

ABSTRACT

I ka wā ma mua, i ka wā ma hope. This Hawaiian saying reminds us that to move forward, we must remember and learn from what has come before. Many of us remember and are able to visualize the pivotal violence that caused George Floyd to literally, lose the breath of life. **For many of us--- such incidents “call up” historic trauma. In the New Normal, we witness the breadth of death owing to COVID-19, assault weapon violence, and environmental disasters exacerbated by social inattention. In the New Normal—we continue to witness disproportionate criminalization, incarceration, & premature mortality of Native Peoples.** As navigators and helping persons--- we cope simultaneously with patient/client losses/deaths, our own personal ones, and the challenge of finding closure in the so-called New Normal.



Weaving to learn. Learning to Weave. In this offering, we commit to ensuring a safe space for reflection on grief, death, and dying through the lens of **Cultural Grief & Death Literacies (CGDL)** -- a family of 8 critical ways useful to navigating the breath of life and breadth of death across diverse health conditions, socioeconomic circumstances, and cultural contexts. **“Cultural Grief & Death Literacies. Learning to Weave, Weaving to Learn Essential Life Literacies” refers to an optimal strategy for resolving cultural conflicts in contentious medical situations,** as demonstrated in the case of a dying Samoan patient who against medical orders, seeks to fly home and spend her last days with the ‘aiga potopoto (ancestral community) in her homeland of American Samoa.

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CULTURAL GRIEF & DEATH LITERACIES

LEARNING TO WEAWE & WEAIVING TO LEARN ESSENTIAL LIFE LITERACIES

Lana Sue I. Ka'opua, PhD, DCSW, LSW

Professor Emeritus-University of Hawai'i-Mānoa

Community Advocate, Community-Based Participatory Researcher & Author

Convener-Social Work & Health Inequalities Network

Research Mentor, Indigenous Samoan Partnership to Initiate Research Excellence (INSPIRE)

Recent Past Visiting Indigenous Scholar, Charles Sturt University

Board Member-NASW-HI & the Wisdom of Kalaupapa Education Project

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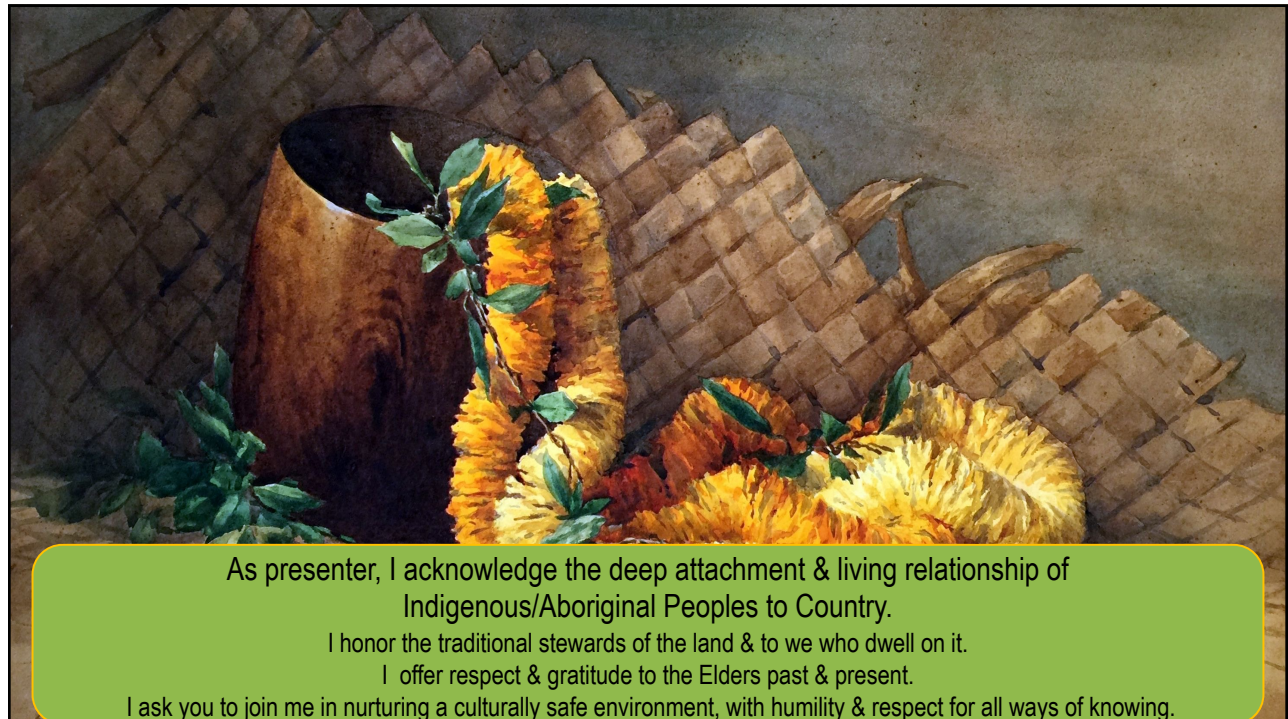
PRESENTATION/DISCUSSION AIMS

