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 breadth 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.
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.

As presenter, I acknowledge the deep attachment & living relationship of Indigenous/Aboriginal Peoples to Country.
I honor the traditional stewards of the land & to we who dwell on it.
I offer respect & gratitude to the Elders past & present.
I ask you to join me in nurturing a culturally safe environment, with humility & respect for all ways of knowing.
Cultural Literacy & Grief Literacy: Learning to Weave & Weaving to Learn Essential Life Literacies

Ka'opua Cultural Safety & Humility

A'oa'oga, Fa'a Samoa Respect for many ways of teaching & learning.

Connected Public Health Crises
Why is Cultural Grief/Death Literacy Necessary? Especially in the “New Normal”? How might cultural wisdoms inspire us to survive...to thrive?

Structural Discrimination
Political Unrest, Violence

Global Climate Change
Red Cross reports significantly more environmental disasters since COVID pandemic.

Police, Militia Brutality
Criminal Justice Disparities

COVID-19 Pandemic, Global Survival
218,946, 836 cases, 4,539,723 deaths as of 09/05/21

Crisis is an opportunity!
He shui shi yao ji zhu de laiyuan. When drinking the water, remember its source.
(Traditional Chinese wisdoms)
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”

New Normal
Affects us all…but hard to process
One planet…many ways of knowing and being.
Around the globe, culture is most evident at end of life.
What is “good” death? What is “normal” grieving?
Does it matter “how” we grieve? How “long” we grieve?

Cultural grief/death literacy doesn’t offer pat answers…
It is a means for understanding and moving toward
a place of compassion for those who have passed…
of understanding for those who grieve.
Because dying, death, & grief are universal
CGDL is considered “a life literacy”.

Ua gatasi le futia ma le umele.
While the fisherman swings the rod, others from the village must assist.
Our personal and professional experiences have strengthened our ability to work collaboratively
across diverse situations.
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)

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.
5. Real & Symbolic Loss (e.g., roles, partners, careers, income, leaving home/homeland).
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.
Due to time, we focus on case study #5. Other cases are provided for your future exploration.

CDL #1. CAREGIVING FOR THE SICK & DYING

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.

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).

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.

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!”

“She Needs to Eat!”

Cultural Death Literacy Reflection

Feeding/eating are relatively common issues in home health care.

From your cultural lens---

What is the meaning of feeding others?
Of refusing to eat what is offered?
Is Kalei’s response one of denial?
Of anticipatory grief (grief occurring before loss/death)?
When is spiritual intercession "appropriate"?

the "bad death" of a loved one?

From your cultural lens

make peace with a "bad death"?

Is there ever any way that survivors might

What is a "bad death"?

From your cultural perspective

Cultural Death Literacy Reflection

Across the continuum of care? Of

life?

From your cultural lens---

How might ensuring funeral practices in Ghana have helped this

family’s grief?

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"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 her male cousin, 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 personal 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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"Heart Pain"

Pastora is a 50-year-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. Pastora’s family insists on a Brigham Young 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.

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.
Might you explore “present and do the best we can.” cannot be helped” generally, may be followed by “so let’s accept the suggest that this value is not a fatalistic belief. They explain that accepting that which cannot be changed. Some Japanese elders emphasize desire for order and peace in traditionally

**Ethno School of Medicine (2021)**

**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?

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**CDL #5**

REAL & SYMBOLIC LOSS

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

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 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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**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” (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?”
From your cultural lens—
Communities that follow traditional rites.
Islands…
Living in the diaspora
For Samoans and other Pacific Islanders
Among people across cultures.
Going home to die is a desire common

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 dissent. 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.

“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 relocated 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 fa’alavealave (interruption in daily life)—the many rituals involved in honoring the dead… community prayer, family meals, weaving of ʻiʻe 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.
“LALAGA” OR WEAVING PROCESS PROMOTES POSITIVE RELATIONS, CAPACITY STRENGTHENING & MEANINGFUL OUTCOMES

See Chapters in Recently Published Books.
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.

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!
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.