

E Nā Pua o Ho'okaulike---
aloha pumehana kākou
mai ka lā hiki a ka lā kau.

Warmest greetings to you---
from where the day begins to
where it settles in the
darkening stillness of the
night.

As we meet he alo he alo
(face-to-face) ---we share the
ha (breath of life).

Aloha! E kipa mai!
Greetings! Welcome!



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Le Malaga.

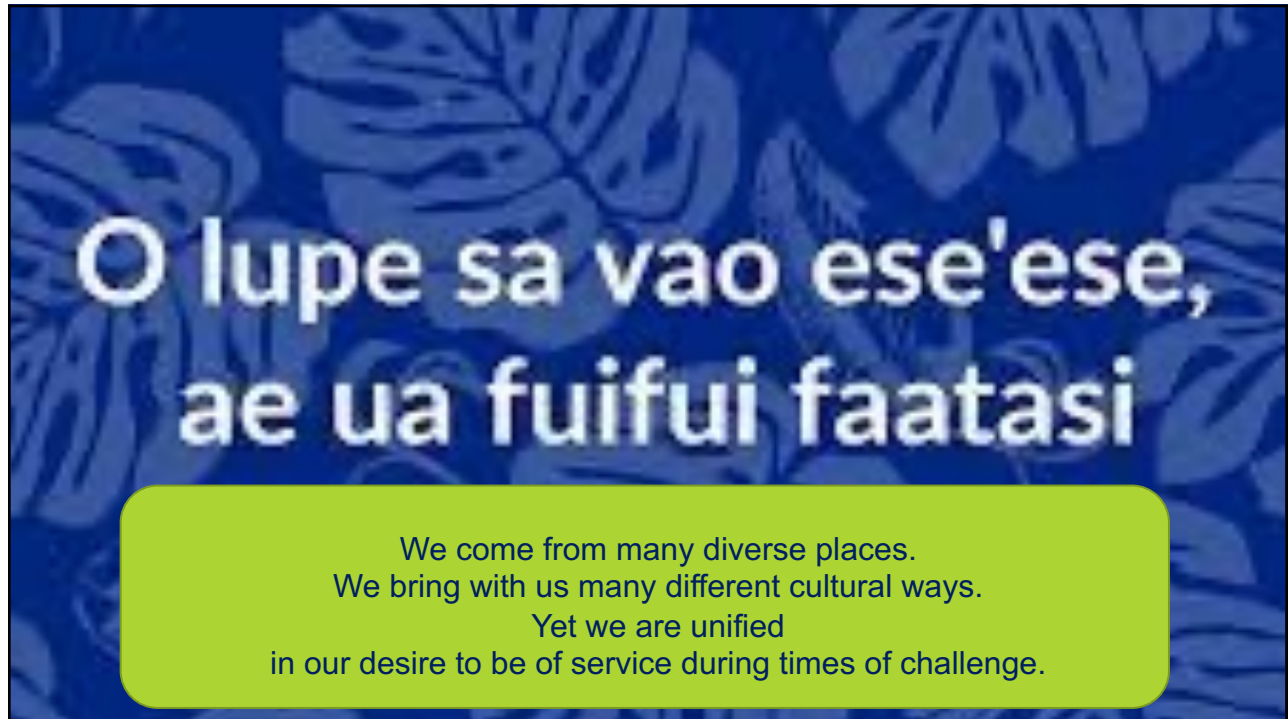
The Journey to Strengthen Health Literacy &
Research Capacity in a Culturally-Rich, Resource-
Constrained Community



