

The Life Transitions Project

July 2023

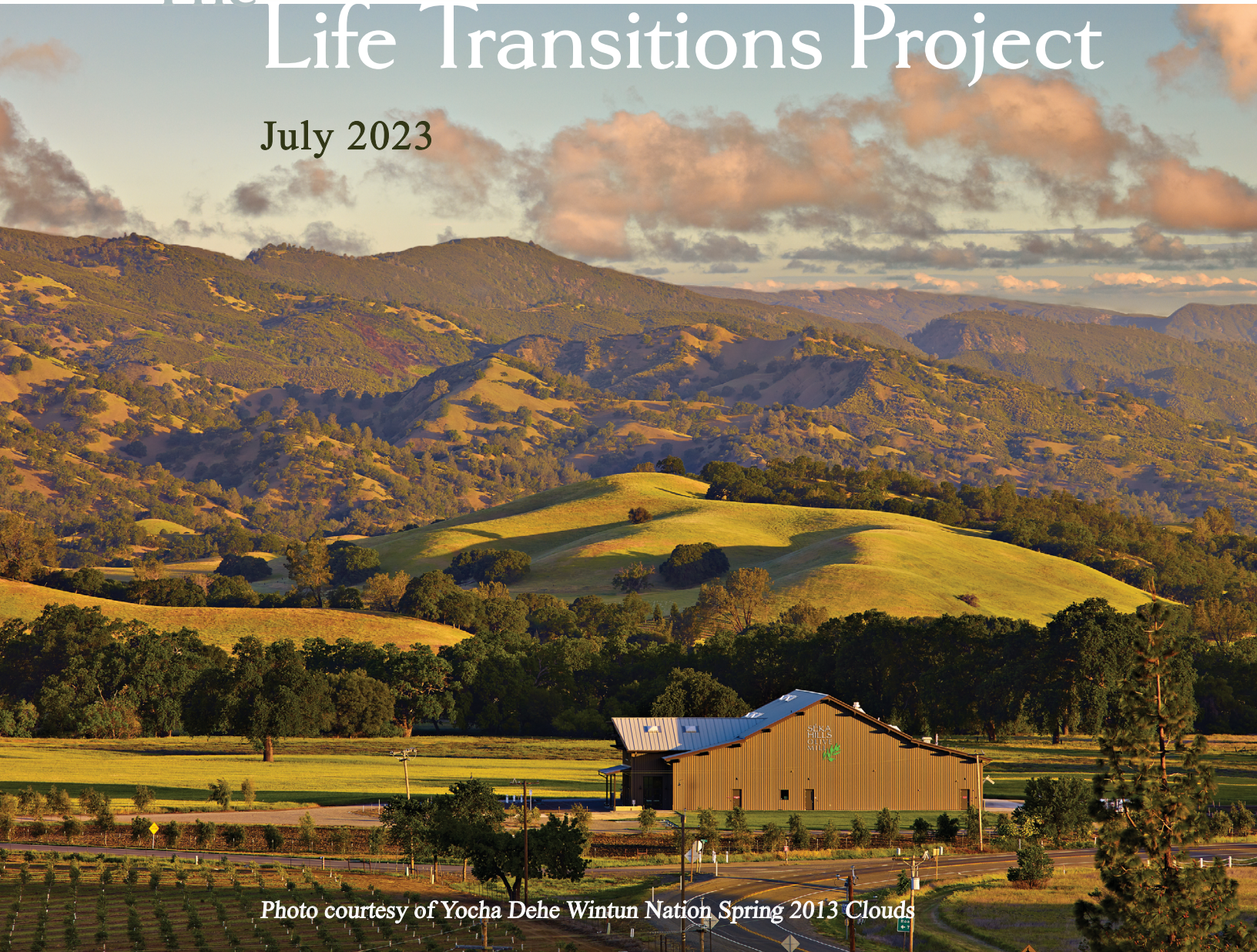


Photo courtesy of Yocha Dehe Wintun Nation, Spring 2013 Clouds

Identifying barriers and solutions to hospice and palliative care service access for Native American and rural populations of the Capay Valley.



Serving Yolo, Sacramento, Sutter,
Colusa and Solano Counties





About YoloCares



Our mission is to provide the highest quality of care to every patient, every family, every time.

YoloCares is a non-profit community-based hospice and palliative care organization and the first established independent hospice in the Sacramento Valley.

Founded in 1979 by a group of compassionate volunteers, YoloCares has a storied history of caring for people living with life-limiting illness. YoloCares is an active member of the National Partnership for Healthcare and Hospice Innovation and is recognized as a national leader in end-of-life care. Offering a variety of supportive care services, from the enriching Galileo Place Adult Day Center to Joint Commission-accredited hospice and palliative care programs, YoloCares is a resource for every step of one's end-of-life healthcare journey.

YoloCares' philosophy of care is first and foremost patient-centered and designed to meet each patient's wishes and goals of care. YoloCares' services

extend beyond the medical needs of patients to also address the social, emotional, spiritual, and psychosocial aspects of the end-of-life experience. Patients and families of YoloCares can expect culturally competent spiritual care, grief support through the Center for Loss & Hope, resources for caregivers, and volunteer support.

All medical, grief and caregiver support services offered through YoloCares are free of charge to any person residing in our five-county service area. No patient is ever denied care based on financial or insurance status. While YoloCares strives to provide culturally sensitive and inclusive care to all, we recognize the social and systemic obstacles and barriers that prevent marginalized communities from accessing transformative end-of-life care services.

Sponsorship Acknowledgement

Thank you for the generosity of the **Yocha Dehe Wintun Nation**, an independent self-governed nation whose philanthropic efforts created the opportunity to conduct this project, improve community health, and will create a far-reaching impact across Yolo County and surrounding communities.

YoloCares would like to acknowledge **Sutter Health** for their generous support of the Life Transitions Project. This important work to improve health equity for Native American and rural communities could not have been accomplished without their vision and support.



Photo 1: The Irene Mastick Therapy Garden at Galileo Place Adult Day Program offers a beautiful outdoor space to host community events, such as community memorials. The garden is also a favorite location for clients who attend Galileo Place. **Photo 2:** Galileo Place participants enjoy a wide variety of activities throughout each day, many of which incorporate physical activity. **Photo 3:** Galileo Place participants take part in an art class. **Photo 4:** Two children light candles at a memorial service held by The Center for Loss & Hope.

A Pomo Creation Story

Native American creation stories are among thousands of accounts for the origins of the world.

*Adapted from the telling of Edwin Loeb
Written by Richard P. Heller*

Originally there was no ocean. Coyote created it.

He was thirsty and he came upon some swamp tussock plants which he pulled up. Water began to flow and he drank. The water continued to flow and raised him up as the ocean began to be. He said, "Water right here stop." And it stopped where he was standing.

