The Life Transitions Project

July 2023

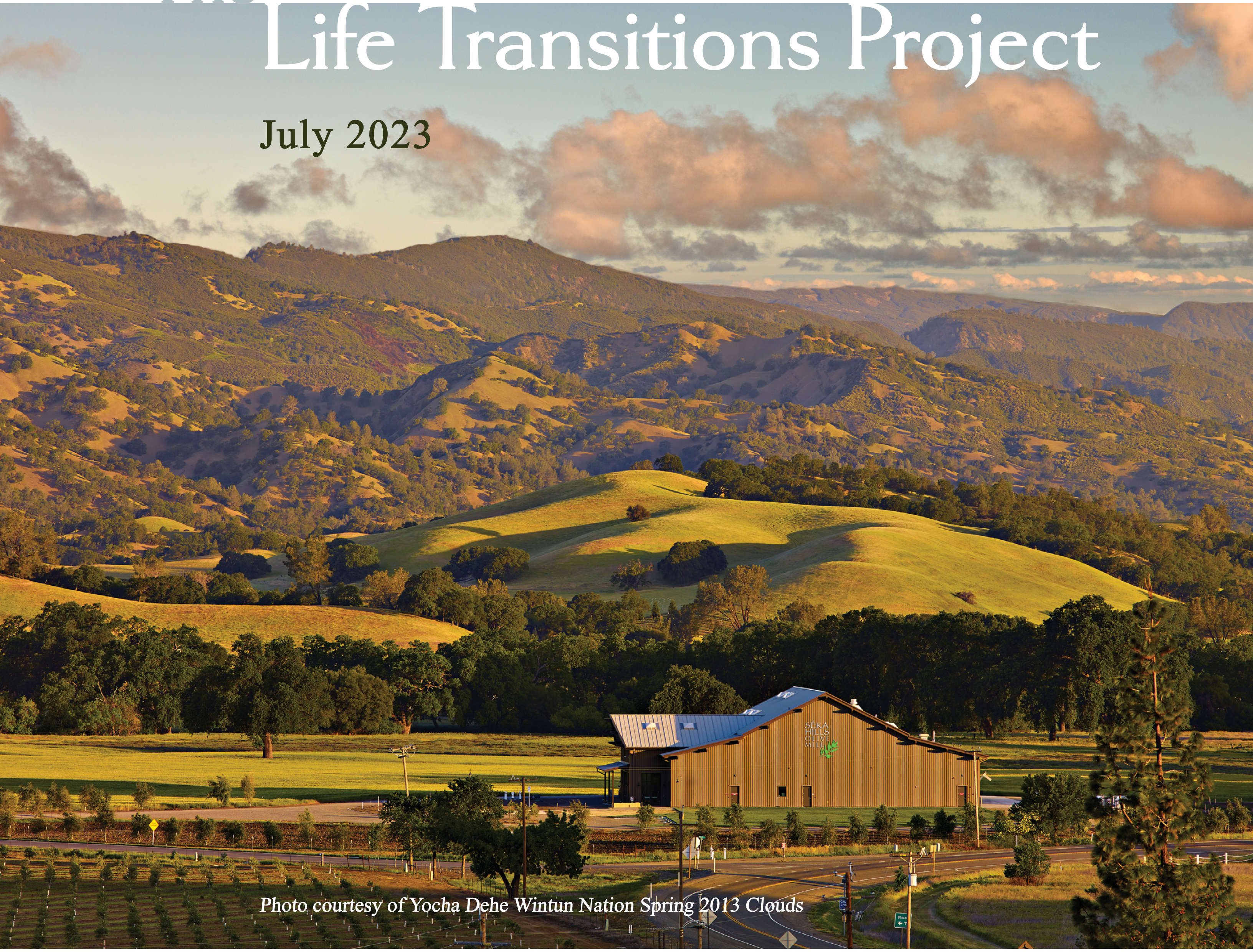

Photo courtesy of Yocha Dehe Wintun Nation Spring 2013 Clouds

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

yolo cares
Serving Yolo, Sacramento, Sutter,
Colusa and Solano Counties

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Glossary of Terms

Asset Based Community Development (ABCD) strategy.	Asset Based Community Development (ABCD) strategy builds on the assets that are found in the community and mobilizes individuals and organizations to come together to develop their strengths.
BIPOC	Black, Indigenous, and People of Color (BIPOC).
Capay Valley	The mostly rural valley northwest of Sacramento in Yolo County, California, which lies east of Blue Ridge and west of the Capay Hills. Cache Creek is an 87-mile-long stream that flows through the valley stretching along Lake, Colusa, and Yolo counties.
CBPR method	Community Based Participatory Research (CBPR) method is a partnership approach to research that equitably involves community members, organizational representatives, and academic researchers in all aspects of the research process. Although the work performed for this assessment is not formal research and does not prove or disprove generalizable knowledge, it was important to conduct it in a manner like CBPR.
Community Health Needs Assessment (CHNA)	Community health needs assessment (CHNA) is a systematic process for determining health needs in a particular community or population and using results to spur community change.
Cultural humility	Incorporates a lifelong commitment to self-evaluation and self-critique, to redressing the power imbalances in the patient-physician dynamic, and to developing mutually beneficial and non-paternalistic clinical and advocacy partnerships with communities on behalf of individuals and defined populations.
Diversity, Equity, and Inclusion (DEI)	Diversity, Equity, and Inclusion (DEI) is a conceptual framework that promotes the fair treatment and full participation of all people, especially in the workplace, including populations who have historically been underrepresented or subject to discrimination because of their background, identity, disability, etc.
Ethnic minority	A group that has different national or cultural traditions from the main population.
Evidence-Based Research	The use of prior research in a systematic and transparent way to inform a new study so that it is answering questions that matter in a valid, efficient, and accessible manner
Indian Health Services (IHS)	Indian Health Services (IHS) is a part of the federal government that delivers health care to American Indians and Alaska Natives (AI/ANs) and provides funds for tribal and urban Indian health programs.

Glossary of Terms

Implicit Bias	A form of bias that occurs automatically and unintentionally, that nevertheless affects judgments, decisions, and behaviors; the automatic association people make between groups of people and stereotypes about those groups.
Indigenous	Descendants of peoples who inhabited the Americas, prior to European colonization
Migrant	A person who moves from one place to another, especially to find work or better living conditions.
Migrant Farmworker	An individual who is required to be absent from a permanent place of residence for the purpose of seeking remunerated employment in agricultural work; also called "migratory agricultural workers."
Minoritize	To make (a person or group) subordinate in status to a more dominant group or its members; refers to groups that have historically been marginalized by society and government institutions; To be minoritized means to be pushed to the margins
Native American	A phrase used to describe a diverse array of Indigenous peoples; Though referring to Native people by their specific tribal name is preferred, the term "Native American," is considered acceptable and is used to describe Indigenous communities in what is now the continental United States
Rural	Primarily an agricultural area (ranch land/farming visible), with no paved road for at least one mile from the residential property line (i.e., walkable sidewalks); significantly smaller choices for shopping and medical offices
Socioeconomic status (SES)	Socioeconomic Status (SES) encompasses not just income but also educational attainment, financial security, and subjective perceptions of social status and social class.
Social Determinants	The conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life.
Sociocultural	Of, relating to, or signifying the combination or interaction of social and cultural elements.
Research Team	Research Coordinators assigned to the design, implementation, report creation, and all outfacing aspects of the Life Transitions Project

Executive Statement

Native American and rural communities are overburdened with chronic conditions that disproportionately lead to terminal illnesses, yet these groups also have the lowest percentage of individuals utilizing supportive care services such as hospice and palliative care. Though all Medicare consumers are entitled to hospice benefits, Native American, and rural dwelling families experience unique barriers to accessing these services even when qualified.

To identify persistent barriers that pose unique challenges to Native American and rural populations across Yolo, Solano, Sacramento, Colusa, and Sutter counties, YoloCares undertook a 3-year Community Health Needs Assessment (CHNA) and Quality Improvement project.

The assessment was conducted using a Community Based Participatory Research (CBPR) approach. Project leads gathered community input through a public survey, community workshops, focus group discussions, and one-to-one interviews. Discussions included community perceptions and thoughts regarding advance care directives, grief practices, healthcare access barriers faced by both Native American and rural communities, and utilization of in-home care services. Bolstered by a CBPR approach, foundational community relationships were built to seek ways to combat historic disparities. YoloCares worked to learn the needs of the community directly from Rural and Native American community members, and to work directly with these populations to provide solutions within YoloCares scope of practice.

This assessment identified a need for greater cultural humility and increased healthcare provider knowledge of traditional beliefs and practices for Native American patients. The need to address geographic and social determinants for the rural population was also identified. The results of this assessment formed the basis for recommended primary implementation strategies for YoloCares and other hospice and palliative care service organizations. Cultural humility and respect, as well as community relationship building, will be key to successful implementation.

Findings and Recommendations

More than 50% of Native respondents lacked awareness that hospice services exist.

Nearly all were unaware of the scope of services offered or how to access services when needed. This lack of awareness is a gross contributor to disparities.

Recommendations include not only widespread dissemination of information but active engagement efforts by hospice and palliative care organizations to meet these families where they are. That means increased outreach in the community, a comprehensive, accessibility-focused overhaul of informational materials, and an informed approach to relationship building.

An intervention practice of providing the community the education before it's needed empowers individuals to make a choice to shift to these services earlier and experience an optimal quality of life for an extended period.

The results of the assessment demonstrate that compassionate care and organizational representation are both needed to bridge gaps in care, though compassionate care was cited as the more urgent need. Organizational accountability is key to achieving both representation and compassionate care. Just as the minority patient population is becoming the majority so should the pool of people available to serve them reflect this.

Where this is not readily achievable, culturally-focused training and staff education should be a foundational value of hospice and palliative care organizations. Organizational staff should be regularly trained and educated on how race, ethnicity, and culture-based experiences shape individuals and their preferences for care. This includes but is not limited to approaching individuals who have developed a lack of trust in medical providers and institutions with sensitivity and flexibility.

The results of the assessment also reinforced common themes found across previous work in rural and underserved populations such as issues of cost, transportation, and language barriers.

Hispanic families within the rural service areas of YoloCares make up a large portion of the population, yet services are often inaccessible due to lack of language compatibility, bilingual staff, and culturally tailored services.

For provider agencies to successfully reach these communities there is a need to focus efforts on language accessibility, increased accessible transportation services, sustained community education and representation within the staff.

Other considerations identified from this work include:

- Hospice and palliative care organizations must become more community minded by leveraging community partnerships and building networks to non-clinical community service providers.

Recommendations for physicians:

- Physicians' interaction and timely referral can mean extending the life and quality of life for a patient. Physicians must become comfortable taking the initiative to approach hospice and palliative care topics with patients of all backgrounds.
- The short time physicians have with patients can be more than a one-way clinical exchange of information. Physicians must become a resource to the whole individual, this can be accomplished by asking the right questions of a patient.

The hospice and palliative care models have always been set apart from the traditional institutional practices of western medicine. From its founding, hospice care has operated from a humanistic perspective, innately designed to address the multidimensionality of individuals.

In this light, hospice programs are positioned to lead the way in culturally responsive care. As the population demographic diversifies at an exponential rate, we must reckon with an overdue need to break from the status quo, becoming deeply intentional about cultural inclusivity in the care we provide.

Hospice and palliative care organizations have a responsibility that is distinct from curative practice to consider the impact of a condition over the entire well-being of patients. We cannot afford to continue to practice a color-blind delivery of care for a very colorful population in need.

Through a culturally responsive, whole person-centered practice of care, we can nurture the treasures that shape an individual life and carry them through life's transitions.