By the end of this presentation/discussion, be able to:

Aim 1: Describe 1 thing learned about “the breath of life and breadth of death” in the case study on Cultural Grief/Death Literacy.

Aim 2. Literacy refers to knowledge and attitudes that encourage action. Eight Cultural Grief/Death Literacies are identified. Identify 1 that you would like to learn more about.

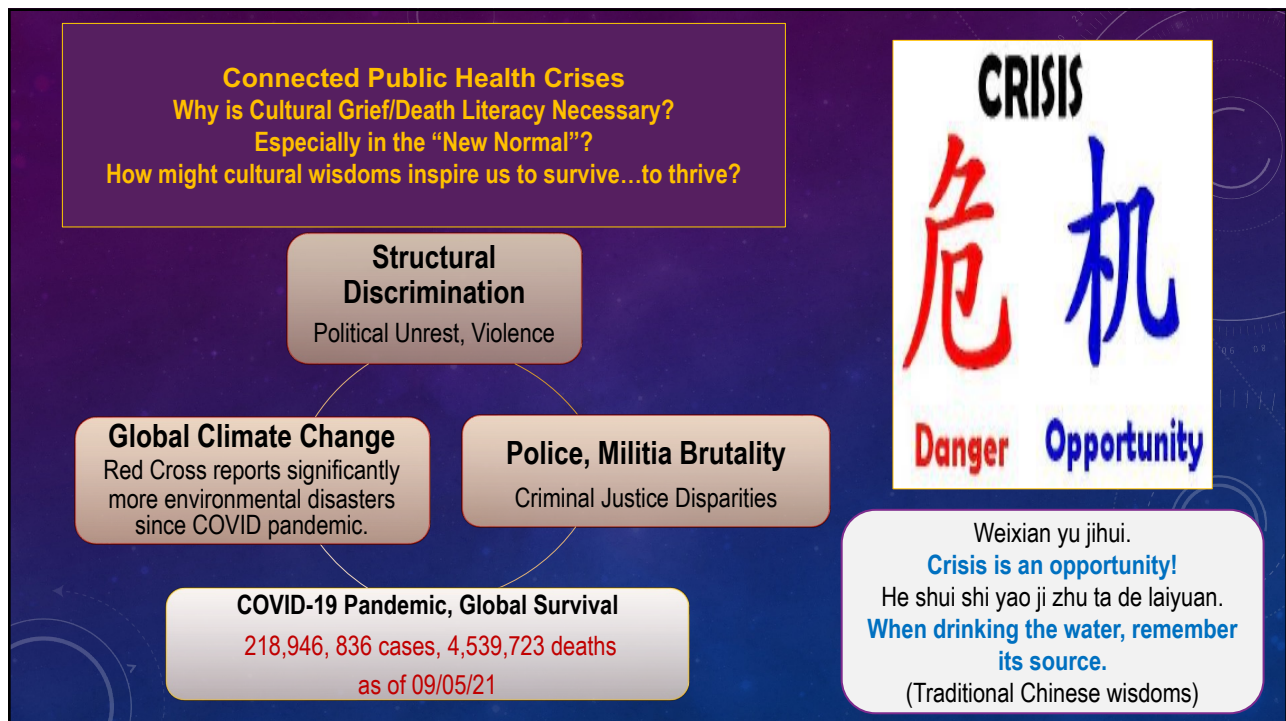
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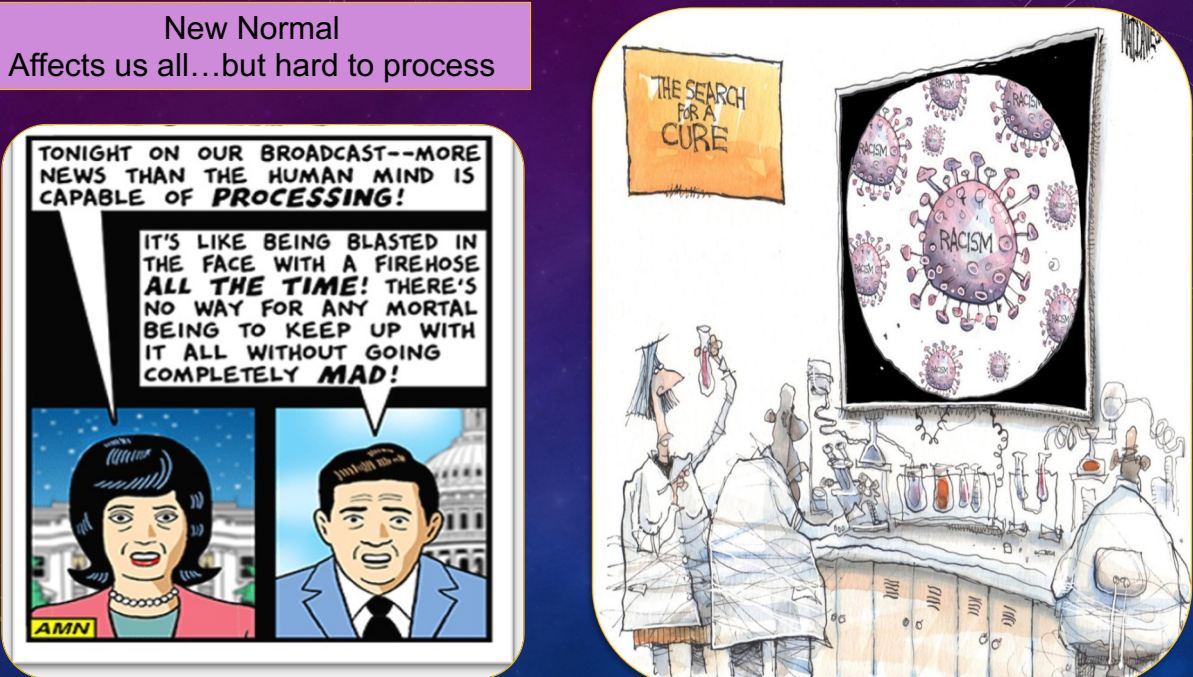


POLL:
From your personal perspective, what is a "Good" death? "Bad" death?
Across these diverse experiences--- what are your strengths? In what situations?
Kumu Linda B will monitor the Chat Field and Relay Group Responses

#1. Aging Parent & Adult Child, #2. George Floyd held down by Derek Chavin, #3. Family gathering, #4. Parents surround ailing child, #5. Healthy child dies unexpectedly—feels no pain, #6. Elder dies in congregate living; cannot see loved ones, cannot say "goodbye".

