. Regional And Global Climate Change Contributing to the Lāhainā Wildfires (Ashley Lee, 2024).²⁵



Figure 7. One of the Resource and Respite Hubs, Dubbed "Kanaka Costcos" in Lāhainā (Ashley Lee, 2023).³⁰

ancestral knowledge, $k\bar{a}hea$ (call to action) the efforts to mitigate climate change, $k\bar{a}ko$ (support) by denouncing harmful policies, kia (protect) by holding industries ac-

countable, 'imi na'auao (seek knowledge) from allies to strategize initiatives, *mālama* (nurture) the development of affirmative policies, and ola mau (perpetuate) sacred places.³⁶ Clinicians must remain attentive to the needs of the Lāhainā community by providing transparency, listening to their stories, and responding to their physical and mental health needs. These community experiences can inform an ethical and culturally informed approach to disaster response.³⁷ As responders, it is important to understand and promote a sense of self-determination by asking what communities lost, what they seek, and what or who will help them achieve their goals of recovery. Above all, Native Hawaiians who are genealogically traced to the land of Lāhainā need to be a part of the conversation to rebuild it. Lāhainā, kukui 'a 'ā mau pio 'ole i ke Kaua 'ula, the ever-burning torch never darkened by the Kaua'ula wind. Lāhainā is resilient and so are her people.

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INSIGHTS IN PUBLIC HEALTH

Weaving Indigenous Methodologies to Enact, Extend, and Innovate Best Practice Survey Measure Development

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Insights in Public Health is a recurring column from the public health community and is coordinated by HJH&SW Contributing Editor Mapuana Antonio DrPH from the Office of Public Health Studies in the Thompson School of Social Work & Public Health at the at the University of Hawai'i at Mānoa and Contributing Editor Nichole J. Fukuda MS from the Hawai'i Department of Health.

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Introduction

Fruits of the global decolonial struggle and ferocious movements such as the Native Hawaiian cultural renaissance of the 1960's and 1970's allowed for the revitalization and resurgence of 'Ike Hawai'i (Hawaiian knowledge, language, practices, values, and culture), 1,2 heralding a powerful generation of Kānaka Maoli (Native Hawaiian) scholars.³⁻⁶ Renowned Kānaka Maoli scholars made waves across various disciplines, and their works continue to inform and inspire Hawaiian researchers and scholarly works today.⁷⁻⁹ One influential example of these efforts include E Ola Mau - The Native Hawaiian Health Needs Assessment, the first comprehensive health assessment primarily conducted by Native Hawaiian doctors and researchers. 10 In addition to identifying stark health disparities experienced by Native Hawaiians, E Ola Mau served as a catalyst to better the health and wellbeing of Native Hawaiians through solutions and recommendations developed by, with, and for Hawaiians, including the integration of traditional Hawaiian practices for health and healing. In today's contemporary society, health disparities continue to persist, many of which stem from structural determinants of health, demonstrating the devastating impacts of continued root causes of inequities that should not be present in today's day and time. 11-13 Landback, demilitarisation, and deoccupation are key to addressing these health inequities at the most fundamental level. The decolonization and Indigenization of social, political, and economic institutions and systems is also central to addressing those health inequities caused by colonialism and occupation.

Measurement is an important site for continuing legacies of Indigenous resistance, especially in the social, behavioral, and health sciences. The movement to decolonize and Indigenize how health and wellbeing related surveys are developed is critical as it gives us the power to tell our stories, using data from our own tools, based on our own lived experiences and in our own unique Indigenous ways.

Decolonizing and Indigenizing are interconnected praxes that, although important, have received little attention in the discipline of psychometrics. While acknowledging that colonization and decolonization are complex dynamic processes and structures that continue to unfold and be (dis)established uniquely across different colonial contexts, there is scope to operationalize these imperatives in the survey development context. The authors hope these following articulations may help to spark dialogue about is-

sues relating to decolonizing and indigenizing within Psychometrics, a central feature of this column.