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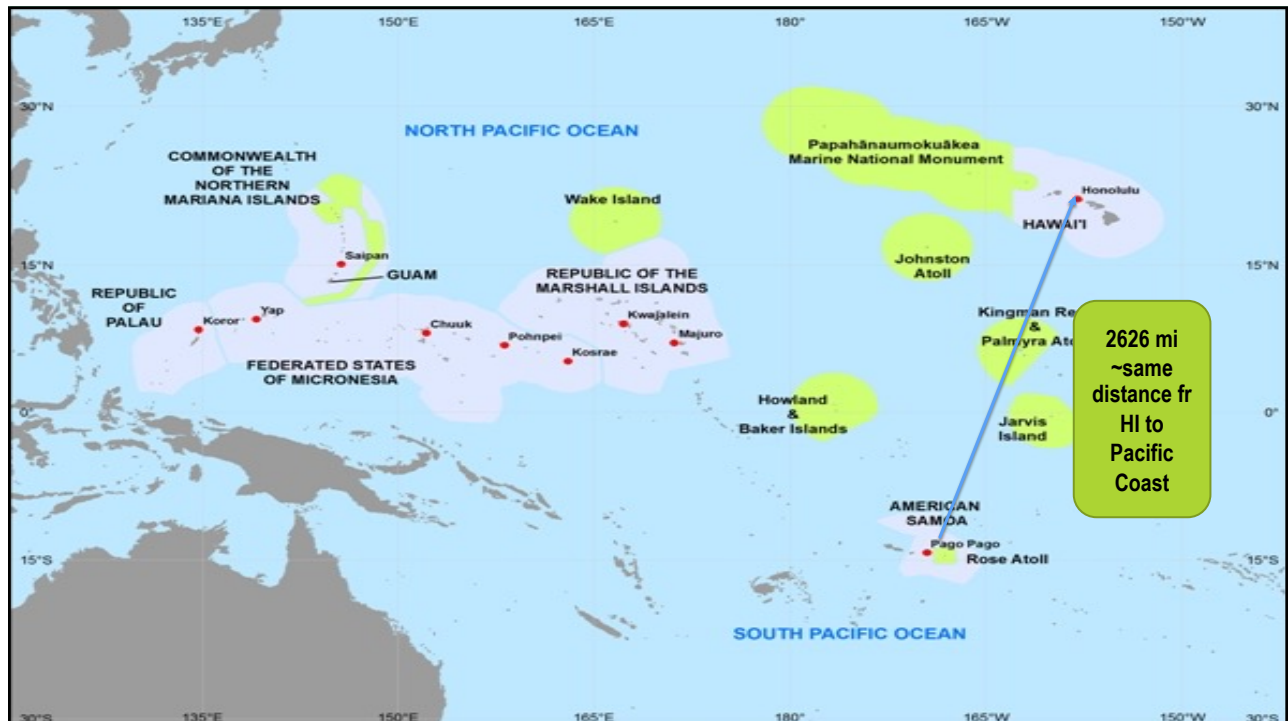
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**JOURNEYING TO STRENGTHEN
CULTURAL HEALTH LITERACY**

Focus 1.
American Samoa is described as culturally-rich, yet resource-limited. In what ways might this be similar to the community (communities) in which you work.

Focus 2.
Literacy refers to knowledge and attitudes that encourage action. Eight literacies are identified. Identify 1 that you would like to learn more about.

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Culturally-Rich, Yet Resource-Constrained


INSPIRE Honored & Introduced through Traditional Kava Ritual

Kava ceremony is a solemn ritual that distinguishes an important occasion. It includes speeches, oratory, and the formal preparation, serving, and sharing of the kava beverage.



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Social Determinants of Health



SES
*Gross National Income Per Capita = \$4126-12,735; many live below US poverty level.
*Medicaid operates under broad waiver—eligibility not determined on individual basis.

Territorial Status
*Non-voting representation in Congress.
*No birthright citizenship; cannot vote for US president.
*Need long-term solution to investment & industry.