Alone, Coyote gathered weeds but the water was too high so he commanded that it go down. Coyote built a sweat house after he came out of the ocean. He wished that the sticks of the sweat house would stand up and they did. He surrounded it with black feathers, which is why Indians are black. He commanded that the feathers would become people.

He said that there should be a dance. He taught the people the dance songs and then he called for a feast. The people never gave Coyote anything from the feast. He became angry and because of this he started the world on fire. He rose on a fog that came. He wanted to put out the fire on the hilltops, so he created a flood.

It rained for five days and he allowed the flood to remain for four days. He caused the water to recede after which he created another race of people. He told him to gather mussels but they made fun of him which made him angry.

Because of this he caused waves on the ocean. They overflowed into the woods but Coyote told it to stop. He then posted four men in the four directions and told them to blow to make winds. He said it would rain in the winter months. There was no daylight. Coyote told Thunder Man to make thunder but not to break the rocks or the trees.

He commanded these things but the people did not believe them. Angry, he turned people into gophers, rabbits, and birds. He told them what to eat. He told him to try to put the sun in the sky. Buzzard did this. Coyote wished the stars to shine at night. Then he made the moon.

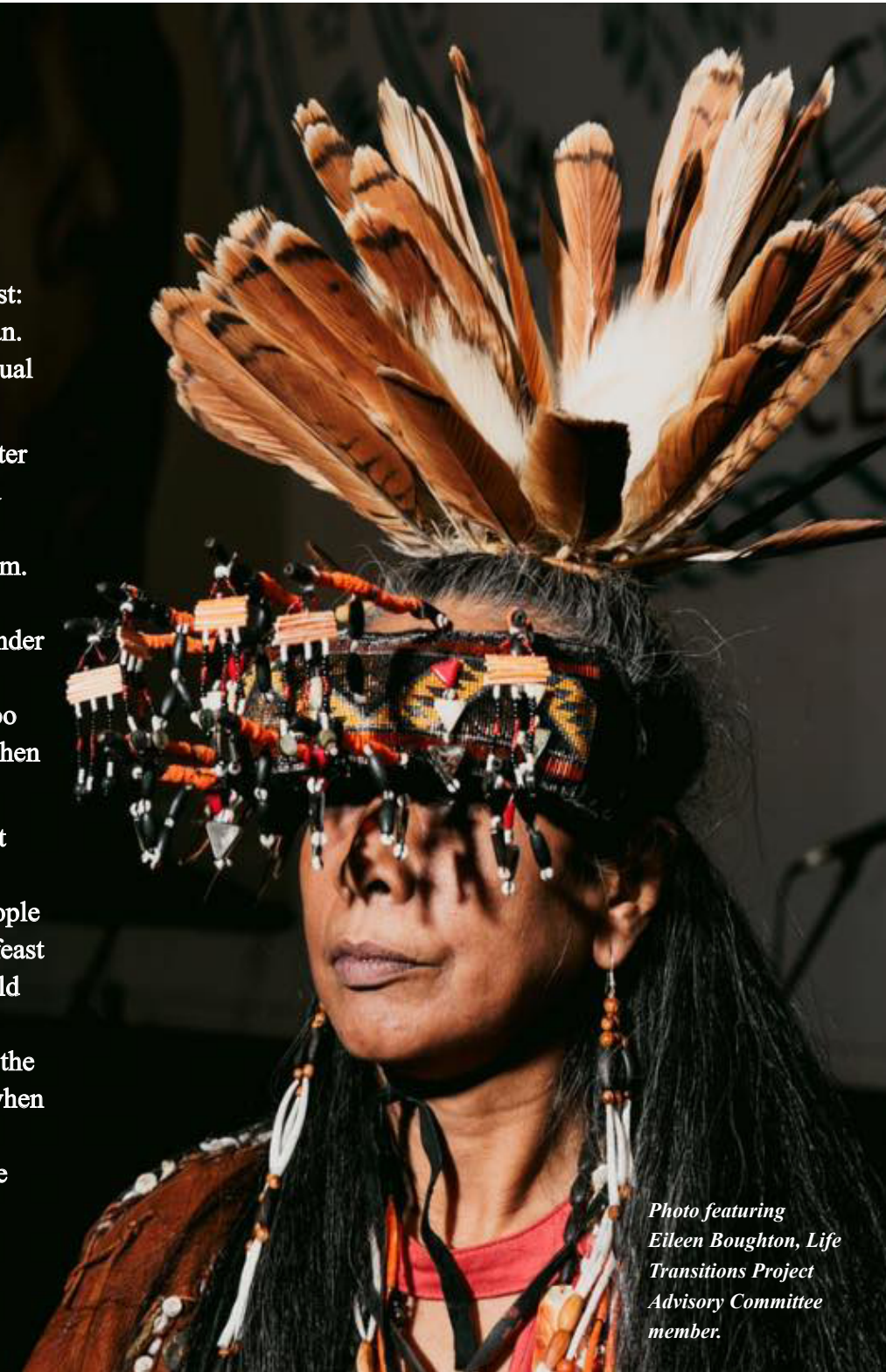
The moon was to grow the food of the buckeye and acorns. He said that if the sun stayed in one place it would burn things up. He swayed to the east and to the west. The earth sank in the West. At the South he created Kuksu to watch over it. He made Kuksu a wife. He told them to do doctoring and people would mention their names. He made the song to cure blind people and the song for scared people.

Coyote placed a man to the North, Cold Wind Man. He showed them how to create wind but he made it too strong and it sheared the earth. It formed hills. It was all flat before. Coyote went to the East where he called a man called Fire

Man. He would be in charge of daylight and heat. Coyote named three people from the East: Daylight Man, Daylight Woman, and Fire Man. He told them to make daylight and dark of equal length.

Coyote went to the North and West. Then Water Man came. The sun set in the West but stayed there. At the West Coyote called for Thunder Man who came and a bad storm came with him. Thunder Man made thunder but Coyote was afraid he would crack the earth. He gave Thunder Man the cocoon rattle and the whistle and the split stick rattle. He told him not to thunder too much for he would crack the earth. He said when the water came he was to let the salmon out.

He told Fire Man, Daylight Man and Daylight Woman that he would make another race of people. He made each village. He told the people to build sweat lodges in their villages and to feast but not every day. He told him that there would be fire again and flood again if the people did not do right. He then named all the plants for the people to eat. They were to have dances for when the acorns grew so that there would be food the next year. Then Coyote went away and the people never saw where he went.



*Photo featuring
Eileen Boughton, Life
Transitions Project
Advisory Committee
member.*



Honoring Community

A Message to the Community

You might have seen us, the Life Transitions Research Team, at a PowWow, Big Time, health fair, food bank, or even just milling around your local senior center and for that we want to say thank you.