Many aspects of U.S. healthcare have long prohibited people of color and the underprivileged from being heard and feeling seen. While all disadvantaged groups experience unique barriers to receiving beneficial health services, the Native American and rural communities' unique needs have been grossly ignored.

This report is a call to action; an invitation to our sister hospices and palliative care agencies to engage in action that holds true to the heart and wonder of hospice practice, by addressing the needs of our most underrepresented communities.

Photography by Trace Manuel

Introduction and Background

YoloCares

YoloCares is a non-profit, community-based, hospice and palliative care organization. As the first established independent hospice in the Sacramento Valley, YoloCares has a storied history of caring for people who have a life-limiting illness.

YoloCares is an active member of the National Partnership for Hospice Innovation and is recognized as a regional leader in end-of-life care.

YoloCares offers a wide variety of supportive care services, from an enriching adult day facility to The Joint Commission-accredited hospice and palliative care programs. Services are not limited to clinical needs of patients but also include wrap-around care for the psycho-social needs of the patient's family.

Community support programs include individual counseling, support groups that address a wide variety of losses in both English and Spanish, as well as resources designed to support caregivers of terminally ill people.

Although YoloCares' services are provided to families whether they can pay for them or not, we recognize that there are social and systemic obstacles and barriers that prevent certain communities from accessing these services.

> "*YoloCares believes that 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 collaborative Life Transitions Project, YoloCares is deconstructing obstacles to ensure equal access for all. Guided by the spirit of community empowerment, YoloCares recognizes that our diversity is what makes us whole.*"

Hospice and Palliative Care Utilization

For patients diagnosed with severe illness, palliative care is a specialized medical approach aimed at improving their quality of life. It is intended to alleviate symptoms, pain and emotional distress while addressing patients' physical, psychological, social, and spiritual needs.

Palliative care can be started at any stage of a serious illness, is not limited to end of life diagnoses and can be integrated into a treatment plan alongside medical treatment for an indeterminant time.

When a life-limiting illness no longer responds to cure-oriented treatments, hospice is a type of palliative care that is specifically designed to address the symptoms of a disease in order to increase the quality of a patient's final days. Support is provided by a patient-centered care team of specially trained professional clinicians and volunteers, whose efforts are integrated with those of family caregivers. Care is focused on pain management, comfort, and dignity.

Since 1960[1] hospice services have been used by millions of Medicare beneficiaries and utilization rates have increased consistently every year. In 2019, 1.6 million Medicare beneficiaries used hospice services, which according to National Hospice and Palliative Care Organization (NHPCO) was an almost 4% increase from 2018 (Figure 1) [2]. However, utilization across certain ethnic and geographic cohorts has not increased, and recent NHPCO data show utilization among Native American and rural cohorts eligible for the services remain alarmingly low. Consistently over the most recent decade Native Americans constitute only 0.4% of hospice decedents [2] [3] [4]. While rural utilization data is inconsistent for tracking individual use, it is documented that only around 12 - 18% of hospice workers provide care in rural areas [5].

There are unique health concerns that exist for both the Native American and aggregate rural population that make the underutilization of hospice and palliative care a concern. In the U.S., chronic illnesses are responsible for eight of the ten leading causes of death [6] and burden rural and Native American populations disproportionately [7]. Native Americans with chronic illnesses are more likely than their White counterparts, to develop into terminal or end-stage illness, such as when diabetes progresses to kidney disease or to end-stage renal disease [8] [9].

In a study of more than 14,000 Native American elders between 2011 – 2014, diabetes, high blood pressure, and arthritis were among the most common reported chronic illnesses. The diabetes rate in this group (54%) is nearly double the national average of 27% [10]. In rural communities, members are more likely to die from the four top treated palliative care diseases–heart disease, cancer, lower respiratory disease, and stroke–than urban dwellers [7].

Native American Considerations

Historic traumatic events resulting from colonization, such as forced relocation, governmental suppression of resources, and many other forms of injustice, have had a significant impact on the health and well-being of the Native American population.

Lasting effects of the introduction of foreign disease to Indigenous peoples as well as to land and livestock, has brought about 500 years of chronic to terminal health disparities [11]. In addition, persistent social and economic challenges continue to contribute to high rates of chronic disease [10]. As inter- and trans-generational traumatization endure through healthcare systems, so do self-preservation behaviors, such as skepticism and mistrust of institutions, social workers, health providers and social service agencies [12].

A reluctance of Native families to enroll or admit loved ones onto hospice care has been steered by negative perceptions and past behaviors of in-home health programs across Indigenous communities. It must be recognized and accepted that these perceptions hail from demonstrated intergenerational medical mistreatment, experienced institutional racism, historically persistent social patterns, and an acute recognition of the almost imperceptible acts of implicit bias, all of which have not been absent in end-of-life care services [13].

This may be evident to some extent in review of significant hospice utilization reports that indicate Native Americans are placed on hospice services within days of their death. A common reason is having sought more curative treatment and lack of a trusted relationship with their physician, as opposed to White patients who tend to accept earlier referrals to hospice by their physicians [14].

Furthermore, research among patients of color receiving hospice and White American patients receiving hospice, reveal clashing perceptions and treatment experiences time after time, such as unrelieved pain and prolonged suffering.

Lack of awareness of hospice as a care option, conflicts between patients' spiritual beliefs and the hospice and palliative medicine philosophy of care, and mistrust of the medical system are all factors that contribute to racial disparities in end-of-life care [15]. Physicians also report a reluctance to discuss end-of-life options, as well as the practice of giving an optimistic inflation of prognosis with patients of color [16], in part due to a lack of training in the scope of hospice practice. Whereas, "end-of-life care" services and terminal illness are taboo topics of discussion in Native American social settings while conversations about physical and spiritual death and dying are not.

Dying, death, and grief are both personal and universal experiences, shared by all. However, meaning and the response to these events are variably shaped by cultural norms and social values.

Embedded into culture and spirituality for Native American families, death in many ways is received as a continuance of life, as opposed to finality and separation from life. In Native American cultures, the anticipated death of a loved one is embraced as moving forward on a spiritual continuum [17]: a paradigm consisting of birth, life, death, and afterlife.

All four stages are believed to be one journey of the human spirit on this continuum. In contrast, finality and separation most often shape the western medicine approach to end-of-life care. Western medicine typically focuses on structured practices, relationships and the aspects of death that provide closure and acceptance to the end of biological and physiological life [15].

Rural Resident Considerations

For members of rural communities, regardless of ethno-cultural makeup, evidence illustrates that they share health and end-of-life care utilization disparities like that of minoritized groups. In fact, rural community members have poorer health outcomes than their urban counterparts, a similar mistrust of healthcare professionals to that of ethnic minority cohorts, scarce resources and obstructed access to primary care and end-of-life services [7].

One example of this urban to rural contrast has been the declining health of rural White women. Since 2000, the decaying health of rural White women has been recorded and observed by the Centers for Disease Control (CDC) [18]. Prior to the COVID-19 Pandemic it was reported that a 30% spike had emerged in the number of premature deaths in rural-dwelling White women, ages 30 - 50, a 50% increase since notice in 1990 [18]. At the same time, no significant reports identify any decline in the health of urban White women.

In an examination of California's predominately rural counties' demographic diversity, the level of challenges to receiving care vary, and the barriers that exist vary region to region. Rural communities surrounding Yolo County, however, are a fair representation of Northern California rural communities. In Yolo County, by census response, the Hispanic population is the second largest racial demographic at 33%, compared to 44% White [19].

In Yolo County, approximately 4.9% of residents are noncitizens [20], 38% of the population speaks a language other than English at home and more than 50% of residents in Woodland and northwest Yolo County are from historically underserved groups [19].

Most vulnerable of these populations are migrant and seasonal laborers that constitute a 42% makeup in northwest Yolo County. Although the county boasts a $635 million agricultural economy [21], those laboring in this industry remain uncounted and underrepresented in receipt of social services.

Until the Capay Valley Health and Community Center opens, the closest access to primary or urgent care for the Capay Valley is Winters or Woodland, a forty-minute or more drive from Yolo County's rural residential locations.

The Life Transitions Project

YoloCares, the community-based hospice provider servicing the most rural families throughout Patwin territories (see map), undertook a Community Health Needs Assessment (CHNA) project. This report is the result of a three-year initative to identify, address, and deconstruct barriers that prevent Native American and rural communities from accessing and utilizing Life Transition services within YoloCares five-county service area.

The project, aptly named *The Life Transitions Project*, is sponsored by the Yocha Dehe Wintun Nation and Sutter Health, and was led by YoloCares' Research Team.

This report compiles identified community-generated themes from surveys, focus groups, a community-led advisory board, outreach, and one-to-one semi-structured interviews with California Native American and Rural participants from the Capay Valley and surrounding areas.

It is important to keep in mind that no ethnic group, culture, or regional cohort is homogenous, hence the findings in this paper are not a universal solution nor are they the view of every member of each represented group.

Please note that the Research Team has replaced "end-of-life" with "life transitions" to respect the values and beliefs of the communities referenced throughout this body of work.

Photo courtesy of Yocha Dehe Wintun Nation Spring 2013 Clouds

Assessment Methods

Design

First, a comprehensive literature review focusing on Evidence-Based Research (EBR) and results was preformed. This entailed learning through academic papers, and health assessments on studies performed previously on hospice and palliative care access for diverse communities.

The review also included ethnographic, and research based on historical accounts through database searches as well as in-person historical site visits to gain better understanding of the history and lived experiences of local Native American communities. To gain a deeper understanding of the local landscape and current culture of the target populations, the Research Team reviewed county and community needs assessments, county level data, and local California Area Indian Health Service Profiles [22] [23] [24].

To become familiar with the geography of the rural culture of the Capay Valley and surrounding areas, the Research Team conducted several windshield surveys, which are informal drives around the community to record observations. Windshield surveys allowed for initiation of situational conversations that helped to build rapport and a presence within the community.

Members from local community labor, volunteer, and social service organizations were interviewed while the Research Team also participated in public hearings, local committee meetings, and health service interest meetings that brought clarity to active social issues across the community [ref. YHAA, Yolo County Culture Competence Committee, 2021 California Health Equity Summit].

This project was conducted using mixed methods assessment design following CBPR methodology. The tenet of CBPR is to engage members of the community most directly affected by an issue. The goal is to gather information directly from community members regarding community perception and experiences, to gain input on identifying existing barriers that community members feel they need to overcome, and to consider what these solutions should look like [25].

CBPR follows the natural direction the community is moving and allows for flexibility of data collection tailored to the community's needs. To integrate the community as an equal partner informing direction of the assessment, and creating avenues for implementation practices that reduce health disparities, the Research Team presented and engaged at local coalition meetings, spoke with attendees at local events and participated in volunteer activities alongside various community health programs.

Asset Based Community Development (ABCD) Strategy

Asset Based Community Development strategy (ABCD) was the underlying strategy for building a strong foundation for community buy-in towards the project. ABCD identifies and highlights assets and community strengths instead of using a needs deficit-based model.

ABCD draws attention to social assets: the talents of individuals, as well as the social capital inherent in the relationships that fuel local associations and informal networks [26]. A needs-based approach makes people feel defective and surrounded by insurmountable problems and barriers, whereas an asset-based approach empowers individuals. As assessments

> ***Just as plants grow towards their energy source, so do communities and organizations move towards what gives them life and energy. To the extent that memory and the construction of everyday reality offer hope and meaning, people tend to move in that direction.*** [26]

are inherently deficit-based, by posing questions around barriers to accessing healthcare, deference must be made to enriching methodologies.