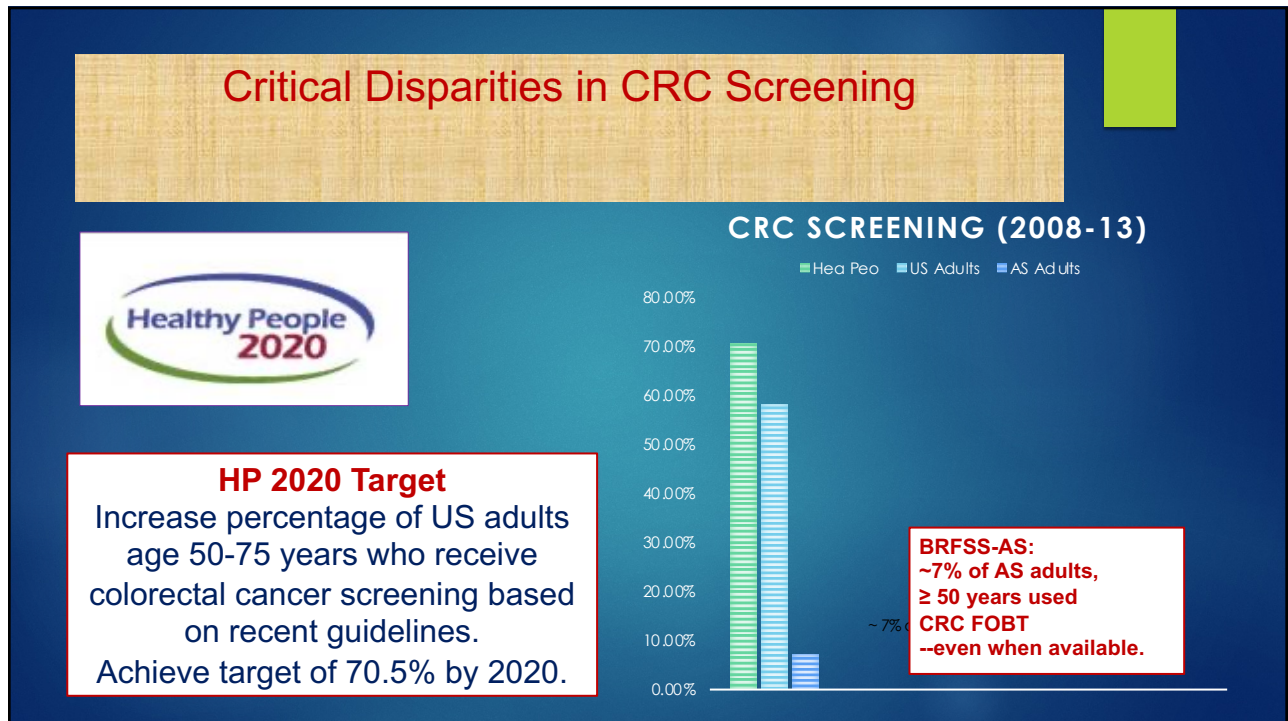
Severely Constrained Budget
Lack cancer care services
Need for off-shore tx referral

Lack of Research Infrastructure
compromises success in competing federal research grants, even when AS is eligible.

Limited data
to direct health policy, promotion, and practice.

Limited career pathways
lead to “brain drain”.

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Premature and avoidable mortality led to initial efforts on developing linguistically appropriate and culturally respectful prevention education.

Loss to f/u is problem--- increased efforts to help patients & family members understand and complete treatment... either in AS or “offshore”.

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Salilo Julia Foifua, LSW, PsyD, & Faletua served as first patient navigator.

“**Tautai** refers to steering or navigating (a canoe) and **lavea'i** refers to rescue or help that extricates one from harm.

We want to provide help that extricates a breast cancer patient from the harm of advanced cancer or death and help guide them to a safe, healthy course.”

Tautai Lavea 'i

- ❖ **Pilot PNP** supported by NCI funding, American Recovery and Reinvestment Act (ARRA) supplement. City of Hope Med Ctr in LA provided in kind support..
- ❖ **Hospital-based PNP**--- designed to reduce **loss to f/u** and increase **timely receipt of cancer services**.
- ❖ Tautai Lavea'i provides **linguistically-appropriate, culturally-grounded** supportive services including: risk assessment, support groups, individual, family end-of-life counseling, & financial subsidies for “off-shore” care.

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E manaomia ai se nu'u!
It takes a village!

Helping the people of American Samoa fight cancer


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Fa'afaletui


Fa'a refers to use of established methods, communal traditions, and networks

Fale refers to a house or place and

Tui refers to weaving, creating, building, or threading.



Samoan social scientists are using terms like **fa'afaletui** and **lalaga** to describe culturally-derived methods of creation—akin to the tradition of plaiting fibers into a fine mat or **weaving** blossoms into a single lei.

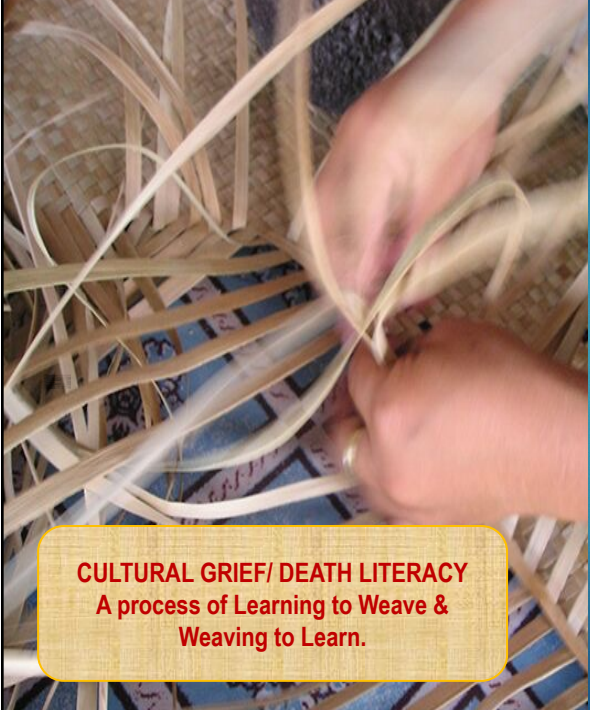


INSPIRE seeks to weave together the rigors of Western scientific method with the traditions, ways of knowing, and social networks of Indigenous Samoans. Our story begins in the cradle of the Pacific...