During the initial development of the Life Transitions Project we quickly realized that the only way to be a part of a community was to be in community. We hit the ground running by circling any event on our calendars that would connect us with the communities we hope to serve. From events like the Native Dads Network Healing Together Conference or the Wilton Rancheria Breast Cancer Marathon Month, to the Capay Valley Almond Festival, it was important for us to be present.

We were careful to make outreach unintrusive but as outsiders to the community, we recognized that there would be some apprehension towards us. We brought with us humility and a desire to learn, and in

turn we were welcomed with kindness and grace. It has been a privilege and honor to witness the power of these local communities and we will be forever grateful for the opportunity to graciously observe these cultural traditions.

Attending these events year after year has created formative memories for us. We have become familiar with the many community leaders and members who make up the heart of these significant events and have had the privilege to watch how their lives have grown and shifted over the last three years. Whether we saw you on a Zoom focus group, had a heart-to-heart at our booth, or shared a deep conversation at one of our workshops, we remain grateful and honored by your choice to show up for us.

We thank you again for allowing us to share space in the moments of your lives.

Land Acknowledgement

We take this moment to acknowledge the land on which our office is located. For thousands of years, this land has been the home of Patwin people. Today, there are three federally recognized Patwin tribes: Cachil Dehe Band of Wintun Indians of the Colusa Indian Community, Kletsel Dehe Band of Wintun Indians, and Yocha Dehe Wintun Nation.

The Patwin people have remained committed to the stewardship of this land over many centuries. It has been cherished and protected, as elders have instructed the young through generations. We are honored and grateful to be here today on their traditional lands.



Photo 1: Alcatraz Sunrise Ceremony to honor Indigenous Peoples' Day on October 11, 2021. **Photo 2:** Group photo of Woodland Adult Day which includes past participants in the LTP project. **Photo 3:** Red tipi erected in honor of missing and murdered Indigenous women and girls at Sunrise Ceremony.

Meet the Research Team Assessment Summary

Aliya Patel



I graduated from Saint Mary's College of California as a biology major with an emphasis in public health.

I spent much of my time in the lab until I realized that I had a deeper interest in community-centered work.

During my undergraduate degree, I worked at a crisis center where I discovered a desire to champion social change through responsible collaboration with community-led organizations. These experiences propelled me to pursue work with underserved communities through community-based participatory research (CBPR), which relies on community immersion to understand the values, goals, and true interests of community members. During my work on The Life Transitions Project, I have been fortunate enough to meet amazing people and build channels of trust in order to receive personal stories with kindness and vulnerability.

I believe that in order to embrace health equity, we must center voices that usually do not have a seat at the table and tell stories that are left purposefully untold. That was the goal of this project and will remain a goal I strive to keep working towards in my own life.

Brandy Jones



Years of firsthand direct patient care in skilled nursing inspired me to gain deeper insight into many of the

non-medical factors that accelerate disease progression for the elderly and contribute to poorer health outcomes for certain members of my community. In my work, I observed a cycle of poor health outcomes related to social determinants surrounding the patient, structural processes, and good and bad health policy.

Motivated to increase my impact, I left bedside care to pursue a degree in gerontology at CSU, Sacramento. My concentration on cross-cultural population health outcomes guided my research on age-related policy, deconstruction of systemic barriers, and structural racism.

I am moved by the needs of community and the notion that community can speak for itself. Much of my research focuses on listening to and responding to the needs of society's most vulnerable voices: minoritized elders. This opportunity to work with the Yocha Dehe Wintun Nation has been an honor and has increased my focus on advocacy and amplified my perspectives on community inclusion.

Native American and rural community members are two populations who are among the least represented in hospice and palliative care supportive services, despite also being among groups with the highest rates of life-limiting chronic conditions.

This assessment aimed to identify the barriers that contribute to this lack of representation in specialty care, specifically in end-of-life services. The assessment used a community-focused approach to gather necessary data. A year-long public survey was created and promoted statewide, alongside in-person community workshops, weekly focus group discussions, and one-on-one interviews.

Through these conversations and survey responses, the community expressed a greater need for language appropriateness in health promotion messaging, transportation services and geographic accessibility, ongoing community education on end-of-life care services, and greater cultural representation among staff.

Findings specific to the Capay Valley rural community identified that although the Latino population makes up a very high percentage of the population, services are not built to fit their needs due to a lack of Spanish materials, bilingual staff, and culturally tailored services.

For the Native community, findings revealed a need for health services agencies to make greater investment in cultural humility, education of traditional beliefs and community preferences, as well as intentional community relationship building, and increased community education on hospice and palliative care services.

This magazine is the result of work done within local communities over two years and is not meant to be an overarching solution to addressing all disparities for all rural or Native communities. We hope you will see this as one of many means to introduce ideas and opportunities for cultural inclusivity in end-of-life healthcare settings.

Project Mission Statement

Every person deserves access to high quality end-of-life care, but for rural and Indigenous communities, access is often compromised by cultural, geographic, and institutional barriers.

Through the Life Transitions Project, YoloCares is deconstructing obstacles to ensure equal access for all. Guided by the spirit of community empowerment, we recognize that our diversity is what makes us whole.

1



Perspectives on Rural Living

Rural community members face difficulty accessing services due to geography.

In the Northwest region of the Capay Valley, there is only 50% broadband internet coverage. Difficulty accessing the internet can lead to negative health outcomes, as people are left without access to information and resources about their health concerns.

During the pandemic, there was a large shift from in-person doctor’s visits to online telehealth appointments. However, if the internet is unreliable and inaccessible, telehealth visits cannot be completed, and appointments cannot be made.

Additionally, many rural service providers have fewer resources and therefore limited staff and hours of operation. When researchers went into the Capay Valley, most agencies were not open or fully functional during and post-COVID. If even the researchers had a difficult time accessing these

services, one might wonder whether community members are able to.

Transportation

The Capay Valley is home to many farmers and farmworkers. However, some have reported that there is a shift taking place as children leave home for urban centers, leaving their parents to become their own primary caregivers.

Many living in Esparto commute to Vacaville or the greater San Francisco Bay Area for employment. As a result, older adult residents often struggle to remain on their land as the pressures of managing their illness become too burdensome without convenient access to medical services.

In the absence of medical services, the volunteer-run fire department must answer calls and serve as a transportation service, as ambulance services are considered unreliable and expensive. An estimated



65% of calls are not fire-related but are made in response to medical crises.

Native American residents covered by Indian Health Services (IHS) who prefer to visit these clinics and hospitals are often required to navigate lengthy drive times to reach a suitable facility.

One participant reported driving one hour in a single direction for a screening and then two hours in the opposite direction for a dental appointment. A lack of clinics creates gaps in care as trips can take between two to four hours just for transportation. For older adults with chronic health conditions, this is not practical and contributes to poor health outcomes.