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New Normal
Affects us all...but hard to process



TONIGHT ON OUR BROADCAST--MORE NEWS THAN THE HUMAN MIND IS CAPABLE OF **PROCESSING!**

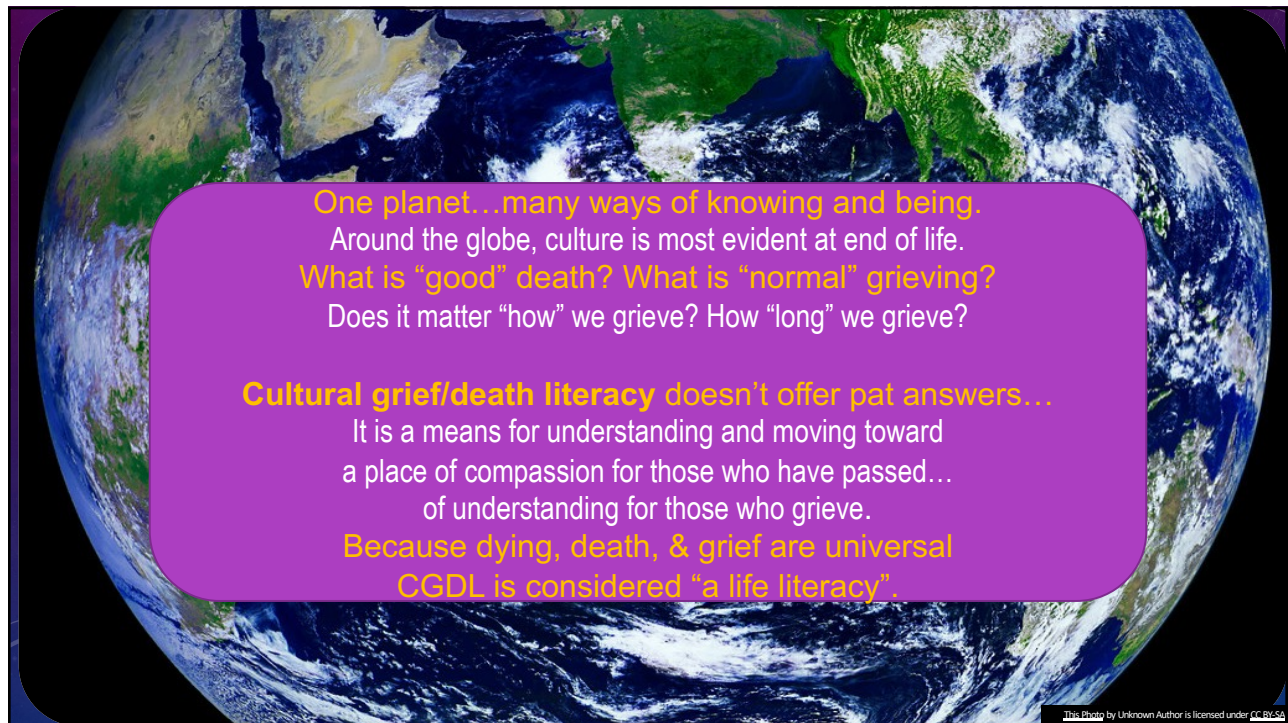
IT'S LIKE BEING BLASTED IN THE FACE WITH A FIREHOSE **ALL THE TIME!** THERE'S NO WAY FOR ANY MORTAL BEING TO KEEP UP WITH IT ALL WITHOUT GOING COMPLETELY **MAD!**

AMN

THE SEARCH FOR A CURE

RACISM


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WHAT IS CULTURAL GRIEF/DEATH LITERACY?

- Knowledge and skills to access, learn, understand other perspectives, & **act on end-of-life and death care options**.
- People and communities with high levels of death literacy have **context-specific knowledge** about the death system and able to apply knowledge to real life.
- DL ideally is **portable and salutary** resource for individuals & communities.

(Noonan et al, 2016)

Tōrō Nagashi
Candle-lit lanterns released to rivers/ocean & guide travel of departed

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CULTURAL GRIEF/ DEATH LITERACY
We identified these literacies through our practice, teaching, and readings.
In CGDL, we found it essential to:
Learn to Weave & Weaving to Learn.

1. Caregiving for the sick & dying.
2. Funerals & other ways to honor the dead.
3. Religion, Spirituality, Aethism, Agnosticisim.
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.