Recognizing personal capital, value in relationships and community, and the inherent skills people can access is most reflective of the unique and transitive nature of Native culture. ABCD prioritizes building relationships and using family, extended family, and the power of community-based relationships to spread the word and give credence to the credibility of a project. ABCD's practical application was utilized by mapping assets, ultimately forming a Community-led Advisory Board (CAB), a foundational strategy in recognition of the value in local resource investment.

Assets were identified and mapped through community health needs assessments, online research, and in person visits to the target areas. These assets included hospitals, community resource centers, health agencies, historical sites, and education entities.

Participation and inclusion were solicited from the principal grantor of the project, Yocha Dehe Wintun Nation Health & Wellness department, RISE, Inc., Northern Valley Indian Health, regional UC, State, and community college Native American Studies Programs and social groups, local federally recognized tribes, local Native American social and advocate groups, and local Tribal and rural Temporary Aid for Needy Families (TANF) programs.

From ABCD inclusion activities leaders (such as community health workers, nurses, educators, healers, tribal liaisons, and government workers) the CAB provided advice and support throughout the project to expand services to rural and Native American communities. The CAB worked to provide insight to specific barriers of the Capay Valley, to guide vital steps, and to provide language and cultural education throughout the project.

While acting as a network to the community at large, more leaders emerged from these relationships to eventually form a more dynamic and complete CAB to inform the project.

Public Survey

With input from a YoloCares in-house strategic work group, an online survey was created and remained open to the public for 12 months. A mailer service was used to send surveys to target demographic groups: Native American residents in all five YoloCares service counties and all residents of the Capay Valley.

The survey was disseminated using a snowball and purposive sampling strategy by encouraging participants to share survey links or QR codes with members of their respective communities. Additionally, the survey was shared through the CAB networks and their respective social media platforms.

The Research Team promoted survey participation while attending local events such as regional Pow Wows, conferences, and festivals.

The survey consisted of 23 questions, with both demographic closed and open-ended questions that assessed:

- knowledge of and willingness to use hospice and palliative care services,
- experience with healthcare access and information,
- preferences for medical treatment,
- cultural preferences, and
- social determinants of health.

The only identifying information was part of the request for mailing information, so an incentive could be returned to the participant. A $25 Visa gift card was provided to all participants that completed at least 90% of the survey.

The online survey was conducted using the Survey Monkey platform and was replicated using Adobe Acrobat for printed mail distribution. The combined approach garnered 180 responses.

Focus Groups and One-to-One Interviews

Focus groups were held on a weekly basis for ten weeks; several focus groups consisted of a sole individual, in which case an oral survey was conducted to complete the survey questions, then directly followed by open discussion.

Focus groups were held at senior centers, low-income housing complexes, and community events. To promote accessibility, focus groups were held on Zoom (7pm for Rural, 8pm for Native) every Wednesday night from the months of October 2020 through January 2021.

These groups were separated to maintain a small group structure and to create a safe space. The small group design was meant to provide insight on health practices, health experiences, beliefs, bedside manner preferences, as well as to foster an environment for unanticipated conversations to naturally occur.

Participants were recruited through a follow-up letter from the online or mailed survey completion, through promotion at events, and through word-of-mouth from CAB members or rural community service organizations.

The focus groups followed a workshop format to promote dual reciprocity in information sharing. They began with a presentation on hospice, palliative care, and advance care planning as well as information on YoloCares services.

To document sessions, key comments were written down and recorded for transcription. All demographic information that included name, addresses, and personal information was kept confidential and access only given to the Research Team.

The team served as moderators during focus groups to ensure safety and comfort of all participants while discussing sensitive topics. After participation, participants had the option of having their comments rescinded, however, no one chose to rescind.

Focus group participants were provided a $50 Visa gift card as a token of appreciation for their investment of time and knowledge.

Focus Groups and One-to-One Interviews

YoloCares is a locally established and trusted community-based, person-centered, end-of-life care service provider, but it too has a historical baseline clientele and employee makeup that reflects disparities in hospice use among ethnic minority populations.

Through an identified need to gain culturally appropriate community support for the project, the Research Team established community presence through culturally directed engagement across the five-county service area. Early on, methods for addressing community members were modified. In building relationships within the Native American community, the Research Team learned that the language being used to promote the project was acting as a barrier to gaining interest in the project.

The Western absolute language, "end-of-life" care, does not culturally reflect the target population's beliefs and values, so "end-of-life" was removed to honor the actual beliefs of the community. This language and change of perception increased ease in establishing solid community contacts and created an observable shift in how the project was received by the Native American community.

Influenced by this lesson in cultural awareness, other aspects of promoting this project to the community were addressed, such as visuals used in marketing, media, and outreach.

Outreach was most effective when the Research Team presented hospice and palliative care education and information sessions to the community. By conducting informational workshops on hospice and palliative care, a health specialty that was unfamiliar to many, community service providers gradually became more eager to invite the Research Team to share at events typically closed off to outsiders.

As the full spectrum of services were promoted in this manner, community members and individuals expressed gratitude in gaining knowledge that such services exist and are available to them. Community service providers and health educators became more willing to host hospice and palliative care information sessions across their networks, and individual interest in the assessment aspect of the project increased.

Participant Characteristics

Purposive designations were set to qualify participation in the project. This meant for Rural participants, submissions were limited to the Capay Valley, the Arbuckle-Dunnigan Valley, Woodland, and Winters.

The federal definition of *rural* is any people, housing, and territory that are not within an urban area [27]. The challenge with this definition is that many zip codes within YoloCares service area include both urban and rural neighborhoods, yet federal guidelines typically consider all these zip codes as urban, since the population is too high to be defined as rural.

For purposes of this project, a new designation was created for the Capay Valley and surrounding rural boundaries based on distance to travel to services, paved roads in proximity, and other specific metrics.

The new criterion was set to include:

- Primarily an agricultural area;
- Ranch land or farming visible;
- No paved road for at least one mile from the residential property line (i.e., walkable sidewalks);
- significantly smaller choices for shopping and medical offices.

Residential addresses meeting these criteria were mapped out in YoloCares five-county service area and have been used to track the number of Rural patients and clients from the early stages of the project.

For Native American survey participants, submission criteria were expanded from explicitly Northern California to all of California. This was done to increase participation and to account for variation of tribal beliefs throughout California.

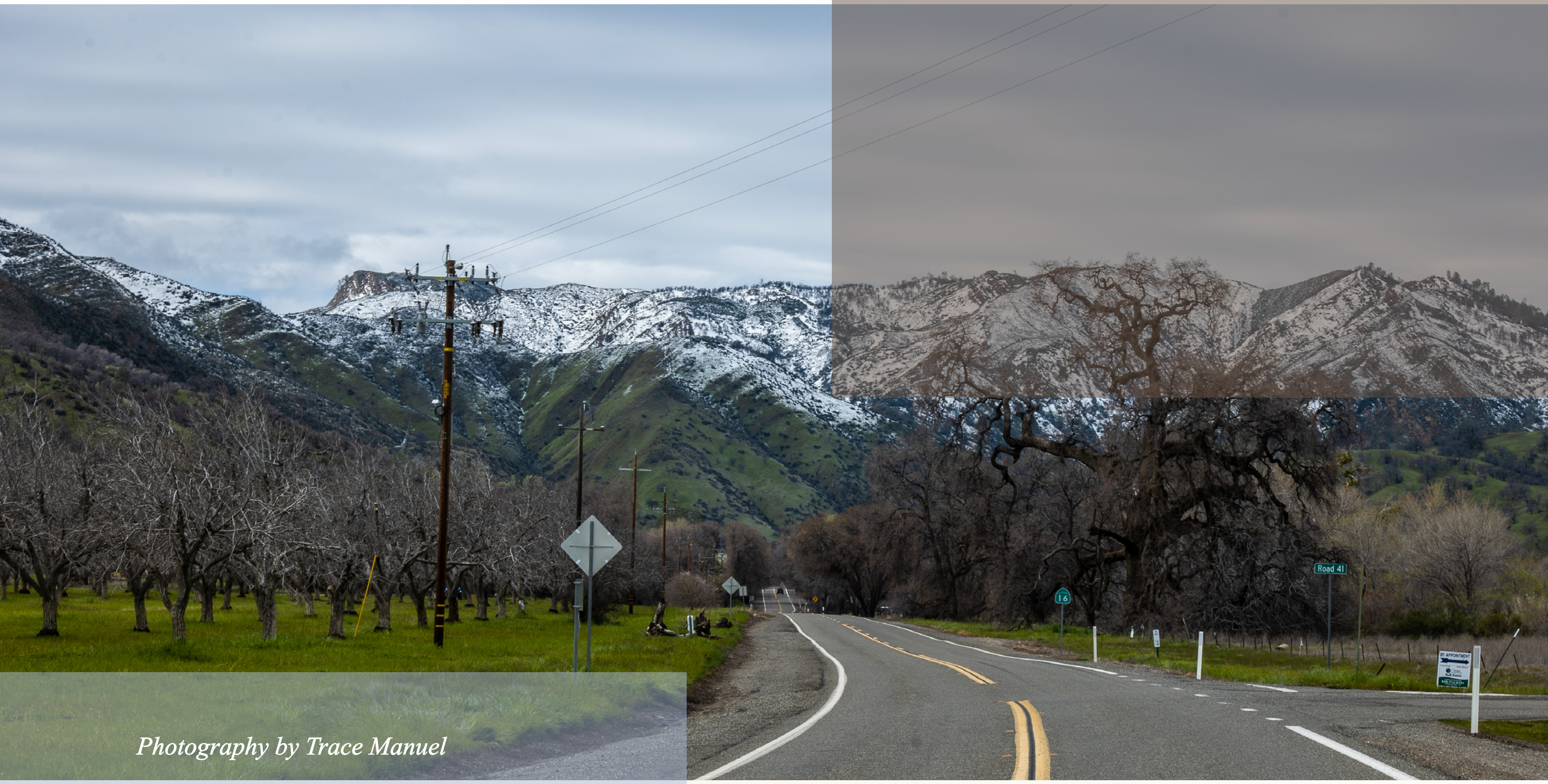
Since the Latin population in the Esparto region of the Capay Valley is two times higher than all of Yolo County, they were deemed a population of interest for this project. The total demographic breakdown is as follows: [Table]

180 total participants completed the survey, 131 of whom used the online platform, 49 of whom participated in focus-group or one-to-one interviews and mailed in surveys.

Most participants in all forms of data collection were female, approximately 75%. The majority of participants were Native American, approximately 57%, identifying with and without a mixed-race designation, followed by Caucasian 19%, and followed by Hispanic, Latin, or Spanish origin at approximately 14%.

All participants lived in the state of California, representing 27 of 58 counties (Map). Many participants' residential counties were Sacramento, approximately 42%, and Yolo County, approximately 18%.

The largest age range of participants was 40 - 55 at approximately 33%, followed closely by 56 - 73 at approximately 32%.



Photography by Trace Manuel

Considerations and Unique Challenges

Ethical Considerations

This assessment was conducted by non-Native American, non-Hispanic, and non-rural dwelling individuals, effectually "outsiders." Given the complex history of research within Native American communities, considerations were taken with account to sensitivity, individual autonomy, and reverence to tradition and culture.

The work performed was meant to inform YoloCares programming and practices, to improve the quality of services for families and individuals within our service area. Safeguards were put in place such as disclosures for meetings, for documents regarding very limited sharing of information, and participants were advised to only share identifying information for mailing purposes.

The Research Team was cognizant of and careful in the design of the assessment project to conduct it in a manner that protected cultural integrity and contributed to empowerment of communities, through a two-way exchange of information.

Unique to Native Americans

Non-federally recognized tribe members make up a substantial portion of the Native American demographic across all of California and are not concentrated to any specific region. Federal recognition or the lack of, is an indicator that the extent of barriers may vary for different members of this population, for example healthcare access.