Decolonizing survey measure development could involve critically examining and rejecting the assumptions, structures, and values that are deeply embedded in mainstream psychometric research, which also stem from colonial logics. This could include addressing harmful notions like neutrality, objectivity, and universality, leveling power dynamics between researchers and participants (eg, communities as co-creators rather than passive subjects), and resisting the academic institutional expectations, incentives, priorities, and values that often direct and dictate research processes and outcomes (eg the "publish or perish" culture that pressures academics to produce quantity over quality).

Indigenizing survey measure development on the other hand, could be more about centering and prioritizing Indigenous knowledges, languages, practices, values, and worldviews in the design, development, and validation of survey tools. This could include taking more community-based participatory research (CBPR) approaches, prioritizing the measurement of Indigenous constructs, enacting Indigenous research methodologies, drawing upon diverse sources of traditional wisdom, and evaluating tools in relation to community and cultural standards.

The purpose of this column is to explore how Indigenizing methodologies are enacting, extending, and innovating survey measure development practices. In this column, the authors share examples of Indigenous survey development research to support the idea that although conventional Western psychometric measures have been useful, new and more appropriate psychometric tools must be developed at the interface of Indigenous knowledges and Western science. Tools that are deeply meaningful to Indigenous peoples and robust from both cultural and psychometric perspectives can only be developed by Indigenizing survey development research.

Indigenizing survey development enacts, extends, and innovates research for all

Enacts. In 2018, Boateng and colleagues published an article outlining best practices for developing and validating scales for health, social, and behavioral sciences. ¹⁴ The authors break the process down into 9 steps across 3 phases (item development, scale development, and scale validation). Mixed-methods research methodologies in the forms of interviews, focus groups, cognitive interviews, and sur-

vey pilots are identified as important steps for identifying domains, item generation, assessing adequacy of items, and testing that the questions are meaningful. These more person-centered, face-to-face approaches are often pedagogically preferred in Indigenous research more broadly, and are often robust in Indigenous measure development research.¹⁵

For instance, *Kānaka Maoli* communities transmitted knowledge intergenerationally through various oral traditions, including rich storytelling and storykeeping practices. These strong legacies are foundational to Hawaiian research methodologies that closely align with qualitative and mixed method approaches. When done authentically, intentionally, and in a *pono* (morally good; upright; and in a rectitude of conduct) way, the research process can facilitate connection, trust, and healing. Developing survey items based on robust Indigenous practices and values, including the incorporation of storytelling and oral narratives, is one example of how Indigenizing this research process can enact best practice survey development.

Extends. Much of health, social, and behavioral sciences research are built upon weirdly scientifically unstable foundations. 16,17 Weird refers to the fact that across the disciplines, the overwhelming majority of research participants have been Western, Educated, Industrialized, Rich, and Democratic (W.E.I.R.D) students from Europe and North America. 16,18 This brings into question the generalizability of many of the longstanding findings, and the scientific rigor of much of the research. 16,17 With more recent research highlighting the impacts of culture on behavior, ^{16,19} biology, ^{20,21} cognition, ^{16,22} emotions, ^{23,24} and language, ^{25,} ²⁶ researchers are making increasing efforts to diversify the participants of their research. 18,27 This speaks to the fact that to understand human health, research must be undertaken with people from all around the globe, especially those who are marginalized and underrepresented in research more broadly.

Research is often Indigenized through taking more collective and community-based approaches. This provides an opportunity to incorporate the voices and perspectives of more diverse and hard-to-reach (for outside researchers) peoples, providing rich and more representative data. Indigenous survey development research often features community-based participatory and co-design methods, resulting in much more iterative and thorough research protocols. An example of this can be seen in research by Howard and colleagues whose psychometric analysis alone weaved together perspectives from their Indigenous Project Advisory Group and multiple collaborative yarns with their Indigenous Research Group at different stages and iterations of the analyses.²⁸ These more collective Indigenous approaches to psychometric development and validation extend conventional procedures and enrich the analysis processes greatly.