Cost

Some farmers must pay out of pocket for medical insurance. With costs ranging between \$1,200 to \$1,800 per month per person, many opt out of coverage. As farmers sometimes do not have

coverage for themselves, it may be difficult to provide insurance for their farmworkers.

These individuals usually only go to the hospital for emergencies and do not utilize preventative care, an important factor to consider when examining usage of hospice and palliative care.

Enrollment on a Medicare hospice program requires a physician referral. Since many of these individuals have little or no access to community clinics, the connection cannot be made. Even if a referral is made, many of these individuals could not afford to access palliative care services due to their lack of insurance.

Everyone has the right to hospice regardless of insurance coverage, however many hospices will often deny patients that do not qualify for Medicare coverage. Cost and lack of insurance remains a challenge for accessing end-of-life care services.

Photo 1: The rolling hills of the Capay Valley during winter 2023, photographed by Trace Manuel. Photo 2: Capay Valley Almond Festival 2023, photographed by Trace Manuel. Photo 3: Rumsey, CA post office located off CA-16, photographed by Trace Manuel.

Perspectives on the Native Community

Native participants expressed interest in services that reflect their spiritual and cultural beliefs.

Hospice and palliative care programs that follow a strictly Western approach to medicine have served as a barrier for many families in need



During the Yuba Sutter Winter PowWow, held on February 18, 2023, the Life Transitions Project offered the opportunity for community members to take free family photos as a way to connect with the community beyond the research. This photo is the result of these efforts. Photography by Trace Manuel.

of care. Many suggested that access to more spiritual healing practices such as saging, healing ceremonies, prayer, and traditional drumming would be beneficial.

Participants reported that when these resources have been requested caregivers have been denied or disrespected, perpetuating historical trauma. For many, finding and using these services can be difficult.

Diversity in Identity

There are roughly three million Native American people in the United States with 574 Native American tribes recognized by the US government. Prior to colonization, there were more than 1,000 Native American Nations residing in the North American landscape. It is important to recognize this is a diverse group representing many Nations which hold to their own solitary traditions, values and teachings. The beliefs held by one group may not represent the beliefs of another.

What is consistent, is that Native American culture and spirituality are not separate. Health providers caring for Native American patients should have a real framework of understanding so as not to romanticize this perspective but proactively create an atmosphere that honors it.

Tribal traditions vary statewide as tribal diversity is high in California. When considering

implementing unified service offerings and improvements, there cannot be a one-size-fits-all solution.

For non-Native run organizations, a separate “Native” program may be exclusionary to the vast beliefs and identities of individual communities. Instead, improving elements of existing services to be more inclusive, accessible, and appropriate to as many elements of culture and tradition as possible should be the end goal.

The Patient Experience

Many community members have internalized the inherent biases that healthcare systems historically demonstrated and rightfully assume that the quality of medical treatment they receive will be reflective of those judgements. Medical mistreatment and discriminatory practices run unchecked in organized healthcare settings and promote fear and discomfort when families consider looking towards agencies outside of their community for help.

Many report feeling unsafe when requesting certain treatment options due to inherited racial stigma that is tied to historical trauma and stereotypes reinforced by medical bias. There is an inherent fear in feeling othered, seen as different, and being misunderstood by care providers. One participant reported, “My father passed from

refusing treatment for needle-induced hepatitis because he was scared of the stigma that he did it to himself.”

Others have felt that care providers see them as mystical and have romanticized indigeneity rather than seeing them as a patient to care for. This mistreatment stems from generations of hurt and repeated offenses towards the Native community in addition to a lack of community awareness that leads to inherent biases.

Major healthcare organizations need to turn a critical eye towards their clinical practices and agency culture. Individual medical providers must also examine their own assumptions.

This is a systemic issue and the primary goal should be establishing patient safety, comfortability and improving quality of life.

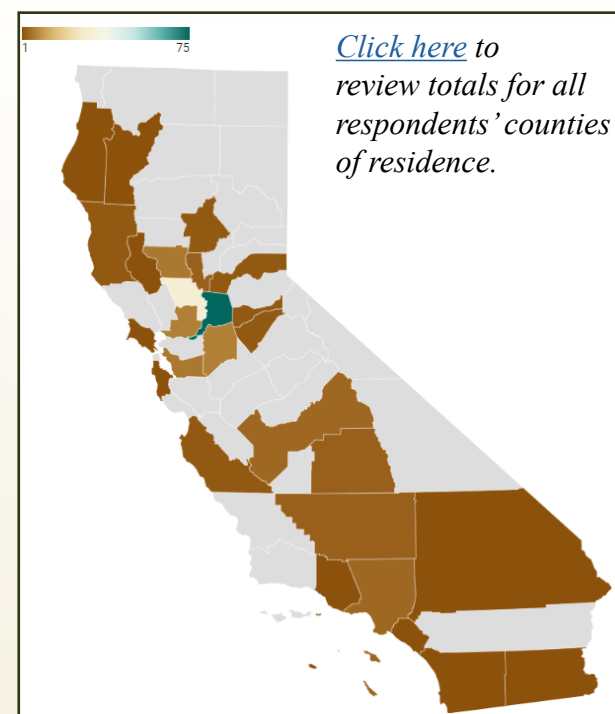
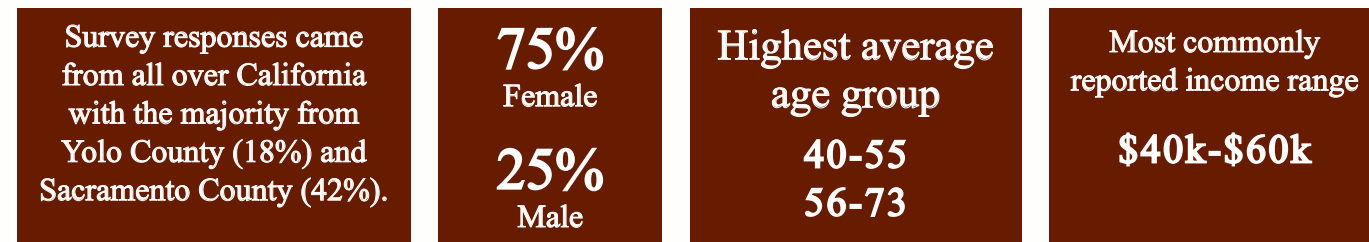
“

My father passed from refusing treatment for needle-induced hepatitis because he was scared of the stigma that he did it to himself.”

Survey Findings

These results were gathered from participants who joined in focus groups, completed online surveys, or responded to mailed surveys.