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O Le FILIGA E AMATA I LE OGATOTONU
When learning to weave, be **DILIGENT** ---BEGIN at the Center


1. Caregiving for the sick & dying.
2. Funerals & other ways to honor the dead.
3. Religion, Spirituality, Aethism, Agnosticism.
4. Grief Expressions & Cultural Variations.
5. Real & Symbolic Loss (e.g., roles, partners, careers, income, leaving home/homeland).
6. Children (parental loss of a child; children grieving loss).
7. Role or acceptance of professional helping and/or professional services in caregiving, suffering, grief, bereavement.
8. Beliefs about life after death.

Anngela Cole & Ka'opua, 2021; Ka'opua, Scanlan, & Yim, 2022 .

CULTURAL GRIEF/ DEATH LITERACY
A process of Learning to Weave & Weaving to Learn.

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CDL #5
Real & symbolic loss



Cultural Death Literacy Reflection

Going home to die is a desire common among people across cultures.

For Samoans and other Pacific Islanders living in the diaspora—dying at “home” means going back to their native islands...re-uniting with ancestors and communities that follow traditional rites.

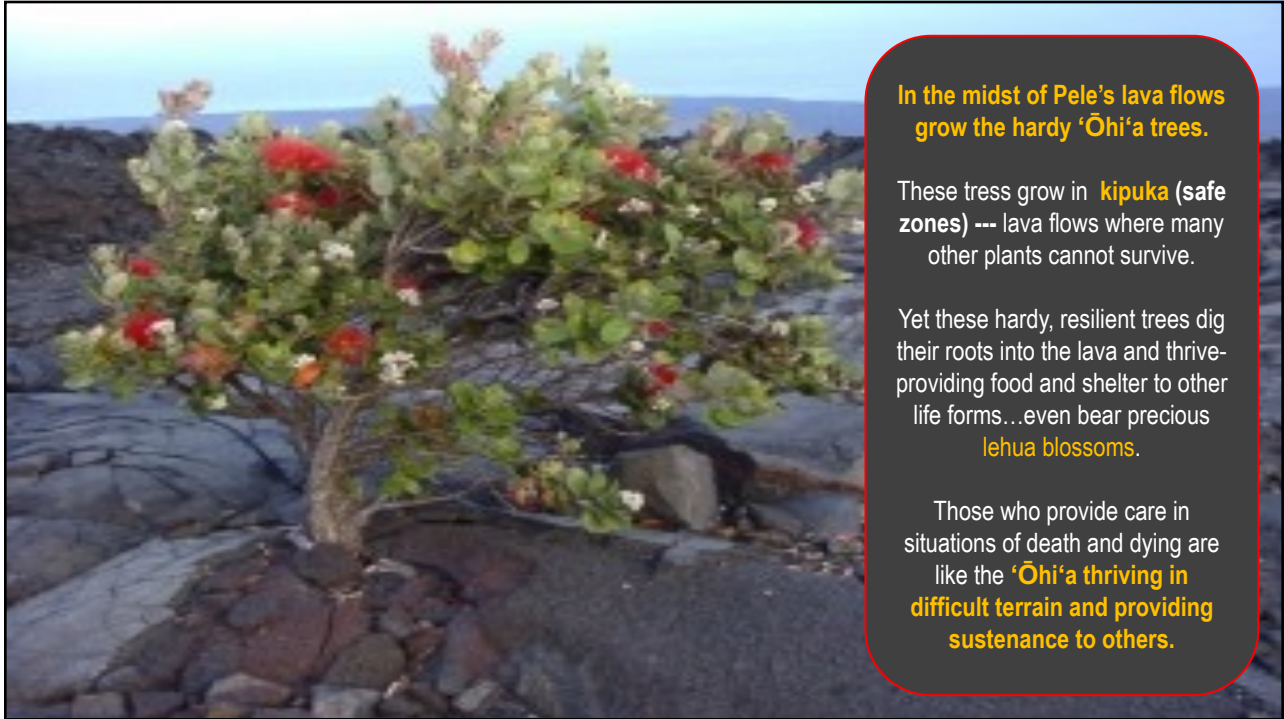
From your cultural lens---

Is there a “middle ground”
if dying at home isn't possible?