These 8 literacies are derived from our literature reviews, our own research, and learnings from our elders, teachers, students, and families whom we have served.
Anngela Cole & Ka'opua, 2021; Ka'opua, Scanlan, & Yim, 2022.

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<p>CDL #1. CAREGIVING FOR THE SICK & DYING</p>	<p>“She Needs to Eat!”</p> <p>Leilani is a 90 year old woman of part-Hawaiian ethnicity. Identifies as “local” (born in Hawaii, with many years of residence & from a working-class family, bi-lingual in standard and Pidgin English.</p> <p>She has been physically and socially active for most of her life. She especially has enjoyed cooking and sharing the fruits of her labor with others. Currently, she has difficulty walking and refuses to eat. Her physician has given her a diagnosis of anorexia. She is certified to receive home hospice care and receives parenteral nutrition (fed through her veins).</p> <p>Kalei is her adult daughter and has a nursing background. She has taken a leave of absence from work to care for her mother. As a healthcare professional, she understands the clinical issues. But as a family member, her kuleana (responsibility) has been to care for others—especially those who are elderly or incapacitated. She has difficulty watching her mother continually refuse food.</p> <p>Weary and worried, she exclaims: “Mama needs to eat but she just won’t...even when I fix the things she likes. It’s so frustrating, she needs to eat!”</p>
	
<p>Cultural Death Literacy Reflection</p> <p>Feeding/eating are relatively common issues in home health care.</p> <p>From your cultural lens---</p> <p>What is the meaning of feeding others?</p> <p>Of refusing to eat what is offered?</p> <p>Is Kalei’s response one of denial?</p> <p>Of anticipatory grief (grief occurring before loss/death)?</p>	

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CDL #2. FUNERALS AND OTHER WAYS TO HONOR THE DEAD



Cultural Death Literacy Reflection

From your cultural perspective---

What might a hospital/healthcare system do to ensure that a person's cultural traditions are respected across the continuum of care? Of life?

From your cultural lens---

How might ensuring funeral practices in Ghana have helped this family's grief?

"Try to Do Better Next Time"

Kisi is a 14 year old female student from Ghana, on a three month vacation visiting relatives in Reno Nevada USA. She becomes very ill two months into her stay, passed out, was hospitalized, and then dies in the hospital. She had a history of sickle-cell anemia, and could not survive this latest bout.

Reaction from her Aunt and Uncle: Her aunt and uncle brought her to Reno for the summer. Kisi was a promising student and athlete. Her Aunt was trying to make arrangements for her to finish high school and enroll in college on the U.S. mainland. The child's death while in their care brings shame to them, and in their grief, they also attempted to reduce their shame by making sure all cultural practices are properly attended to. The most important one is that Kisi's body be returned to Ghana.

Reaction from Hospital: When Kisi was brought to the hospital, she was unresponsive and never woke up. When she passed out, she was with age-mate cousins, and no adults. Therefore, after her death, the hospital did not want to release her body for transport to Ghana, but rather, insisted on autopsy. This was in direct contrast to the Aunt and Uncle's wishes, and her relatives in Ghana. Cutting into the body is sacrilege, and again, the importance of immediate body transport is imperative.

Aunt's Reaction: Kisi's Aunt presented to hospital personnel with rageful grief. When facing resistance from the hospital workers to release Kisi's body for transportation, Kisi's Aunt's reaction included yelling, screaming, and wailing among hospital personnel. They took her to a private room, and "tried to get her to understand their point of view, and U.S. regulations about unattended death". Initially, no one was listening to Kisi's Aunt in her state of profound grief.

Resolution: After several days, one of the hospital social workers who had travelled to Ghana during a college student exchange program, suggested that Kisi's Aunt be "listened to", to determine all of her concerns and needs right now. In addition, this social worker insisted on having a cultural representative present to help hospital staff understand the importance of the requests Kisi's Aunt was making. Although too many days had passed to have the body transported back to Ghana without embalming, Kisi's body was able to be transported back without autopsy.