Demographic Data



Self-reported race or ethnicity

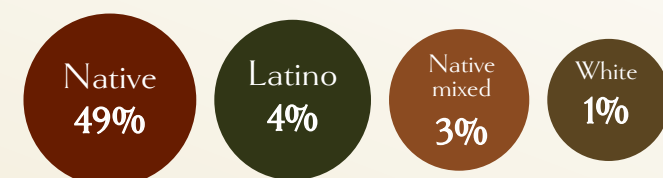


Racial and ethnic breakdown based on location

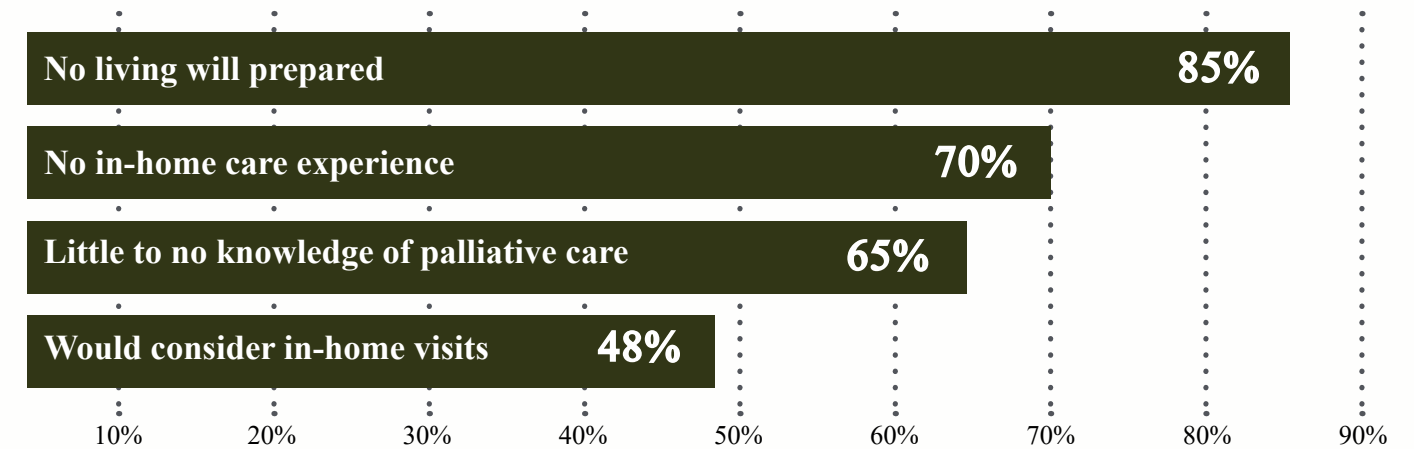
Rural Communities



Urban Communities



Experience, knowledge, and willingness to use end-of-life services



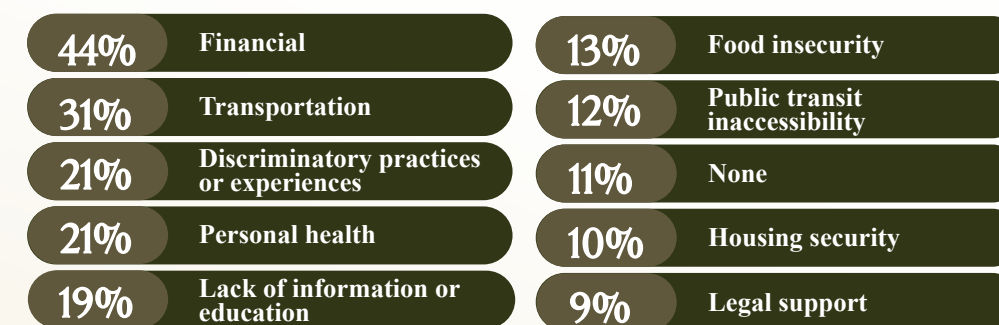
Focus groups and one-on-one interviews revealed that, for the most part, participants had no prior knowledge that hospice and palliative care services existed.

Frequently reported barrier to accessing regular medical care*



Native American participants reported barriers related to **discriminatory practices** more frequently than all other participant cohorts. Rural participants more frequently reported **food security and personal health issues** as barriers related to unmet healthcare needs.

Frequently reported barrier to accessing healthcare/social services*



Participants were given the following when answering this question: **“Social determinants are economic and social conditions that influence differences in health status.”**

*Figures do not total to 100 percent as respondents could select more than one answer.

Community Conversations

The following quotes were given by participants of workshops, one-on-one interviews, or focus groups led by Researchers Patel and Jones. These individuals represent a wide cross section of rural and Native communities, ranging in age from 18-65. Participants were connected to the Life Transitions Project through outreach at community events, social media advertising, postcard mailings, and word of mouth.

Participant experiences in end-of-life care

“It is a very sensitive subject. Mother would say, ‘I’m not dying yet, no need to talk about it.’ Father was a migrant farmworker for 30 years. He never had health insurance. He denied medical services, and when he finally asked for help, he got denied. They would only go if it was an emergency, no preventative services. Her other relatives believed that if you talked about hospice then you are terminal, basically a death sentence.”

“Medical providers don’t understand that Native people need culturally-based care that is outside their everyday norm for non-Native patients. Every urban Indian clinic I ever went to always had directors who would vocalize how they don’t understand why they need Native-specific care and push back each time. It’s offensive, racist, and makes me distrust off-rez Indian clinics.”

“How they present themselves; there is a general disrespect for American Indian culture, a view that we are inferior. That makes us somewhat hesitant.”

Participant suggestions for improving services

“Have ceremony incorporated into the passing an option to have a gathering after you pass to have songs sung and drums beat in the traditional way.”

“Hospitals and care facilities should have access to singers and smudgers so families can call for them just like a priest for last rites. Why is it that one religion seems ‘normal’ but the other seems ‘out of line or unreasonable’?”

“Have Spanish speakers and free trainings offered to the community so that we can make informed choices when planning end-of-life services. Our Hispanic culture does not talk about these issues.”

“Song and dance are prayer and medicine. It’s a way for the transitioning loved one to prepare with good energy. Speaking from my own cultural experience this is something I think is lacking from end-of-life services.”

The Power of Healing

Written by Kendra Marlow

The first time I was told my father, Gale Marlow Jr., should go home from the hospital with hospice care, I was completely against it.

All I knew about hospice was that they helped people when they were close to dying. I was scared and so I decided to care for him by myself. About four years later, I was again told that my father needed to go on hospice. I was reluctant, but I agreed to meet with some staff from YoloCares.

When they came and talked to me about their program, I felt reassured and happy, so I agreed. We had a hospice nurse, Stephanie, who was amazing. Over the two years my father was on hospice, we had many conversations about our Native American background and my father's wishes, and Stephanie did not miss a beat! She made sure we had everything we ever needed.

Then, when my dad took a turn for the worse, Stephanie spoke with me about a hospice



Catherine Marlow and family with Din performing the drum healing ceremony.

volunteer, Jana Din, and her Indigenous-based healing services which utilized soft, calming drumming. Stephanie reached out to Din who immediately came to the house and led a drum ceremony for my father. It was healing for the whole family to know that my father's spirit was supported as he peacefully passed, surrounded by his loved ones.