Participants from non-federally recognized tribes reported receiving extremely limited options for healthcare services. Even members of federally recognized tribes reported traveling long hours to receive different health care treatments and services, as Indian Health Services (IHS) do not house the same services at each location.

Rural Access

Rural community members face difficulty in accessing services due to geography.

In the Northwest region of the Capay Valley, there is only 50% broadband coverage [22]. Difficulty accessing the internet can result in adverse health outcomes. At the height of the pandemic, there was a dramatic shift from in-person visits to online telehealth appointments. However, where internet service is unreliable and inaccessible, telehealth visits cannot be completed, and primary care and preventative health care appointments are often postponed.

Additionally, rural service providers tend to have more limited hours and resources. When the Research Team traveled to the Capay Valley for outreach and to establish connections, many health and social services were closed during their listed hours of operation.

In other cases, some programs that were open were severely understaffed, which led to long wait periods and extremely poor or miscommunication of service availability. These access difficulties are experiences shared by the community members that rely on them.

Transportation

The Capay Valley consists of a large demographic of farmers and farmworkers.

In conversations with this demographic, it was commonly reported that there is an urban diaspora taking place consisting of children leaving home for the city and elderly parents becoming their own primary caregivers.

Many living in Esparto commute to Vacaville (a 30-mile drive) and some to the San Francisco Bay Area for work (+/- 80-miles one way). Participants reported that the aging are struggling to remain on their land as some are feeling forced to move due to lack of medical services in the nearby vicinity.

The volunteer-lead fire department must answer calls and serve as a transportation service, because the ambulance is considered unreliable and expensive.

An estimated 65% of calls received by the volunteer fire department are not for fire-related issues but for medical response. Native communities want to go to clinics and hospitals that are covered by IHS, but to accomplish this requires lengthy drive times. 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.

Having disparate clinical settings creates gaps in care. More participants reported that certain trips can be between two to four hours for transportation to the clinic for elders with chronic health conditions.

Cost

Farmers pay out of pocket for medical coverage, which can be between $1200 -$1800 a month, so many do not elect coverage.

As farmers sometimes do not have coverage themselves, it may be difficult to provide insurance for their farmworkers. These individuals usually only go to the hospital in emergency situations and do not have the ability to utilize preventative care services.

This is vastly important to consider when examining elements of rural utilization of hospice and palliative care services. Hospice requires physician referral and because many of these individuals do not regularly visit doctors or have access to community clinics in the first place, the connection cannot be made. Even when it is possible to get a referral, many of these individuals cannot afford to be on palliative care services with lack of coverage.

Everyone has the right to hospice regardless of insurance coverage, however some hospices will still often deny patients who do not qualify for Medicare coverage. Cost and lack of insurance remain prohibitive factors for accessing end-of-life-care services.

Assessment Results and General Themes

Community Education and Awareness

More than 50% of participants expressed a lack of education and awareness of available hospice and palliative care information in the places individuals go to seek care and health related information.

Participants reported the first place they go to identify health-related issues is their healthcare provider (53%) and second, Google (34%) (Table). Around 23 participants reported their healthcare providers were larger healthcare systems, secondary mentions included regional Indian Health Service providers. Palliative care is a developing field and many participants, focus group and workshop attendees had little knowledge of what these services are, how they are provided or what they entail (see description in Table).

When looking at living will statistics, 90% of participants do not have one completed (Table). This disparity falls upon all medical care providers in lack of guidance and education provided for non-dominant ethnic groups.

The most common complaint of Native American participants was a lack of knowledge that full spectrum Life Transition services exist. YoloCares developed several marketing materials that specifically addressed the Native American audience and placed those materials in partner community clinics and social service offices. Working with these clinics and agencies to promote the project proved promising as Native American interest in the project increased.

It is right to assume that setting, culturally appropriate messaging, and content that reflects the changes and services of the agency will act, at some capacity, to increase community awareness and availability of information.

The Research Team made additional efforts to immediately respond to this need, by collaborating with service providers to offer on-site workshops as a resource to this community. This work took place in addition to the assessment project.

Need for Compassionate Care

The consensus amongst all groups was that, irrespective of ethnicity, faith, and identity, quality compassionate care must be the most underlying precedent.

Most responses surrounding this topic expressed the need for extra care from the care team for family caregivers; and treatment grounded in warmth over preference towards a solely clinical role, "someone that is treating the patient as a person and not a diagnosis."

This expression of compassion is severely lacking in generalized healthcare settings and can be the deciding factor between a positive experience and a negative one.

> **"*Someone that is treating the patient as a person and not a diagnosis.*"**

Need for Compassionate Care

Community participants reported that inherent biases by physicians and healthcare providers affect medical treatment and perceptions of safety by patients.

According to the majority of Life Transitions Project survey respondents, medical mistreatment and discriminatory practices run rampant in organized healthcare settings and purportedly promote fear and discomfort when individuals consider looking to others for outside help.

Participants reported feeling unsafe to ask for certain treatment options due to inherent racial stigma that is tied to historical trauma and stereotypes reinforced by medical bias. There is an inherent fear in feeling “othered” and being perceived as different 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 felt that care providers see them as mystical and romanticized indigeneity rather than seeing them as a patient to care for.

This mistreatment stems from generations of repeated offenses toward the Native community, reproduced by institutional unwillingness to reflectively work on cultural humility through provider education on inherent biases. Major healthcare organizations and agencies will need to take a critical look at their internal systems as a whole and medical providers themselves, as individuals.

This is a systemic issue, and the goals of providers should include nurturing a safe environment for patients and establishing the trust of culturally diverse communities. This will require re-education, relearning, and room for honest inquiry of self as relating to treating others.

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

There are also considerable power differentials between clinicians and patients that need to be understood. History has been perpetuated by systems of oppression validating power imbalances.

Enforcing Western centric domineering ideologies through medical care has often come at the expense of invalidating Indigenous spiritual care. Western medicine and Spiritual healing are often more connected than many would like to believe. With proper direction, there can be opportunities for collaboration between Western medical care and traditional holistic healing.

They are often seen as an “either/or” choice, but if care practitioners openly advocated for patients to have the right to elect the kind of care they wished to receive, then care has the chance to be meaningful and personal.

Need for Compassionate Care

Cost was reported frequently as a prohibitory factor. In 2021, 64% of uninsured adults said they were uninsured because the cost of coverage was too high [28]. This lack of coverage often leads to many gaps in preventative care.

One in five uninsured adults in 2021 went without needed medical care due to cost [28]. This is important to note for this study as well, as cost is the second highest reported reason for avoiding healthcare (Table). Creating avenues for affordability and case-based opportunities for individuals is vital. At times, coverage is not an option when considering undocumented and migrated individuals.

Rural community clinics are often overrun and do not have the full resources and capability to attend to the needs of this group. Focus group attendees reported that palliative care is a service they would be interested in, however, no information on palliative care is generally available to the community.

Inclusionary materials and information should be available in all clinical settings, especially community clinics, a place where people rely on brochures to gain awareness about new topics, as clinicians have little time on each visit.

Native American Representation

Participants mentioned that a way to improve their experiences in health and in-home care services would be to increase Native American staff representation throughout the clinical care infrastructure.

Participants mentioned that when staff representation is not an option, another desire would be for programmatic expansion, through increasing cultivation of culturally aware and responsive systems.

Although clinical representation and diversity are known to improve healthcare experiences and outcomes, the amount of diversity in clinical hospice care has not kept pace with the changing demographic of its field. Hospice, being a specialty care field, can respond to the needs of this demographic by creating appealing clinician pathway opportunities for Native American clinicians.

There is an active drive to increase Native American medical program enrollment across the country, and involvement in this effort through local college programs can increase representation and familiarity with the cultural nuances among these groups.

Rural Resident Representation

Rural White participants mentioned little regarding representation in a clinical setting. However, rural Hispanic respondents were adamant regarding representation.

Language and access to programs with Spanish speakers was the most reported barrier by respondents. It was also reported in interviews with members of social programs that almost exclusively serve the Hispanic rural population.

Mexican-born, first-generation families expressed not only a dire need for Spanish-speaking representatives, but also a need for immigrant representation. About 90% of Mexican

> ***“When thinking about the experience my grandparents had in assisted living, it would have been nice to have someone Native come in to visit them during their end of life to reassure them and our family members of the ancestors waiting for them.”***

immigrants speak or learn fluent English as they adjust [29], however, respondents feel there is little representation by way of clinical care and health service navigation to address the unique experiences and needs of immigrant families.

Representation among staff is a crucial factor in service utilization. Native and Latin participants reported that they and their family members would be more likely to use services if there were staff that looked like them. More Native American and Hispanic clinician representation would promote comfort and familiarity to those nervous that medical staff would not understand their cultural beliefs.

A commitment to recruitment and equitable hiring of culturally representative staff needs to be a priority of leadership in organizations. This intentionality in hiring ensures that there are people with differing perspectives, experiences and cultures promoting decisions that appropriately serve these individuals.

Hiring practices usually limit diversity to low level managerial and clinical positions, but there is dire need for increased cultural diversity in administrative leadership and director positions. Having representation at every level of decision making ensures that communities are heard and have representatives with vested interests.

Rural Resident Representation

There are roughly three million Native American people in the United States with 574 Native American tribes recognized by the U.S. Government.

Prior to the implications of colonization there were more than one thousand recorded Native American nations residing in the expanse of the North American landscape. It is important to recognize this is a heterogenous group representing many nations which hold to their own unique traditions, values, and teachings. The beliefs of one group may not represent the beliefs of another.

What is almost ubiquitous, however, is the view of the Creator. The ideal that Native American culture and spirituality/religion are not separate, tends to be something harder to conceptualize.

Health providers caring for Native American patients should be aware of this cultural perspective and 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.

Participants suggested there should not be a separate Native program in a non-native run organization; to do so would be exclusionary to the vast beliefs and identities held among Native community members.

Instead, organizations should improve elements of existing services to be more inclusive by building Native networks, making programs and information accessible where Natives are, and allowing programs to be dynamic to welcome as many elements of culture and tradition as possible.

Table 1. General Themes Adapted from Open-ended Responses

Key Findings	Summary	Participant Responses
Holistic Offerings	Many tribal-affiliated participants expressed interest in service offerings that reflected spiritual and cultural beliefs. Many organizations follow a Westernized approach, which limits access to more spiritually healing practices such as **saging, healing ceremonies, prayer and traditional drumming**. When these resources have been requested, caregivers have been denied or disrespected, often perpetuating historical trauma. Locating and obtaining these services can be difficult. Some tribal members have relatives that can be contacted to perform a ceremony, but for others that may not, this can serve to be a barrier.	• "They brought in a Chaplain to perform last rites, and my father had been in a residential school growing up. Seeing the Catholic chaplain triggered him, and he passed immediately after being traumatized. It was hard on him and also us to see that happen." • "I would come from it through a heart space and share the cultural teachings of the 8 stages of life to explain what stage we need to consider end of life care and explain that it's part of life just like the 4 seasons (spring, summer, fall, winter). It's natural and it will be our time to move into the next world while understanding that everything in this world will be okay. They will need to let go during that time so their spirit cannot linger"
Education	Community members feel that caregiving agencies should make information about services readily available. Clinicians should be prepared to provide thorough instruction to fully aid in the caregiver's journey as well as to assuage fear and promote comfort. However, there is already a large disparity in knowledge about available services across communities in our region. Within the target populations addressed in this research project, if families know the services exist (and many do not), most have a vague understanding of how to access them, and many believe they are unaffordable. To address this barrier, consistent community outreach through events, workshops, and information sessions must take place.	• "I feel like care providers don't always explain options or offer additional information. They don't make sure I understand what's happening. I don't ask questions because I don't know what questions to ask." • "As someone who works with seniors on a daily basis, it would be nice if the services available to seniors and their families were more visible and available in more rural areas. Easier to access." • "This topic is not spoken about enough among families or cultures. The documents should be available and offered to all, when visiting a medical facility. Perhaps seminars to community groups about the importance and usefulness of these documents." • "Providing education pieces to Natives in their communities or in homes."