Follow-up: Kisi's family sent photos back to the hospital after funeral services, in hopes that the hospital workers would more deeply understand the importance of a proper Ghanaian funeral.



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CDL #3-4. RELIGION, SPIRITUALITY & GRIEF EXPRESSIONS/CULTURAL VARIATIONS



Cultural Death Literacy Reflection

From your cultural perspective---

What is a "bad death"?

Is there ever any way that survivors might make peace with a "bad death"?

From your cultural lens---

What helps family members recover from the "bad death" of a loved one?

When is spiritual intercession "appropriate"?

Is it "enough"?

"Heart Pain"

Pastora is 50-years old Pilipina. She migrated from the PI to Hawai'i about 30 years ago. She presents at the community health clinic with complaints of "heart pain". The PCP finds no physical abnormalities and refers her to the clinic psychiatrist. She is fluent in 3 Pilipino dialects and speaks English well. Nonetheless, she is most comfortable when speaking in dialect.

She explains that the spirit of Antonio, her deceased son is causing disturbances in the home. He is trapped and cannot move onto "the next world". The psychiatrist renders a diagnosis of **Major Depression with Psychotic Features**. Anti-psychotic medication is prescribed and a return visit to clinic scheduled.

When Pastora misses her appointment, the social worker visits Pastora in her home— notably, located in a community known for its use of manufacture and dealing in "batu", "ice" or crystal methamphetamine. **The social worker meets Pastora's family and learns that all members are experiencing "disturbances". They seek a spiritual intercession that will permit their family member to "move on".** They are ashamed to approach their parish priest. They disclose that Antonio was in trouble with dealers and had committed suicide. They seek a "spiritual intercession" that might release Antonio to the next world. They request a Native Hawaiian minister.


A Hawaiian minister/substance abuse counselor agrees to help. He and the social worker conduct a **ho'oponopono** (spiritually-based, family problem-solving). This is followed by the minister's "cleansing" and blessing the home with wai (fresh water), pa'akai (Hawaiian salt), and ti leaf.

After the ho'oponopono Pastora no longer complains of heart pain. The disturbances have ended. Antonio is understood to have "moved on". As is common in their Pilipino tradition, the family celebrates his passing by sharing traditional foods and song.

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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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**CDL #7.
ROLE OF ACCEPTANCE OF
PROFESSIONAL HELPING /
PROFESSIONAL SERVICES**



Cultural Death Literacy Reflection

From your cultural perspective---

Is there another way SW services might be offered? Was it OK to show up unannounced with nurse?

From your cultural lens---

Is there any benefit to not acknowledging the impending death?

From the lens of hcp specializing in practice with the elderly---

****Ethno-geriatricians at Stanford School of Medicine (2021)** emphasize desire for order and peace in traditionally-oriented Japanese. How might this dynamic be at play?

****Shikata ga nai** (I=it cannot be helped) is discussed as a means for accepting that which cannot be changed. Some Japanese elders suggest that this value is not a fatalistic belief. They explain that “it cannot be helped” generally may be followed by “so let's accept the present and do the best we can.” (Ka'opua et al., 2005).

Might you explore “shikata ga nai” with the couple?

Is There a Cultural Meaning to “Not Talking”?

Mr. & Mrs. Kamemoto: Mr. Kamemoto was an 89 year old Japanese man who had resided in Hawaii for over 60 years. He lived with his wife. Grown children and grand children on the U.S. continent. He was dying from cancer and had Hospice service.

History with Hospice: Mrs. Kamemoto did not want to have people come into their home to care for Mr. Kamemoto; however, the challenges of in-home caregiving were too much for Mrs. Kamemoto alone. She reluctantly agreed to allow Hospice nurses to come in 2X per week. Nurses felt social service also were needed and asked for a social worker.