Then, four years later, my paternal grandmother, Catherine Marlow, became ill and was placed on hospice. Because my grandmother had been present when Din led my father's healing ceremony, she requested that I arrange to have Din provide the same spiritual support for herself. Again, Din's healing ceremony, during which she lightly drummed and encouraged each family member to express what was in their hearts to my grandmother, united the family in preparation for her passing. She peacefully passed that evening. I was comforted by Din's healing support a second time for my family.

Eleven months after my grandmother passed, my childhood friend, Jeramy Gutierrez, had a devastating stroke and became severely brain damaged. He too was Native American, and his family asked me to contact Din because they wanted to provide Jeramy with a healing ceremony. This time, Din came to the hospital and during the drum ceremony, she again encouraged each family member to share their feelings with Jeramy. It felt like he was present with us, letting us know that he was okay and ready to let go.

Continued on page 27

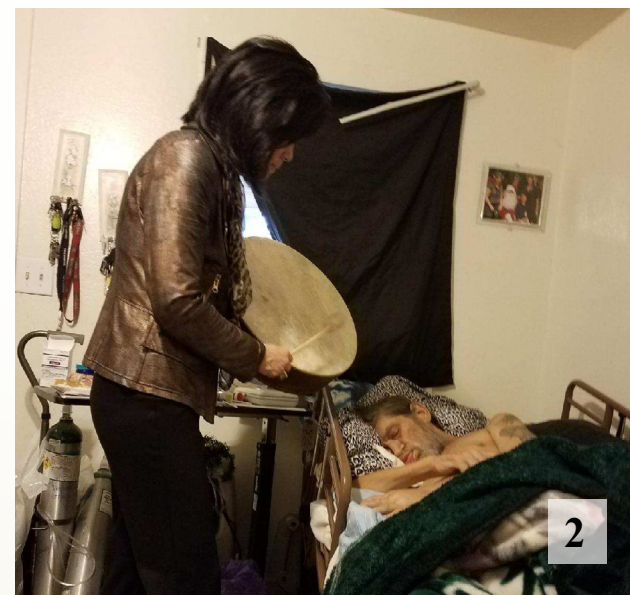


Photo 1: Kendra Marlow cares for her grandmother, Catherine while Din drummed at bedside.

Photo 2: Din stands over Gale Marlow Jr. during a healing drumming ceremony.

About Jana Din



Jana Din is a retired 35-year veteran high school child psychology teacher, co-founder of the Tao Center for Healing in Sacramento, CA and since 2000, a shamanic healing

practitioner, and frequent national and international lecturer. Jana's preparation as an integrative medicine healing practitioner includes Reiki, Medical Intuitive Training, and in depth apprenticeships with indigenous, traditional healers world-wide.

Since 2013, she has provided over 100 volunteer healing services for critically ill and hospice patients, their families, and the clinicians that care for them, in an extensive collaboration with David Steinhorn, M.D., pediatric palliative care consultant for Capital Caring Hospice. It is Jana's privilege to provide indigenous based, volunteer healing in hospice patients' homes, hospitals, hospices, and across the nation.

Go to the website <https://www.healingjourneys.life/> to learn more about the healing work that Jana provides critically ill and hospice patients and their families to find comfort and peace in the midst of their distressing circumstances, and to discover the meaning in the challenges and experiences they endure.

Caregiver Corner

Participants from rural and Native communities are often wary of allowing strangers in the home.

There are many reasons for this discomfort, from fear of being judged to fear of re-traumatization; all natural expressions of Race-Based Traumatic Stress (RBTS).

In-home care providers must consider elements of historical trauma, and the reality of how this fear continues today (see quotes to the right). External non-familial care providers must give special attention to the practice of building and earning trust. In-home care providers must recognize that providing personal care at this time in life means connecting in a deep and meaningful way.

As noted in charts below, these Latino and Native communities tend to err towards family-based, in-home caregiving. This can be due to fear of outsiders, as well as cultural associations to familial ties.

In a lot of communities, only family members

can care for family in order to uphold tradition and maintain the bonds that strengthen multigenerational families. When considering how to support these families, supportive service workers should first determine whether these families truly want in-home help. If families elect to have additional in-home help, then caregivers should serve as additional support. Caregivers should learn from the family how to be actively involved while working alongside family caregivers to give compassionate care for the loved one.

The assessment revealed that 90% of unpaid caregivers are women and the majority of them are between the ages of 56-73. This often is due to the fact that women of this age are now caregivers for their parents and/or spouses. This draws attention to the hardship that women face when they are solitary caregivers and struggle with moving, transporting, and fulfilling all the needs of a loved one by themselves.

Quotes from Caregivers

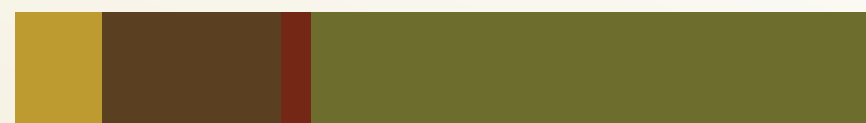
“It is hard to welcome outside people into the home since you already feel like an outcast if you’re older, and the last thing you want is a stranger also making you feel that way.”

“I left a family member in the care of [a professional] caregiver and when I returned home, regalia that had been passed down for many generations had been stolen to resell. It was heartbreaking.”

“It is super awkward and scary to have a stranger in the house, it could be nice to have a conversation first to get to know them, so they match the vulnerability of the patient, because there are unequal power dynamics at play.”

“Organizations have a history of taking kids away from their families. That trauma of having new people coming into the house still prevails.”

Preferences towards caregivers



- Unpaid family caregiver: 10.4%
- Would hire professionals: 21.4%
- Combination of unpaid family and professionals: 4.6%
- Familial caregivers only: 63.6%

Note: Unpaid caregivers differ from family caregivers in the sense that unpaid caregivers can be family members but not all family members are unpaid caregivers as some families receive tribal benefits to pay for their time caregiving. Unpaid caregivers refer to those that are actively taking time off work and putting time aside outside of work to actively care for a loved one.

Preferences towards caregivers’ ethnicity



- Native: 53.6%
- Latino: 20%
- Caucasian: 14.5%
- Other*: 11.8%

**Other includes Asian and African American ethnicities grouped together due to falling outside research designations.*

61% of caregivers surveyed are between the ages of

56-73

- Of the caregivers surveyed:
- Ages 24-39: 11%
 - Ages 40-55: 22%
 - Aged 74+: 6%

Considerations for Clinical Agencies

For medical agencies that are active within rural and Native communities, special considerations must be acknowledged in order to best serve patients.

Crossing Cultural Barriers

Providers must be aware of the cultural demographics within their service areas and intentionally connect with organizations and agencies that serve multicultural and predominantly minority communities. It is irresponsible and unproductive to make assumptions about the needs of a target community without gathering context from the community itself.