Table 1. General Themes Adapted from Open-ended Responses

Key Findings	Summary	Participant Responses
Transportation	Community members felt that transportation was a pressing issue and significant barrier to accessing care. Many seniors need buses to go to appointments, socialization programs, and errands. Buses usually do not cross county lines so getting to hospitals, and other healthcare-related appointments is a challenge.	• "Transportation to hospital is a problem. Ambulance has dropped him numerous times while transporting him. They usually call the fire dept (Dunnigan) for transportation to the hospital. Wife is the primary care-taker but it is difficult for her as her husband is paralyzed through half of his body and is bed bound. She has tried to pick him up on her own and has almost dropped him." • "Could not find buses which go from one city to another for 50 - 100 miles." • "Better transportation was needed for medical appointments."
Language	Many Spanish-speaking community members expressed concern over language access issues. Many individuals stray away from utilizing services, because they feel that organizations do not have adequate resources to provide the same amount of care in Spanish that they would in English. Few staffing positions in medical settings are filled by bilingual staff, creating an inequity in care.	• "Bilingual social worker for sure. There are not many bilingual social workers that can communicate with the Hispanic families after the death of a terminally ill person." • "Having a bilingual spiritual counselor. Usually there are no spiritual people that speak Spanish, and then how can the dying person fulfill their spiritual need."

Table 1. General Themes Adapted from Open-ended Responses

Key Findings	Summary	Participant Responses
Acceptance of In-home Caregiving	Participants from all communities (Native and Rural) are wary of allowing strangers in the home. There are many reasons for this discomfort, including fear of being judged and fear of retraumatization. In-home supportive services need to consider the subversive elements of historical trauma, and the convergence of where the past meets the present today. Care and tact need to be considered when dealing with communities that have been harmed in the past and continue to be to this day.	• "Organizations have a history of taking kids away from their families, that trauma of having new people coming into the house still prevails." • "Left family member in the care of caregiver and when 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." • "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."

Implementation for YoloCares

Fostering Organizational Accountability

Significant hospice and palliative care data makes clear that the ethnic minority disparities in these services are not shrinking [1] [2] [3] [4].

Agencies that do not have a history of working primarily within ethnic minority populations should plan to devote considerable time to assess the needs, experiences, and past and present barriers within these communities.

Internal strategies should focus on building a solid yet flexible framework to address these needs. Internal actions should be strengthened by building community trust and extending partnerships to local community-based organizations actively involved with underserved populations.

All employees, from administrative staff to clinicians, are representatives of the organization. Significant consideration, time, and effort should be dedicated to organizational Diversity, Equity, and Inclusion (DEI) efforts. Identifying and deconstructing organizational culture and behaviors that foster resistance to cultural humility and patterns of implicit bias from within must be addressed first.

Only when significant efforts have been made to change these often-overlooked behaviors can any organization make serious strides in addressing the hospice and palliative care needs of underserved populations.

Community Education

As determined by the assessment, dedicated time and effort must be given to the creation and delivery of educational material. Development of information materials and hosting of educational community workshops will continue to be done by clinical teams and through caregiver education services.

To truly break the informational access barrier, outreach must be done directly where community members gather organically. Outreach performed by YoloCares Research Team has already established a widened community presence throughout the project, but a presence at pow wows, health fairs, and other community events must continue.

Along with outreach, educational workshops about YoloCares services will continue to be offered to Native and rural communities within the 5-county service area.

Sutter Health has provided funding to build a Community Champions Program within YoloCares. Community Champions will be key community members and active leaders from the identified target populations. The champions will complete outreach through participation at events and dissemination of information of our services through their respective communities.

The expectation of this program is to reach underserved communities in a more organic way than would be possible for the agency as is, because the Community Champions are already trusted and respected members of their community.

Assessment and outreach findings demonstrate that individuals with limited literacy levels and limited English proficiency tend to avoid healthcare visits. This avoidance may be due to a fear of being misunderstood, and embarrassment due to lack of language and systems proficiency.

Implementation for YoloCares

The Community Champions program should serve to alleviate language barriers as some Champions will be bilingual and culturally representative of the respective communities.

Media

One of the barriers for information accessibility was lack of materials thoroughly explaining services in Spanish. All of YoloCares' main informational brochures and booklets are now available in Spanish, with a commitment to getting all admissions materials fully translated and distributed in 2023.

Still remaining is the issue that prior informational brochures only use high level terms and do not consider uneven literacy levels. This burden leaves families with gaps in knowledge they cannot fill without guidance, resulting in the disuse of services.

To address this, YoloCares will recreate its materials adhering to more accessible formats and simplified language to promote comprehension.

Due to the high language diversity in California, all local health organizations should assume that everyone has lower literacy levels and adjust accordingly. Media should reflect all literacy levels. YoloCares is striving to offer programming and materials that can better accommodate the diverse populaces of our Sacramento region.

Spirituality

Many individuals reported that hospice and palliative care organizations should have more spiritual elements incorporated alongside clinical care. In one urban IHS setting, of 150 adult Native American patients, 38% reported seeking medical care from both a physician and a traditional healer [30].

Survey respondents have suggested bringing on a spiritual healer, having sage and other medicinal alternatives available, and incorporating drumming. While deliberated internally, it was not deemed appropriate to hire a healer to perform services through the organization.

This decision was based on reports that (1) healing is usually a personal experience for families and is traditionally done through community-based connections, and (2) an inability to account for tribal diversity. One healer could not and should not encompass the diversity of the Native experience and would not be able to properly serve differing tribal traditions.

In response to this, YoloCares will create partnerships with healers in the local community and build 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. This will serve to supplement or, if desired, replace the YoloCares spiritual care team.

Representation and Training

It is crucial that staff represent the populations that they are hoping to serve. YoloCares is actively seeking Native social workers or nurses to join the clinical team.

In the interim, priority will be given to volunteer recruitment for Native and Spanish speaking individuals. Volunteers provide both companionship to the patient and respite for the caregiver. Increasing the diversity of volunteers can serve as a key connection point to culture for patients that are in transition and are searching for a friendly, familiar face.

In addition, cultural humility and DEI training is necessary for all staff to promote avenues for reeducation. A training series has been launched with an in-house video featuring a Native historian. It covers Native history and how it relates to the present, as well as tribal diversity. This series will be continued with more training specifically focused on Indigenous communities.

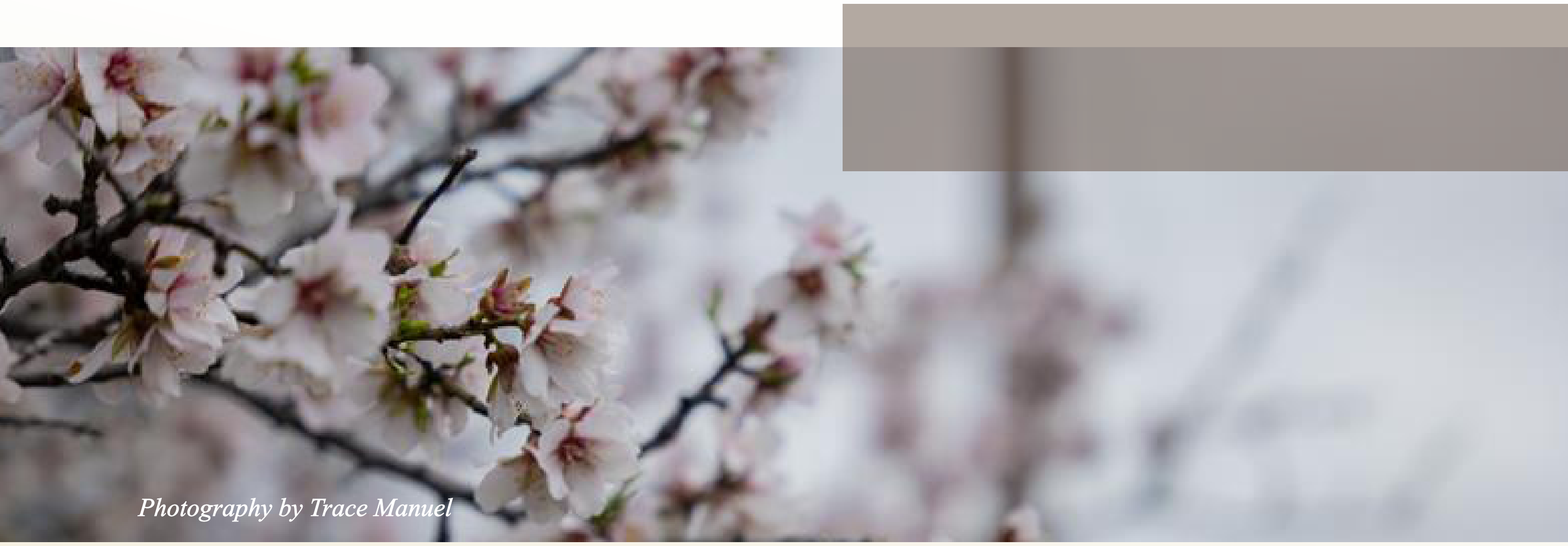
Transportation

Transportation and personal health choices are the two most frequently reported barriers to accessing end-of-life care among the target populations.

One financially viable response to these barriers is to partner with the Capay Valley Health and Community Center to create an onsite clinic for palliative and other end-of-life services. This satellite presence would make services more accessible to rural residents living furthest from current service locations.

Consideration should be given to the demographic characteristics and cultural landscape of the Capay Valley. Bilingual service is very important, as the Hispanic population throughout the Capay Valley region is on average two times higher than all of Yolo County [22].

A Yolo County needs assessment completed in 2000 [22], identified that Hispanic residents in all of Yolo County make up 26% of the population, and in the Esparto region of the county 42%. Additionally, the population of the county has grown approximately 19% every 10 years [22].



Photography by Trace Manuel

Considerations for External Agencies

Being Community-minded

For community-based organizations to create better channels of care, we need to grow stronger together. By utilizing the power of community as a resource we can leverage stronger partnerships and better delivery of care.

This might mean coming to speak at another group's event to share information, having other organization's flyers in your clinic, or building formal partnerships. Stronger partnerships lead to a stronger referral system and innovative pathway building for consistent models of care.

This is why organizations should take any chance they have to collaborate or, at the very least, become mindful of the resources that already exist in the community. Broadening the availability of information and networks helps shift the direction from patient-centered care to person-centered care.

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 entails unstable housing, limited access to food and water, or disturbances in their home life, 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 comes in for routine appointments for dialysis, and while she is there, she discusses her living situation and how she is in between housing. Having the information to offer a local women's shelter and instructions on how to pick-up food from Meals on Wheels creates the opportunity for full wraparound, person-centered care. This is reported as lacking by many participants and makes the difference in comfort levels to receiving care while increasing service utilization rates.

Get Comfortable Approaching End-of-life Care Topics

Many physicians and nurses admit they received very little training in hospice and palliative care, and if there is knowledge, usually it is only due to personal experience with it.

As many have little training and familiarity with the scope of services, there is a lack of comfort approaching conversation about life-ending illness. Our society focuses on cure and admission of death often feels like a failure for the care team, the family, and the patient.