In Hawai'i, *Kānaka Maoli* scholars and allies continue to extend the work of health research by moving beyond community-based participatory research (CBPR) approaches by allowing communities to be in the driver's seat and develop research with, for, and by Native Hawaiian communities.

For instance, in the Ke Ola O Ka 'Āina project, the Research Team and Thought Partners co-developed an 'Aina Connectedness Scale to explore the relationship between 'Āina Connectedness, health, and health-related outcomes including resilience.²⁹ The Ke Ola O Ka 'Āina Research Team and Thought partners comprised communities and organizations across the Pae 'Aina of Hawai'i (Hawaiian archipelago) and included broader Hawaiian communities from Waimānalo Community, Mauliola Ke'ehi, O'ahu Island, Hoʻokena Community, Hawaiʻi Island, Maui, Moloka'i, Lāna'i, Kamāwaelualani, and Kaua'i Island. Co-development of the survey required ongoing partnership with, for, and by various communities, including proper permissions and vetting to proceed with the various research processes. In another study, CBPR approaches and decade-long partnerships between academic and community partners led to the development of the Hawaiian Homestead Health Survey research team, who successfully implemented a comprehensive community-based survey in Hawaiian Homestead communities to address community priorities. 30-32

Innovates. The interface of Indigenous knowledge and Western Science has long been recognized as a site of great potential for collaboration and innovation related to knowledge production and global flourishing. ^{28,33} Research sitting at these interfaces often weaves together different cultural concepts, histories, practices, and protocols, resulting in new and unique tapestries of understanding. ⁴¹ The indigenization of survey development research has resulted in the release of a number of new and unique measures that integrate Indigenous languages, concepts, and understandings, using innovative cultural methodolo-gies. ³⁴⁻³⁷

In Aotearoa, the Māori Cultural Embeddedness Scale is one example of how Indigenous scale development research has innovated the measurement of identity more broadly.³⁷⁻³⁹ Issues arising from the conflation of ethnic and cultural identities, and perceived contradictions between being Māori (through genealogy) and being Māori (through enacting cultural values) are addressed through re-examining the issue of identity through a new concept of cultural embeddedness. Cultural embeddedness reflects the extent to which a person has taken opportunities to become embedded in Māori cultural beliefs, values, and practices. This research highlights how bringing the lived experiences of Indigenous peoples to survey development can foster innovation. The many other aforementioned points relating to the Indigenisation process enacting and extending best practice survey development further demonstrate such innovation.

Conclusions

Embarking on the journey to decolonize and Indigenize survey measure development practices, contributes to a greater movement working towards the reclamation of science as a pluriversal project by peoples of the global majority for the collective health and wellbeing of everyone and everything that co-inhabits this earth.

An initial step that all can take on this journey is to identify, critically examine, and work to deconstruct the often invisible cultural and societal assumptions, priorities, values, and worldviews that underpin current approaches and practices. This allows people to reflect upon how they personally relate to these paradigms, better positioning them to decolonize and Indigenize survey development practices. To see more Indigenizing methodologies enacting, extending, and innovating best practice, 'Western Scientists' must exercise greater epistemic humility and make more room for Indigenous knowledges and peoples within academic and research institutions.

This insights column highlights the fruits of Indigenizing survey measure development for both Indigenous communities and scientific fields more broadly. The matters raised in relation to the themes enact, extend, and innovate are mere starting points in a broader conversation. They barely scratch the surface in describing the true benefits of

Indigenizing measurement processes to public health research and in addressing the persistent health inequities amongst Native Hawaiians and our other Indigenous relations, from across the Pacific.

We the authors want to close this column with an affirmation and reminder that us as Indigenous peoples have long been experts in measurement, utilizing everything from the movement of the stars, ecological cycles, objects fashioned from nature, and parts of our own bodies to measure changes in things that matter to us. Measurement will continue to be an important practice for us Indigenous peoples, especially in research contexts, as we continue to Indigenize survey development practices with and for Indigenous peoples. Finally, when researchers enact, extend and innovate best practices in any form of measurement, we honor our Indigenous ancestors, and make both our Indigenous ancestors and our future generations proud.

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