• “I Just Want to Go Home”

- **Background.** Mareta is a 39 y.o. Pacific Islander female of Samoan ethnicity. She was born and raised in the culturally-rich, yet resource-constrained Territory of American Samoa. Due to limited employment and educational opportunities, Mareta, her husband Ioane, and their two children relocate to a U.S. state.
- The family adjusts well to their new environment. Mareta operates a small business within her home and is active with the local Samoan church. Ioane secures employment in a unionized hotel; the family has access to excellent health care. The children have made exceptional academic and social progress in middle school. They support the household through feau (chores).
- **Diagnosis & Medical History.** ~18 months after re-location, Mareta complains of chest pain and breathing difficulties. She is taken to the local hospital and diagnosed with **Cervical Cancer, Stage IVB with metastasis to the lungs**. She is hospitalized and given a one-year prognosis.
- As the year progresses, Mareta becomes vehement about going home to American Samoa. HCP strongly discourage air travel as it poses a significant medical risk. She threatens discharge against medical advice. One physician speculates that she has limited decisional capacity and orders a psychiatric evaluation. **“This is the last straw,” states Ioane. “My wife is not crazy. She just wants to go home. Can't you give a dying person their last wish?!”**
- **Assessment/Planning.** The social worker on the Interprofessional Palliative Care Team (IPPCT) meets with Mareta to learn about **cultural death literacy from a Samoan perspective**. SW learns about Mareta's deep connection to the homeland, ancestors, and elders. The sw listens to Mareta's stories of **le fa'alavelave** (interruption in daily life) ---the many rituals involved in honoring the dead... community prayer, family meals, weaving of **ie toga** or fine mats.
- The IPPCT meets with Mareta, Ioane, and members of their community to discuss 'what' might be done. **They settle on a plan which weaves Indigenous cultural customs with current health constraints.**

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In the midst of Pele's lava flows grow the hardy 'Ōhi'a trees.

These trees grow in **kipuka (safe zones)** --- lava flows where many other plants cannot survive.

Yet these hardy, resilient trees dig their roots into the lava and thrive---providing food and shelter to other life forms...even bear precious **lehua blossoms.**

Those who provide care in situations of death and dying are like the **'Ōhi'a thriving in difficult terrain and providing sustenance to others.**

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Like the hardy, resilient 'Ōhi'a many of us support others in rough terrain.
We don't just survive. We often thrive!

We close with the gentle reminder that we are not 'Ōhi'a trees.

**While serving others, let us (re)commit to also caring for ourselves.
E mālama pono!**

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O Le FILIGA E AMATA I LE OGATOTONU
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Bio-Psychosocial/Spiritual History:

- **Mareta is a 39 y.o. female of Samoan ethnicity from the Territory of American Samoa.** She is a U.S. National. Due to limited employment and educational opportunities, the family re-located to a U.S. state about two years prior to Mareta's hospitalization.
- Mareta works within the home and is active with the local Samoan church. loane secures employment as a sous chef in a unionized hotel. His benefits include medical coverage for the entire family.
- The children are described as making good academic and social progress, active with their church youth group, and support the household through feau (routine chores).
- Contact with A.S. dwelling family is maintained through weekly voice or video calls. **About one year after re-location, Mareta complains of chest pain and breathing difficulties; she is taken to the local hospital.**

Diagnosis: Cervical Cancer, Stage IVB with metastasis to the lungs.

- One-year prognosis.
- Due to family's work and school schedules, she is hospitalized for respiratory difficulties and serviced by the Interprofessional Palliative Care Team (IPPCT).

Psychosocial/Spiritual Issues: As one-year prognosis decreases to a few weeks, Mareta consistently states: **"I just want to go home... now!"** Doctors strongly discourage air travel as it poses a significant medical risk. **Crisis ensues. Mareta threatens discharge against medical advice.** The IPPCT physician speculates that she has limited decisional capacity. A psychiatric evaluation is ordered. **When loane learns of the referral, he strenuously objects: "This is the last straw. My wife is not crazy. She just wants to go home. Can't you give a dying person their last wish?!"** You meet with Mareta in hopes of better understanding her **cultural death literacy.** You hope to find ways of meeting Mareta's overall needs. You learn the importance of dying in the ancestral lands and le fa'alavelave as ritual for honoring the person who has died and giving le 'aiga/potopoto the opportunity to collectively grieve. (Ka'opua, Scanlan, & Yim, 2022)