Broaching the topic of death in a death-positive way can lead to a meaningful and impactful relationship created 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. Underserved patients are often only on hospice services for less than a week before passing and the highest cited reason being late referrals coming from physicians.

To bridge this gap, there needs to be increased comfort and understanding of death on the provider's end. This could lead to earlier referrals and the chance for patients to have the option for increased quality of life due to comfort care.

By having open and frank conversations with patients about their healthcare goals and the trajectory of their illness, medical personnel can help patients make informed decisions and choose the level of care that aligns with their goals.

Auxiliary training and preparedness surrounding education on hospice and palliative care would be beneficial for all providers working with patients in any capacity. Often, we only see this present in sectors dealing with aging adults; however, efforts must shift to also reach individuals of any age who may need these services. A life limiting diagnosis can come at any age, so it is best that providers are prepared for every situation.

Participants reported a lack of clinical humility and compassion when delivering news of a life-limiting diagnosis. It is crucial to be mindful that families receiving terminal diagnoses are facing challenging times and need kindness from the care team to get through it.

Be Proactive about Cultural Humility and DEI

Many participants felt that they did not want to go to health clinics and hospitals due to unfair bias and racial stigma that continues to be perpetuated by medical providers.

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

This happens by being intentional in conducting ongoing community-guided engagement and needs assessments on patients being served or not being served, and on the diverse culture of the communities in the surrounding areas.

Specializing in the demographics of each clinic's respective area creates the opportunity for improvements in culturally attentive care. Assessing customs, traditions, beliefs and having the willingness to learn can start the work on deconstructing generational medical trauma and reducing utilization disparities. Being a well-informed provider means being a better caretaker.

Example:

The Central Valley has the highest number of Hmong populations as farmworkers in the United States. If a care provider wants to bolster 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 encourage trust and increase community knowledge of the agency's services.

Patients feel comfortable being seen by providers that look like them as they feel that they might understand them better and may not judge when it comes to certain culturally tied health determinants. It is important to hire and be considerate of the staff that are being recruited.

Within preexisting staff, DEI training and resources should be made available and encouraged. Staff will benefit from learning and relearning how to properly navigate interactions with community members of differing beliefs and customs. Everyone wants to go to a provider that they feel understands them, makes them feel comfortable, and does not perpetuate racial discrepancies.

Cultural competency is something that many companies strive for and should remain a starting place. However, cultural competency creates a baseline of cultural understanding but is sometimes only a means to checking a box.

Cultural humility, in contrast, critically reevaluates the notion that we all have biases. These are implicit and often formed subconsciously from the media we consume and the social environment we occupy.

Cultural humility asks us to actively reconsider and relearn what we think we know through a personal journey that can be enhanced through education, meaningful training and conversations and connections we build with other people.

Cultural humility looks at the power of community and reciprocity of communal relationships. Organizations need to consider intentionality when striving to establish and practice cultural humility in the workplace.

Gaining insight into a patient's self-identification and cultural denomination positively serves to benefit providers with knowledge of personal health beliefs and patient preferences.

Asking the Right Questions

Learning how to ask the right questions is key to successful care delivery among the target populations. One response included, "Clinicians should have knowledge of culture and feel comfortable learning from clients and possibly experience customs together."

Another response said, "The first thing that should be asked: Are there any cultural/spiritual beliefs I should know about? Are there any foods/ceremonies?" Providers must be open to learning and must enter new patient relationships earnestly.

Patients can sense when providers feel uncomfortable broaching the topic and this can hamper trust. Providers are not expected to know everything, but are expected to be comfortable asking appropriate, culturally guided questions to inform care.

Once such knowledge has been gained, maintaining comfort and trust in accommodating any customs or traditions that families want is paramount. When delivering care to Native communities, the practices used themselves must be culturally healing.

> ***Clinicians should have knowledge of culture and feel comfortable learning from clients and possibly experience customs together."***
>
> ***"The first thing that should be asked: Are there any cultural/ spiritual beliefs I should know about? Are there any foods/ ceremonies?"***

It is also important to note that it is up to providers to be open-minded but not forceful in the face of customs and tradition. There are certain sociocultural beliefs that are sacred and will be kept under discretion by the family. Often, in the past when key cultural information has been shared it has been stolen, used to oppress, or even commodified. The key is to be open to listen and not quick to assume.

Incorporating culturally relevant questions into patient intake could serve as a natural and respectful mechanism for inclusion. The key is to ask open ended questions that allow patients to fill in the words themselves instead of using pre-established categories that hinder conversation and prescribe culture to an ill-fitting box.

Photo courtesy of Yocha Dehe Wintun Nation Spring 2013 Clouds

Discussion

Native American

Social determinants have an impact on the longevity of life for everyone, but it is important to keep in mind that members of BIPOC communities have poorer health outcomes when it comes to chronic illness. To serve these populations, hospice providers must work intentionally to weave in values which hospice traditionally has not.

The study shows that there is room for improvement in delivery of care to rural and Native communities. The barriers to care lie at the convergence of social health determinants and lack of cultural humility.

There proved to be a wide gap in knowledge and awareness of services on the part of the survey population. Many participants knew very little about palliative care. Those that knew of hospice knew so through personal experience.

As these respective communities are tight-knit and relay information through word of mouth, a negative hospice experience for one family may change the perception of hospice for others that hear about it.

The Research Team found this was often the case, as participants would report other friends or family member's negative experiences as reasons for mistrust. Many participants who believed they knew a lot about hospice and held to negative hospice stigma were often shocked to learn the benefits of hospice after attending an informational workshop.

For providers working with the Native community, there needs to be a greater understanding of history's lasting impact today. Understanding and accepting our communal role in the perpetuation of racial bias towards the Native community is vital to forging a new understanding.

As a society we have been complicit, often ignoring the ongoing repercussions of historical trauma and contemporary inequities. Creating harmony and building strong relationships across groups and communities takes meaningful action.

Providers must be willing to be uncomfortable as they reexamine personal biases and commit to meaningful efforts to engage these groups that have been largely without compassionate medical care for generations. This will take reeducation, as well as designated strategic efforts to place cultural competency at the forefront of incoming change.

Cultural competency that is not solely designed to check a box for a grant, or to be done for public perception's sake, but to truly start to unpack multiple generations of harm, trauma, and strife tied to the real life, lived experiences of these communities.

Care must not be viewed and delivered through the lens of whiteness, but through a spectrum of cultural resolution. To circumvent invisible yet omnipresent structural violence, care practitioners must be willing to admit the system exists within innate whiteness.

While there are many differing views on the inclusion of cultural healing, it is still necessary to understand the need and desire for beliefs to be considered for treatment. Maintaining cultural identity and personal identity as intrinsic qualifiers for personal healing is paramount.

Intersecting Cultural Literacy and Humility into the fabric of company mission and directive creates reverence towards these communities and works to circumvent further mistreatment. Native and rural communities need to be met where they already are and appreciated for their strengths of resiliency and community collectivism.

Providers must view these communities holistically, as people with storied pasts, but also with the strength of family and community to overcome. The culmination of the two serving as the intrinsic life force of a forward-facing people.

Rural

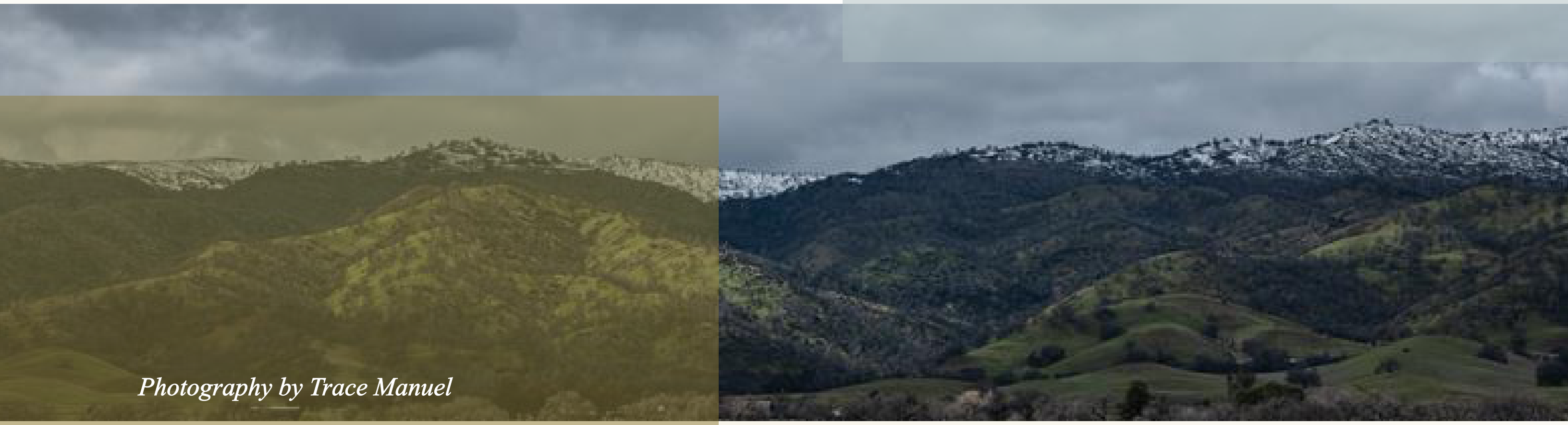
Through interviews with rural community members, we commonly identified indifference to the needs of the community between wealthier and lower Socioeconomic Status (SES) community members.

Wealthier community members in the Capay Valley were familiar with YoloCares services for families in need. Knowledge of the existence of these services did not necessarily indicate a guarantee to use them. The wealthier demographic of the Capay Valley expressed a value for independence and reliance on self as a reason they were not naturally inclined to ask for outside help.

The rural-urban diaspora and growing evidence that women are not outliving their male counterparts in rural communities, may become cause for rural dwellers to reconsider their long-term care plans. For those whose wishes are to remain at home for life transition services, organizational strategies should include bringing the services to them.

Lower SES and Spanish-speaking communities were unaware of YoloCares as a resource available to them. When informed of the services, through workshops or focus groups, they often expressed apprehension about welcoming an admittedly much-needed service into the home.

A main concern was culturally-representative health workers, if they were not Spanish speakers or had no cultural knowledge or understanding of the nuanced experiences of immigrant families, this community would also prefer to rely on itself.



Photography by Trace Manuel

Limitations

COVID-19 Pandemic

The COVID-19 Pandemic presented unique challenges throughout this project. Its impact included slowed response times and decreased engagement opportunities.

Gatherings with Elders, who tend to have more experience with and knowledge of these services, were often prohibited. Workarounds were created, through YoloCares-hosted online discussions, and events and postcard mailing distribution to promote these.

However, much of the older adult population were either (a) in geographic areas with unreliable broadband service, or (b) found the technology of the pandemic period a challenge that came too rapidly and was ultimately too large to overcome.

Many of the Life Transition Project partners also faced tremendous pressures due to the pandemic. Those who usually connect best with the community through outreach were unable to hold partnered events or maintain consistent follow up concerning the project, without direct efforts by the Research Team.

Smaller community-based organization hours became limited, and with most employees teleworking from home, connections were difficult to make and interest in the project harder to maintain.

Missed Opportunies

Many attempts to gain access to the Spanish-speaking farmworker community of the Capay Valley failed, one plausible reason being a lack of Spanish-speaking capacity at YoloCares to dedicate time to engagement opportunities.

Due to COVID-19 and poor timing, informational workshops planned at local migrant centers failed to occur. Once the opportunity was presented again, internal deliberations were made to decide that a dedicated Spanish speaker must be tasked to this project for better success. This person was hired but not until after the assessment phase had concluded.

This population was underrepresented in this project. Going forward, this disparity has been acknowledged, and the agency plans to target outreach through multiple channels.