Social Worker Involvement: The social worker was politely denied entrance into the home on three occasions. But when paired with a nurse, SW was allowed to enter the home. Mrs. Kamemoto asked to speak to the SW alone before seeing her husband. She agreed to the SW that visit but stated: **“Do not mention that he is dying, because he does not know this yet!”**

The SW then went to see Mr. Kamemoto. He was grateful to have someone with whom to talk. **“because my wife does not know I am dying, so I have no one to talk to about my dying”.**

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CDL #6 & #8.
CHILDREN: EXTENT OF INCLUSION IN GRIEF PROCESS & BELIEFS ABOUT LIFE AFTER DEATH



Cultural Death Literacy Reflection
From your cultural perspective---
Good death, bad death?
If dying person has what is requested at time of death, is anything else needed to establish "good" or "bad"?

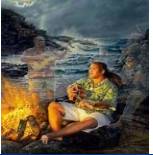
From your cultural lens---
Is there any harm in the inclusion of children at the time of a family member's death?

"Don't Worry. I'll Be With the Ancestors"

Kainoa was a 43 year old male of Native Hawaiian / Pilipino descent. He was the father of six children, ages 3 – 11 years old. He and his family had a hospice service due to his declining health and terminal cancer diagnosis.


Family situation: Family of nine (including grandmother) lived in a 3-room house in a remote valley on Oahu, HI. The family got by financially due to Kainoa's ability to work part-time jobs. When he became sick, the household relied on food programs for sustenance. They received Hospice services pro-bono. Family members were very close, without much outside influences; adhered to Native Hawaiian cultural practices.

Time of Death: As Kainoa became weaker, I asked him who he would most like to have with him when he passes. He said **"no worries – my ancestors will be here"**. I asked who else he would like, and he said **"of course my children, my wife"**. I asked him which children, and he said "all, of course". He then asked for a "Kahuna" (traditional spiritual healer/priest) to help him gather with the ancestors. All of this was arranged and at the time of death, Kainoa and his wife asked me to stay... that is, until the very moment of his impending Death. Then, his wife, children, and I were asked to leave the room. Only the Kahuna remained---staying with Kainoa until he died and joined his ancestors.