Example:

The Central Valley has the highest number of Hmong people working as farmworkers in the United States. If a care provider wants to increase their support of the Hmong community, they must first build collaborative partnerships with local centers that already offer resources for this group.

The purpose of this partnership would be two-fold; it would serve as an avenue for the agency to gain further insight to the cultural customs and beliefs of the Hmong community and would build trust and increase community knowledge of the agency's services.

Transitional Care Discussions

Many physicians and nurses admit they received very little training on hospice and palliative care, and if there is knowledge, it is often due to personal experience with end-of-life care.

As many have little training and familiarity, there is a sense of discomfort when approaching the conversation with patients. Society often focuses on curative treatment and admitting that death is approaching can feel like a failure for the care team, the family, and the patient.

Approaching the topic of death in a death-positive way can lead to a meaningful and impactful relationship between the care team and the patient, allowing the patient to embrace the realities of their healthcare journey. This radical honesty can allow patients and families to reevaluate their goals for care and priorities for their final days.

Statistically, patients are often only on hospice services for less than a week before passing, meaning that most hospice recipients lose out on specialized care that can improve their quality of life before their passing. The most common cause of short length of hospice stays is receiving a late referral from physicians.

To bridge this gap, medical providers must have a better understanding of the transition to death and embrace the discomfort of discussing decline with their patients. By having open and frank conversations with patients about their healthcare goals and the trajectory of their illness, patients can make informed decisions and choose the level of care that best aligns with their goals.

Additional training and coaching on hospice and palliative care would be beneficial for all providers working with patients in any capacity. Often, we only discuss end-of-life needs in regard to aging adults, however it should be taken into account that individuals of any age may need to receive hospice or palliative care. A life-limiting diagnosis can come at any age, so it is best to be prepared for every situation.

Addressing Patient Needs Beyond Healthcare

While all care providers aim to help their patients, they must also recognize that providing help may extend beyond their scope of medical care. When a person's primary needs are not being met, whether that means unstable housing, limited access to food and water, or disturbances in homelife, they are less likely to prioritize their health or pursue treatments.

While medical providers are not equipped to

seriously address these disruptive factors in a patient's life, clinicians can prepare themselves to have conversations with their patients about resources available in their area.

Example:

A woman who comes in for routine appointments for dialysis mentions that she is in between housing, which in turn affects her ability to attend appointments.

If the clinician is well-versed on local resources for unhoused people, they would be able to offer pamphlets about a local women's shelter and instructions on how to access Meals on Wheels. This creates the opportunity for wrap-around, person-centered care that goes beyond addressing the patient's immediate medical needs and helps to minimize barriers in accessing care.



Researchers Jones and Patel lead outreach efforts with Antonia Gonzalez, previous volunteer coordinator and Spanish speaker.

Resources for Agencies

The Research Team produced two videos to help caregivers and clinicians navigate discussions around increasing care needs at end of life. Scan the QR code to visit YoloCares' YouTube channel to view the videos.

View all YoloCares educational videos at: www.youtube.com/@yolocares.



YoloCares Programmatic Implementation

By honoring the perspectives of rural and Native communities, YoloCares is prioritizing practical solutions to make end-of-life care more accessible.

The following solutions came directly from feedback we received from countless community leaders and members.

As the Life Transitions Project was built around a desire to listen to the voices of these communities, YoloCares will create a community-based advisory committee, made up of local community leaders, members, care providers, and experts. The advisory committee will be actively involved in the implementation of the following solutions and will continue to function as the voice of rural and Native communities.

Community Relations

Prioritizing outreach through community health education would promote and strengthen community-wide familiarity with end-of-life services. Increasing community knowledge

results in more openness to engage in services when needed. This requires ongoing collaboration with local health and social service organizations that are currently active within rural and Native communities.

To truly break the informational access barrier, outreach must be done directly where community members gather organically. Maintaining community engagement through a continued presence at cultural and community events will help sustain relationships within the community, thus increasing familiarity with YoloCares and end of life care services.

YoloCares will create a team of *Community Champions*, leaders and influencers from Native and rural communities who will be valued members of the YoloCares Community Education Team. The Community Champions will be educated in YoloCares' services, and will be paid a monthly stipend to engage in continued community outreach conversations within their

own communities.

This will be done by developing the Community Champions Program, which will act as a bridge between rural and Native communities and YoloCares services. Along with directing outreach to historically underserved communities, this department will deliver educational workshops about YoloCares services. YoloCares has hired a dedicated community educator who is responsible for overseeing implementation of these programs and maintaining the relationships between Native and rural communities that have been developed through the project.

Media

Another barrier that prevents families from accessing end-of-life services is the lack of educational materials that meet community members at their literacy level and are inclusive of their cultural beliefs around death and dying.

This leaves a lot of families with gaps in understanding around end-of-life care and often results in the disuse of services. To address this, YoloCares will recreate materials following more accessible formats and including simpler language to promote comprehension with a commitment of completing the translation and dissemination of new materials by the end of 2023.

While all of YoloCares' main informational brochures are now available in Spanish, all brochures use language that was translated from English and prioritize Western-centric ideas around death and healthcare. These direct translations may

contain language that is unfamiliar or out of line with Native and Latino ideas on healthcare and death.

To honor non-Western views on death, inclusive language such as 'life transition services', will be used in place of 'end-of-life care services' in materials produced for diverse communities. The community advisory board will play an important role in providing input for the creation of culturally inclusive materials.

The assessment also pointed towards a need for materials designed to be accessible for those with differing literacy levels. YoloCares will also recreate educational materials to be accessible for those with limited English proficiency which will utilize pictures and visual cues.

Spirituality

Many individuals reported that hospice and palliative care organizations should have more spiritual elements added alongside clinical care. Suggestions have included the hiring of a spiritual healer, having sage and other medicinal alternatives available, and offering drumming.

Through internal discussions, it was not deemed appropriate for YoloCares to hire a healer to conduct these services as these cultural practices are viewed as an intimate experience for families and are usually accomplished through their community.

As there is a wealth of diversity in Native cultural practices across communities, one healer's work would not be representative of all cultural



YoloCares produces brochures for all programs and services. In 2023, YoloCares will rework these documents to be more accessible for individuals with different literacy levels.



YoloCares will reevaluate grief and spiritual care services to be more inclusive of communities with beliefs that differ from Western culture.

Continued on page 29

Program Partners

Honoring Al Striplen

Written by Al Striplen

The opportunity to work with YoloCares was an experience of synchronicity.

My beliefs and search for truths about life have evolved over many years. Personal experience in formal church communities and immersion in Native American community and ceremonies afforded rich opportunities for me to explore my own beliefs as well as those of other spiritual communities, but more specifically the beliefs of Native American cultural communities. My involvement with YoloCares synchronously arrived at a time when I was exploring the thread that connected my formal science education with what I learned in Christian community, Native American/Indigenous cultures, and with what I call Universal Spirituality. Involvement with YoloCares compelled me to dig deeper into my beliefs, to question more precisely what life means and then to find the words that allowed me to share with others.