Engagement Challenges: Partnerships with Tribal Communities

Reaching and creating strong partnerships with local tribes has been challenging. This difficulty ensues as tribally-affiliated people usually take care of their own, and non-tribally affiliated members can be displaced and are usually hesitant towards outside organizations.

Even once interest in the project was established, relationships remained sporadic. While some potential community partners have shown interest, follow-up has often failed to solidify partnership work. This may be due to a combination of the various barriers such as: lack of trust in outsiders and systems; conflicting priorities; COVID-19 restrictions; communication failures; lack of a credible “warm hand-off” introduction from a trusted source.

YoloCares’ position as a non-Native run agency has also served as an exclusionary factor. This has led to inherent distrust, and lack of response that may have been overcome if this same project were completed by a Native agency.

Self-Identification and White/Native Determination

Surveys were mailed out to all residents in YoloCares' five-county service area that identified as Native American.

When these surveys were returned, it was noticed that individuals marked that they were Caucasian while still listing a tribal delineation. Where explanations were cited, some were due to having mixed identity, identifying as Caucasian due to stronger familial ties, and privacy concerns with being identified as Native.

As this may have been the case for more submissions, ethnic demographics could be skewed.

For example, an assumption based on the few explanations received might be that more individuals of Native American and White lineage choose White only, although this remains an invalidated assumption for this project's purposes. However, to account for this, demographics were determined solely by individuals who chose to self-identify as Native.

Knowledge of Hospice and Palliative Care Services

The individuals that participated in focus groups received a thorough background on what hospice and palliative care were before being asked to answer questions on barriers and how to improve service offerings.

Survey participants, however, were not granted the same opportunity, thus creating a vast discrepancy in response value. While some responses were insightful and complete, this was usually due to previous personal experience with hospice and palliative care.

Without personal experience or education on these topics, other participant responses were often incomplete and indicative of lack of understanding of these topics.

In hindsight, a supplemental educational PowerPoint for survey participants to read before survey completion would have inspired more creative and complete responses.

Photo courtesy of Yocha Dehe Wintun Nation Spring 2013 Clouds

Conclusion

The aim of this project was to identify barriers to access and solutions to underutilization of palliative care service for Native American and rural populations of the Capay Valley.

The specific areas of concern were hospice care, palliative care, grief support, caregiver respite, and advance care planning at YoloCares. The project explored access to primary healthcare for these target populations.

The process began with examining existing work and assessments to find similarities and unifying themes to create a foundation for the direction of the project. This foundation was then amended to reflect the unique perspectives of Northern California and to uncover the nuances present in past and current health disparities.

The next step was becoming familiar with preferences rural and Native American communities held when it came to death and topics around death.

Bolstered by a CBPR approach, community relationships were built to combat historic disparities. This meant learning directly from the community what the community's needs were and exploring ways to provide solutions within our scope of practice.

The purpose of the focus groups was to give members of the Native American and rural community a platform to share personal insights into barriers to Life Transitions care and how utilization for families and individuals should look.

Discussions included perceptions and thoughts regarding:

- Advance care directives
- Grief practices
- Burial preference for members of non-federally recognized tribes
- A conversation regarding barriers that exist in both communities to accessing health care and using in-home care services.

The results suggest that for rural populations, the disparity in access lies in geographical barriers, lack of educational opportunities, lack of providers, and lack of existing healthcare organizations.

For Hispanic populations, discrepancies in access lie in lack of understandable materials and services in the Spanish language, as well as representation of bilingual staff.

For Native communities, disparity in access lies in lack of cultural competency and understanding by providers, mistrust of outsiders and the medical system, absence of holistically spiritual services, and the lack of community-based organizations, networks, and partnerships throughout the community.

These issues are not mutually exclusive. These communities converge around identity and difficulties in accessing care.

Considerations for addressing barriers in these populations should include generating intentional, nontraditional relationship building between minoritized populations and social service institutions. Hospice and palliative care organizations must prioritize establishing consistent cultural competency training for employees working intimately with these populations.

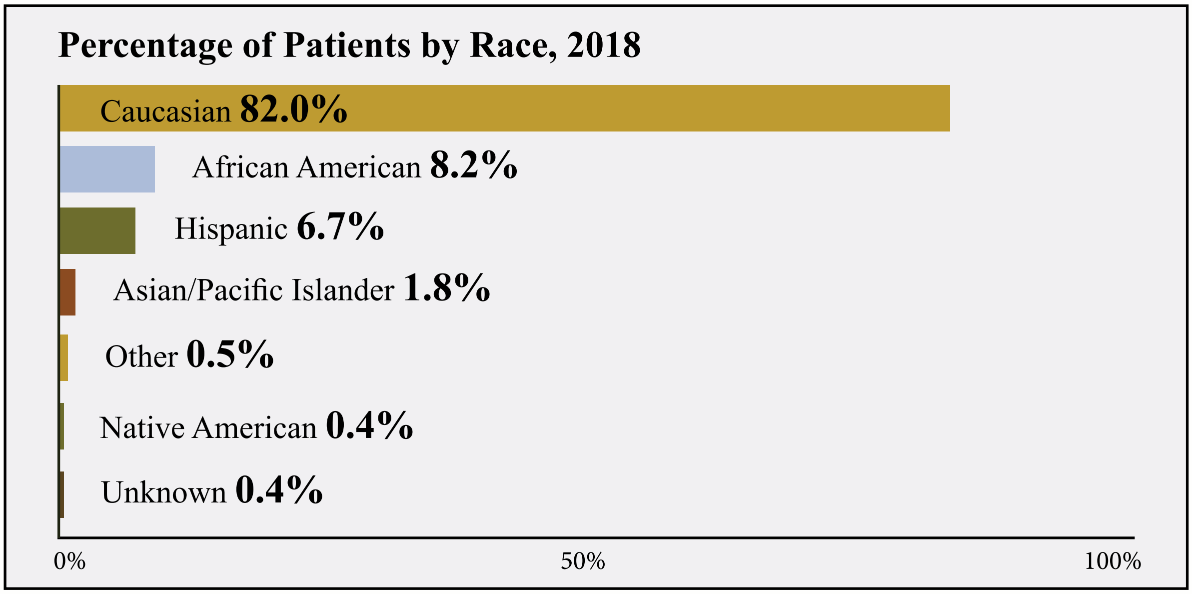
Providers seeking to engage these respective communities should approach them with openness, humility, and compassion to understand and serve members afraid of racial discrimination and other perpetuated inequities.

Tables and Charts

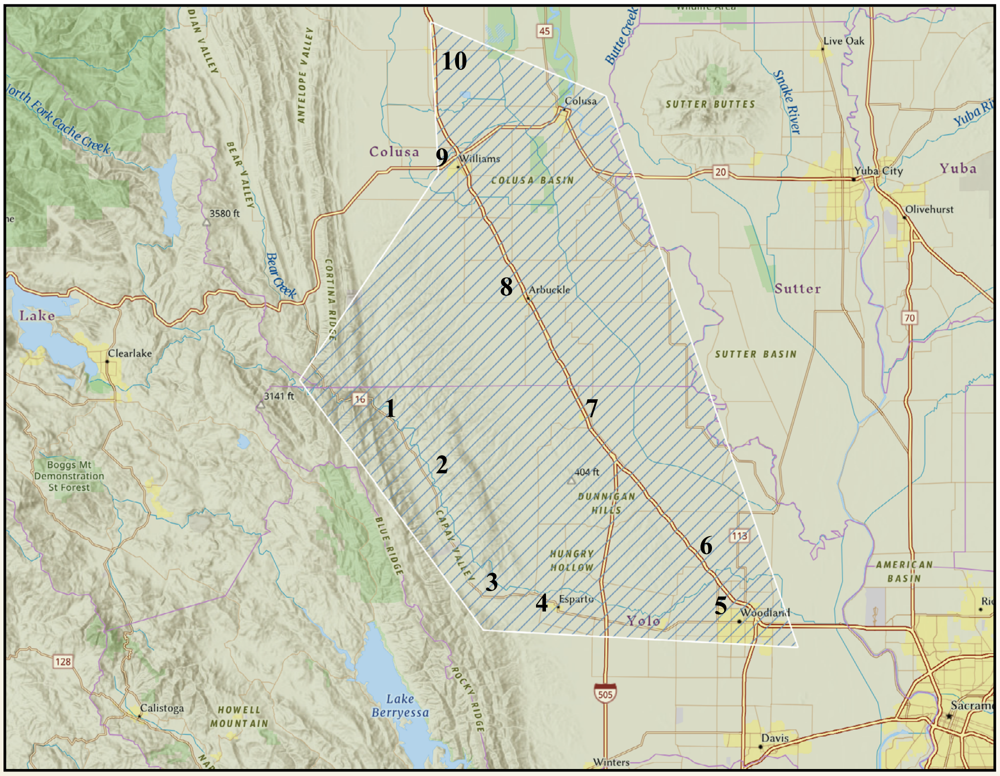
Figure 1: NHPCO 2018

Who Received Hospice Care?

What are the characteristics of Medicare beneficiaries who received hospice care in 2018?



Patwin, Capay Valley Map



Rural townships in the Capay Valley include:

1. Rumsey
2. Guinda
3. Brooks
4. Esparto

Rural townships on the I-5 corridor include:

5. Woodland
6. Yolo
7. Dunnigan
8. Arbuckle
9. Williams
10. Maxwell

Figure 2: Community Advisory Board Directives

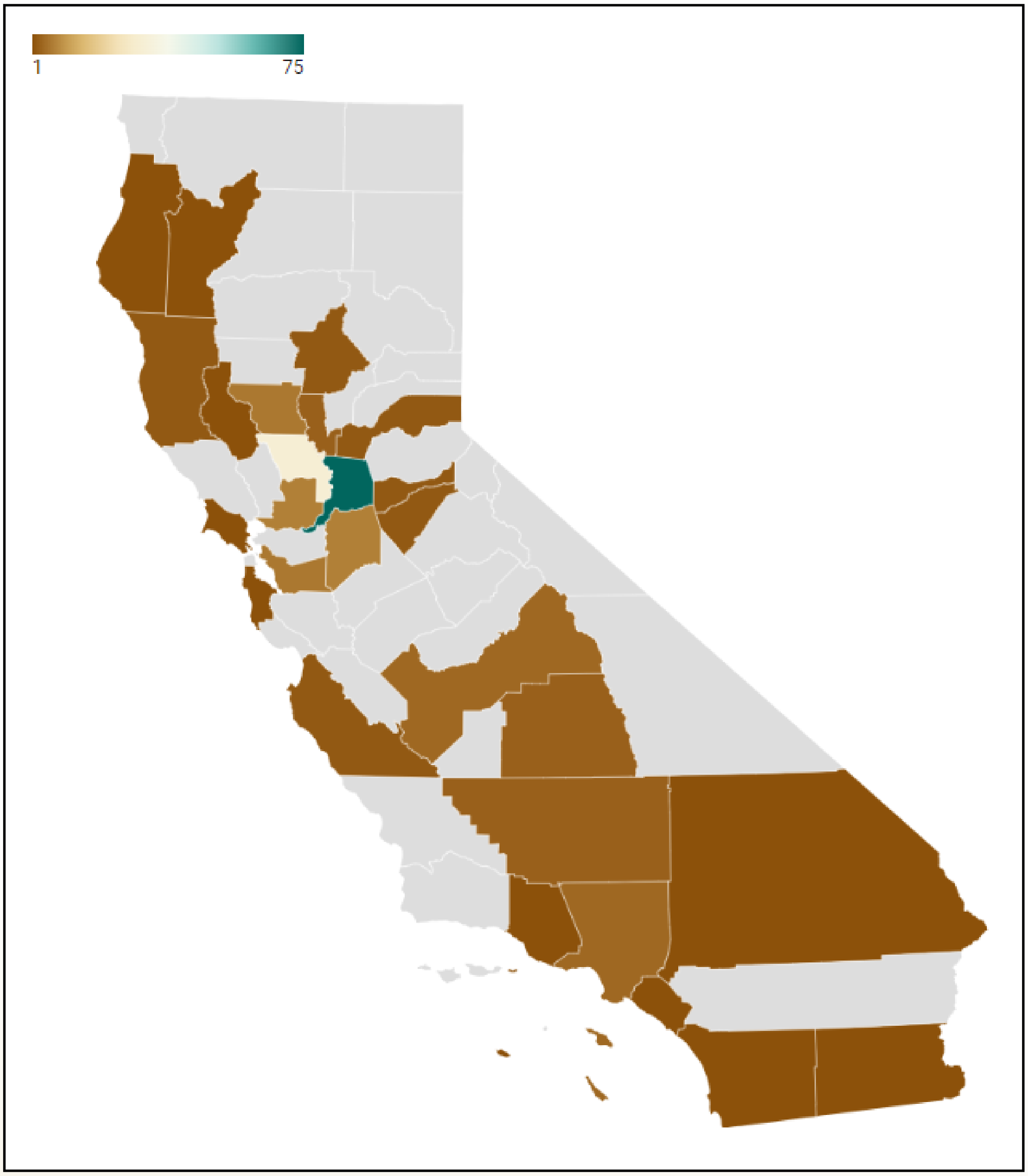
The Community Advisory Board (CAB) was formed to give advice and support throughout project and be a mutually beneficial partner in expanding services to rural and Native American communities. The CAB provided insight to specific barriers of the Capay Valley and included as many vested community partners and service organizations as possible. The CAB also provide access to respective community residents for research input and engagement and eventually, became a part of developmental phase by reviewing compiled data and landscape analysis, then helping to drive actionable implementation of findings.