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REAL & SYMBOLIC LOSS



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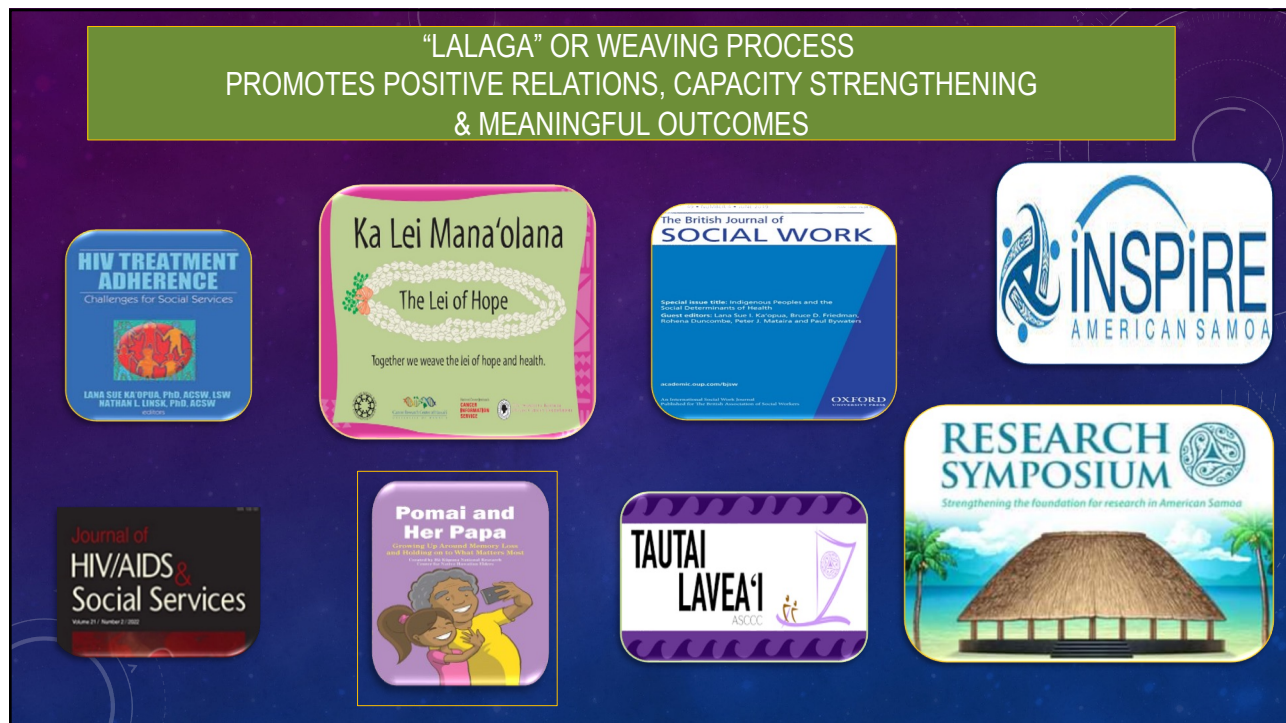
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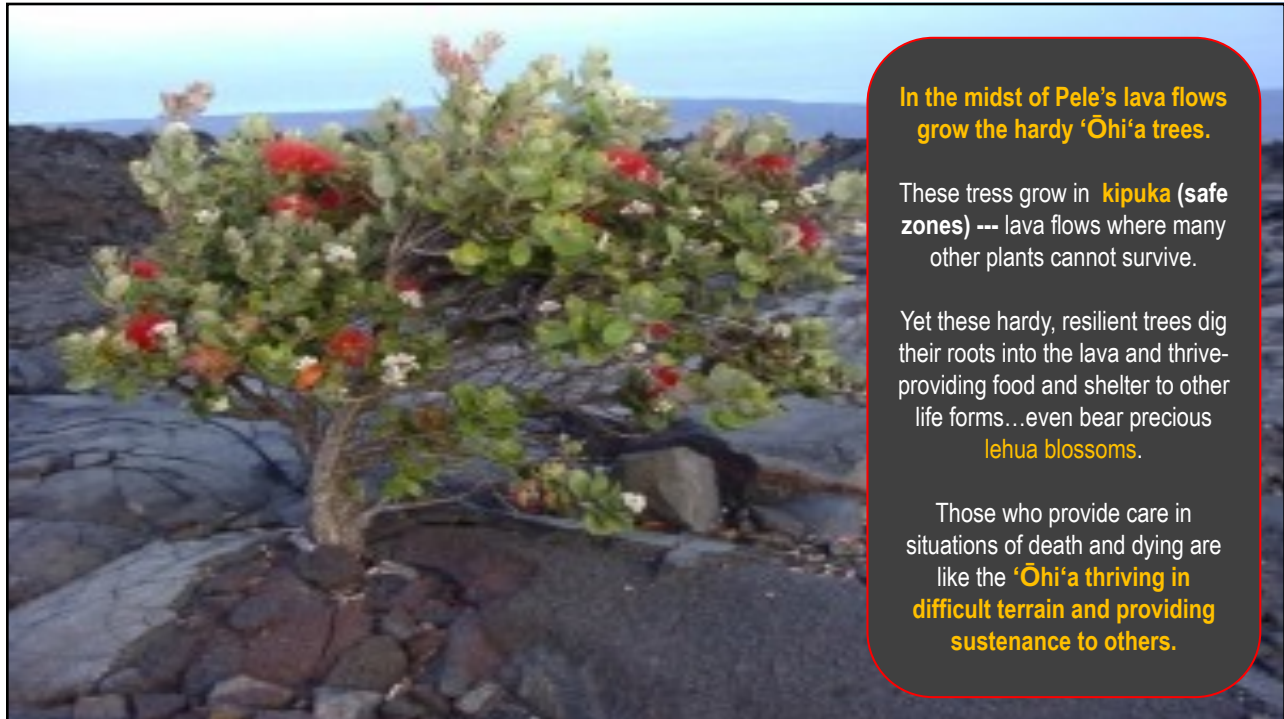
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