I have found that my efforts have affirmed time and again my belief that we each have a life that is continuous. Most indigenous communities of which I am aware believe that we, our soul or

spirit, transitions from Earth physical experience back to Source then to another physical Earth experience. Our soul is continuous while our physical body remains with the Earth.

I believe now is a grand opportunity to reframe our understanding of “death” or “end of life.” Indigenous communities have the concepts humanity can learn from. All over the world there are Indigenous communities that have an understanding of the universal Spirituality that we are all part of...the “Oneness” that we so often talk about. Grieving is of course part of the experience of loss, but grief need not be fueled by the fear of unknowing. If we are made in the perfect image of Love, then Love is who we are...then in transition, we return to the source of Love. Somehow, I believe, there is room for learning more about the joy in this experience.

These are my thoughts as I reflect on my experiences with YoloCares, and the opportunity it has given me to review how I understand my own life. I trust that any individual working with YoloCares, staff and clients both, will be enriched as I have.

About Al Striplen

Al Striplen, author, illustrator, and counselor, is of Amah Mutsun Ohlone and Aztec heritage. He received a B.A. in sciences from CSU, Humboldt and an M.A. in counseling from CSU, Sacramento. He has been teaching and guiding young people through life experience for more than 50 years. As a counselor and professor of Native American studies, Striplen has been devoted to advocacy for diverse communities, ethnic student groups, women’s groups, pride centers, and Native American students and

their families.

Striplen is an artist whose works span a variety of mediums and has provided illustrations for several publications. He currently provides spiritual guidance, energy healing sessions, and teaches meditation. Playing and teaching Native American flute enrich his role as a docent at the State Indian Museum as well as his other endeavors.



The Power of Healing

continued from page 19

Din’s presence was deeply helpful during the most difficult part of Jeramy’s passing.

My family has suffered tremendous losses, but with YoloCares and Din’s healing support, it has made each journey a little bit easier. To know that my family was able to receive emotional support that represented our Native culture and incorporated familiar healing traditions made me happy knowing that was what my loved ones had requested.

In our Native background, we learn that life is a circle. The first thing you hear is your mother’s heartbeat. That’s why drumming is so calming and relatable. During a drumming ceremony, you’re hearing the same sounds you came into this world with as when you are leaving it. Not only did it calm my family members prior to their transitions but it calmed the family too, knowing the beat of the drum got us all in the same rhythm; one heartbeat.

You forget about your anxious feelings and are enveloped in this peaceful feeling, as if you’re connected with your ancestors. As if they will take the hand of your loved one, helping them to transition peacefully. That YoloCares was able to refer us to someone like Din who could help with the transitions of my loved ones in a way that honored our ancestral and cultural roots was immensely helpful. To know that other Native people like us, who don’t live on Reservations, can receive help like this, was comforting for my family and me.

Program Partners

The Community Advisory Board

We would like to recognize the Life Transitions Project Advisory Board members and all community partners who provided us with support and insight throughout this process. Their contributions to this project and their communities are invaluable.

Arzoo Mojadedi, RN, PHN
Community Health & Outreach Director
Northern Valley Indian Health, Inc.

Kim DeOcampo
Caseworker
California Tribal TANF Partnership

Bambie Eagle, MA
Community Health Representative
Northern Valley Indian Health, Inc.

Maraia Gonelevu
Health & Safety Manager
Elder Program Coordinator
Wilton Rancheria

Jana Din
Shamanic Healer
Tao Center for Healing in Sacramento

Wendy Carrion
Director of Health Services
Sacramento Native American Health Clinic

Elisa Stone
Grief Specialist & YoloCares for Kids Coordinator
YoloCares

Deanna Moore
Director of Health & Wellness
Yocha Dehe Wintun Nation

Eileen Boughton
DLC 789 President
Chair Native American SEIU

Tina Minges
Senior Program Coordinator
Rise, Inc.

Michelle Sanchez-Higginbotham
CalHope Redline Navigator Team Lead
California Consortium for Urban Indian Health

Kate Snow
Coordinator of School Climate
Davis Joint Unified School District

Al Striplen
Docent
State Indian Museum

YoloCares Programmatic Implementation

continued from page 25

customs. In response to this, YoloCares will create partnerships with healers in the local community with the purpose of building a strong referral network. This will allow for people to elect if they want to be connected to a local healer rather than a decision being made for them. These partnerships will serve to supplement or, if chosen otherwise, replace the current structure of the spiritual care team for that patient.

Transportation

The most reported challenge to accessing healthcare services by the rural community in Yolo County is transportation. To address this barrier, YoloCares is exploring the option of bringing services to the Capay Valley by leasing space in the Capay Valley Health & Community Center. This partnership would provide residents with a part-time satellite office that is more easily accessible and would offer office space for clinicians to make home visits more easily to rural residents.

Representation

It is crucial that clinical staff represent the populations that they serve. YoloCares is actively focusing hiring efforts toward Native American clinicians through Native networks. In the interim, priority will be

given to volunteer recruitment for Native and Spanish-speaking individuals. YoloCares volunteers can offer both companionship for patients and respite for caregivers. Having diverse volunteers can also serve as a key connection point to culture for patients that are in transition and are searching for a friendly, familiar face.

Internal Training

All staff are required to complete numerous health or hospice-related training courses annually and licensed clinicians are required to receive additional training on topics related to patient care. However, that is not enough to address gaps in cultural understanding that have led to the mistreatment of minority patients and families.

Research revealed a need for an intentional, ongoing, organization-wide commitment to cultural humility which must be weaved into the cultural fabric of YoloCares. Currently, YoloCares is developing the framework for a quarterly agency-wide education series aimed at increasing cultural humility among staff.

Familiar Faces

During the Yuba Sutter Winter PowWow, held on Feb 18, 2023, the Life Transitions Project offered the opportunity for families to take free family photos as a way to connect with the community beyond the research. These photos are the result of these efforts. Photography services were generously donated by Trace Manuel.





The exploratory work of the Life Transitions Project has identified themes throughout the Native population that also act as barriers that prevent other minoritized populations from accessing hospice and palliative care services.

As there are clear deficits present in accessing end-of-life services, YoloCares is committed to doing the work to reduce barriers for all underserved members of our community.

This is all thanks to the generosity of Yocha Dehe Wintun Nation, an independent self-governed nation whose philanthropic efforts created the opportunity to conduct this assessment, improve community health, and will create a far-reaching impact across Yolo County and surrounding communities.

To view the full Life Transitions Project Report, [click here](#).



1909 Galileo Court
Davis, CA 95618
(530) 758-5566
yolocares.org