The following table includes the initial directives given to the CAB.

Objectives	Activities
Encourage respective communities to participate in research discussions	• Distribute project marketing materials • Create space for research to take place • Partner on workshops, talking circles, roundtables
Share outreach and community engagement event opportunities	
Engage in research objectives	• Respond to requests such as survey questions *Advisory board members were encouraged to complete the survey.*
Remain abreast on project progress	• Attend CAB meetings • Attend other project and YoloCares community events
Assist with cultural fortitude	• Advise on cultural narratives, language, approach • Recognize and communicate on appropriateness
Engage in clinician search efforts	• Promote position on respective agency sites or through word of mouth
To improve processes, determine best practices, suggest methods/ideas	• Provide input
Remain active in developmental phase	• Active in developmental phase by thorough review of research data, findings and final landscape analysis

Life Transitions Assessment Participants by Region

Respondents' counties of residence was predominently concentrated in Sacramento and Yolo Counties, with highest percentage of participation by residents in Sacramento County.



For participant totals from each county, please review the table on page 43.

Survey Evaluation

Survey Summary

The following summary represents the quantitative results obtained from the Life Transition Project Survey.

The Reserach Team adopted a mixed-method approach in data collection and analysis. Throughout 2022, 180 total participants responded to the survey. Additionally, the Research Team conducted one-on-one semi-structured interviews and focus groups, meeting in-person or virtually with approximately 42 participants.

Items excluded from the quantitative summary include open-ended responses from surveys and focus groups or open-discussion responses which are explained throughout the written report.

Count (N) and Percent (%). Count is represented as total responses to the question listed on the survey. Null responses are questions that were skipped. Although some surveys were less than complete, the completed responses to surveys have been counted in the final analysis.

Race and Ethnicity. Race was self-reported. In the survey, six common categories were designated with a multiple-choice option so as not to restrict respondents with biracial or unlisted ethnic identities. 'Indigenous' and 'Other' were included as additional options. Multiple ethnicities were categorized in the final analysis by either 'Mixed with Native American designation' or 'Mixed with no Native American designation'. All others remain separate.

Approximately 60% of respondents were Native American, with counts of 68 Native American and 31 Mixed Native American designation. 16 people in the Mixed Native American designation reported their ethnicity as Hispanic, Latinx, or Spanish origin.

County of Residence. Participants reported 65 different cities as their primary residence. Of those, 30 are cities with a population of less than 20,000. The majority (18 cities) have populations of less than 5,000. These fall under the HRSA rural definition for clusters of less than 10,000 in outlying metro counties without urbanized areas of more than 50,000 [27].

Demographic of Survey Respondents

Values	N	%
Gender and Gender Identity		
Female	134	75.3
Male	43	24.2
Male: two-spirit, he/they	1	.5
Age Groups		
18 - 23	6	3.35
24 - 39	44	24.6
40 - 55	59	32.9
56 - 73	57	31.8
74 +	13	7.3

Values	N	%
Race and Ethnicity		
African American	7	3.9
Asian	5	2.8
Caucasian	33	18.8
Hispanic, Latinx, or Spanish origin	24	13.6
Indigenous	2	1.1
Mixed: Native American	31	17.6
Mixed: Non-Native American	4	2.3
Native American	68	38.6
Native Hawaiian/Pacific Islander	2	1.1
Other	1	.6
Counties of Residence		
Alameda	6	3.4
Amador County	2	-
Butte	2	-
Calaveras	2	-
Colusa	6	3.4
Fresno	4	-
Humboldt	1	-
Imperial	1	-
Kern	3	-
Lake County	1	-
Los Angeles	4	-
Marin	1	-
Mendocino	2	-
Monterey	2	-
Orange	1	-
Placer County	2	-
Sacramento	75	42.4
San Bernardino	1	-
San Diego	1	-
San Joaquin County	7	4
San Mateo	1	-
Solano	7	4
Sutter	3	-
Trinity	1	-
Tulare County	3	-
Ventura	1	-
Yolo County	31	17.5

Socioeconomic Status of Survey Respondents

Socioeconomic status was self-reported. The average income for participants was $40,000 - $60,000, 40% of the participants had obtained a college degree or higher. 65% of the participants were employed, followed by the next largest work status of nearly 23% retired.

Values	N	%
Income		
Under 20,000	33	19.3
20,000 - 40,000	35	20.5
40,000 - 60,000	65	38
60,000 - 80,000	30	17.5
80,000 or above	8	4.7
Highest Level of Education		
Did not complete high school	13	7.4
High school or equivalent	30	17
Some college	62	35
College degree	52	29.4
Graduate Education (Masters, PhD, MD)	20	11.3
Work Status		
Student	6	3.5
Employed	112	65
Unemployed	16	9.3
Retired	39	22.5

Assessment of Life Transition Services, Tools, Knowledge

Participants were asked a series of questions to gauge knowledge and comfort level with topics such as: healthcare professionals entering their homes, whether they were familiar with advance care planning tools and services and how family would be cared for in the event of a health emergency.

Nearly 80% of participants have no advance directive prepared but said they have knowledge of what an advance directive is.

69% of participants have not had experience with in-home visits from health service providers. Approximately 15% of respondents have existing knowledge of what palliative care is. Nearly 50% of participants reported they would probably welcome in-home visits.

Values	N	%
Prepared Living Will		
Yes	28	18.2
No	122	79.2
Don't know what that is	4	2.6
Experience with In-home Visits		
No	103	69
Yes	49	31
Current Knowledge of Palliative Care		
A great deal / A lot	23	15.1
A moderate amount	30	19.7
A little	49	32.2
None	50	32.9

Comfort Level with In-home Visits

This question was followed by an open-ended explanation of their answer choice.

59% of **Native responses**, including Native and Rural Native, expressed that they felt comfortable due to a past experience or felt strongly that if the service was needed they would welcome care into the home with conditions.

28% expressed they would not welcome outsiders into the home and do not welcome the idea. 6% expressed access concerns, such as cost and lack of available information, while 6% expressed that they would rely solely on family or community. 3% were unsure.

79% of **Rural, Non-Hispanic, Non-Native** participants expressed that they would welcome care into the home. 17% expressed they would not, due to privacy concerns and one respondent (4%) expressed concern with access to care.

54% of **Rural Hispanic** participants expressed they would not be comfortable. 31% would welcome in-home care and expressed they preferred it, while 15% of respondents mentioned access issues such as having no knowledge of what an in-home service would provide.

This question was followed by another: **"What can healthcare providers offer or change that would make you comfortable welcoming a caregiver into your home?"** The overwhelming response to the question was "take appropriate actions to establish trust."

Respondents expressed that having prior knowledge of the healthcare workers personal character and level of training/experience would make them more comfortable welcoming this level of care from someone outside of the family or social network.

Another common response was a "warm-hand-off," a referral by a trusted community member or healthcare provider with whom they have a good relationship. Respondents expressed that they would be more likely to welcome the care if it was coming from an individual that was from their same ethnic and cultural background, Hispanic respondents discussed language and immigration background.

Values	N	%
Comfort Level with In-home Visits		
Definitely	34	22.2
Probably	74	48.4
Probably not	36	23.5
Definitely not	9	5.9

Reported Healthcare Service Access Barriers

The survey and focus groups provided a definition of social determinants before participants encountered these questions and could select multiple responses.

The most frequently reported determinants of unmet health needs and barriers to healthcare service utilization were resources; financial (44%); time, such as the ability to take time off of work (37%); and transportation (30%).

Distrust of the health system and discomfort with medicals providers combined make up approximately 30% of total responses.

Priority population. Native American participants reported barriers related to discriminatory practice more frequently than all other participant cohorts. Rural participants more frequently reported food insecurity and personal health as barriers related to unmet healthcare needs.

Values	N	%
Social determinants of health		
Time	67	37.2
Cost of insurance	33	18.3
Discomfort with medical providers	28	15.5
Distrust of health system	26	14.4
Transportation	20	11.1
Preference for self-care or alternative healing	18	10
Distance to care	14	7.7
Other - Work related	4	2.2
Lack of insurance	2	1.1
Other – various/combined	7	3.8

Values	N	%
Barriers to social service and healthcare access		
Financial	80	44.4
Transportation	55	30.5
Discriminatory practices or experiences	38	21.1
Personal health	38	21.1
Education / Information	35	19.4
Open ended response	25	13.8
Food security	24	13.3
Transportation or public transit accessibility	22	12.2
None	19	10.5
Housing security	18	10
Legal aid	16	8.8
Other - various	9	5

Assessment of current health status and practices.

Participants were asked to report their perceived current health status. The variables were limited to "Excellent/Good" or "Fair/Poor." The responses to this question were overwhelmingly in favor of "Excellent/Good."

Values	N	%
Health Status		
Excellent / Good	110	64
Fair / Poor	60	35
Other – Good, Good/Fair	2	1
Most Frequently Used Source for Health Information		
Google search	62	6.1
Health Clinic	16	8.8
My doctor	96	53.3
Naturopath	4	2.2
Other: Family, Native American Resources, online medical site	22	12.2
*Miles Traveled to for Healthcare Visits**		
0 – 25	3	6.1
25 – 50	7	14.3
50 - 75	39	79.6

** The online survey question related to distances traveled for healthcare visits was miscalculated and fewer participants responded to that question compared to others; 49 participant answers were collected.*

Values	N	%
Current caregiving practice		
Family members care for family	110	61.1
Hire professionals	37	20.5
I am an unpaid caregiver	19	10.6
Other	1	.6
Other - Community	1	.6
Other - Only as a last resort	2	1.1
Other - Self	1	.6
Unsure	3	1.7

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Program Partners

Project Sponsors

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. Their commitment to improve community health 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.

The Community Advisory Board

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The Research Team

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 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.

As 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.