

**Hā Kūpuna National Resource Center
for Native Hawaiian Elders:
Decolonizing Research through
Qualitative Methods and Community
Partnership**

Caring for Data in Hawai'i Symposium
April 14, 2023



Introduction



University of Hawai'i at Mānoa
***Thompson School of Social Work
and Public Health***



Hā Kūpuna
***The National Resource Center
for Native Hawaiian Elders***
US AoA/ACL 90OIRC001

Our Name, Our Center - 2006



- **Hā:** a strong expulsion of breath; to exhale; to breathe; breathe upon; **breath; life**
- **Kūpuna (plural) - grandparent, ancestor, relative or close friend of grandparent's generation**
- **Hā Kūpuna** - ritual in which kūpuna chose to pass on specialized mana to a specific person through breathing into/onto them
- **Mission:** to improve health and increase life expectancy of kūpuna so that they can pass on their gifts to future generations.



Dr. Kekuni Blaisdell
named our center Hā
Kūpuna

Qualitative Protocol

Protocol for a qualitative study exploring perspectives of Native Hawaiian Elders to improve health outcomes



To help researchers avoid extractive practices by increasing their awareness of Hawaiian history and respectful research processes

Engage Native Hawaiian communities in research

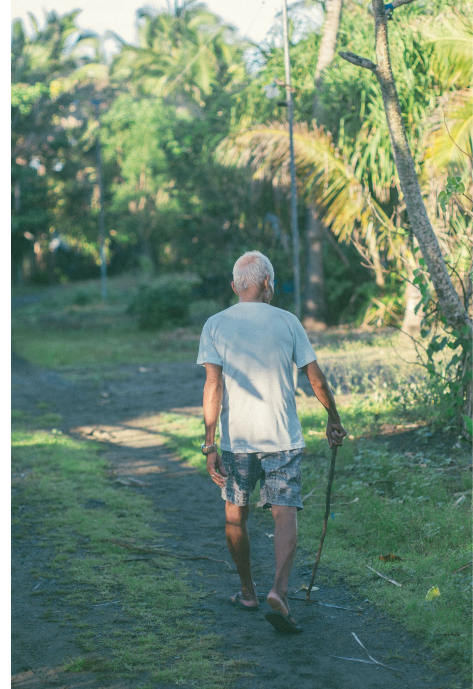
Create safe and trusting research environments

Methods

- 25-page protocol
- Developed based on years of gathering qualitative data from Native Hawaiian elders through a partnership with community-based service providers
- Discussed in depth with researchers, non-profit stakeholders, and past research participants

Overview

- Summarizing the history of colonization and instances of poorly executed research in Hawai'i that caused harm
- A step-by-step guide on how to successfully join with community partners to conduct one-on-one interviews



Sections

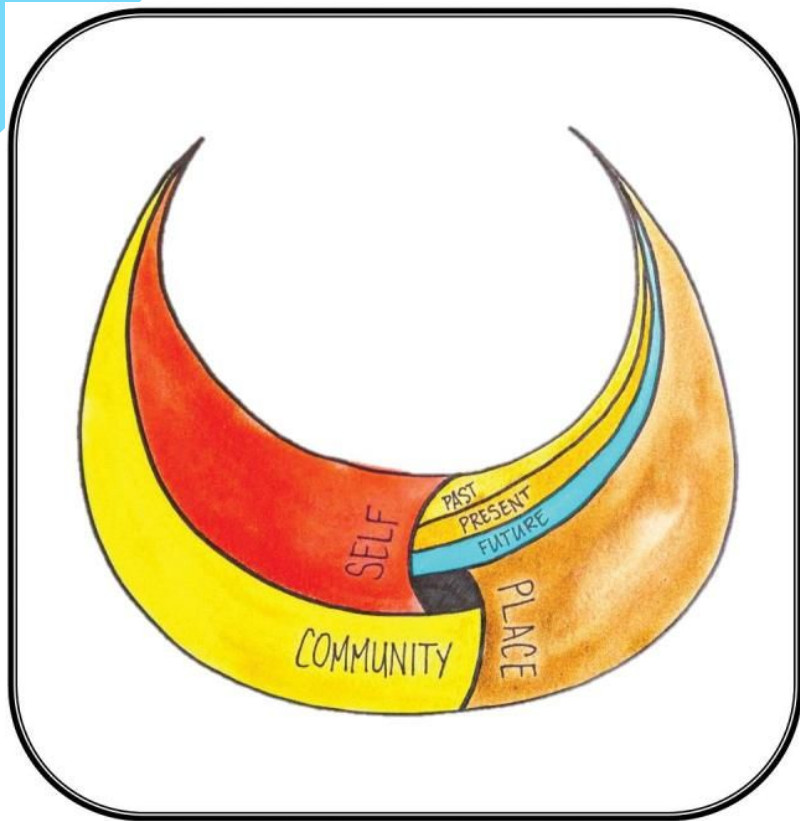
- Section 1: Who We Are
 - Purpose of the Guide
 - **Historical Context**
 - Kānaka Maoli Research Today
 - Native Hawaiian Research Frameworks

Historical Context

- Research Harms in the Past
 - Unethical experiments on people with leprosy
 - Research attempts to genetically modify kalo (taro)
- Growing Number of Native Hawaiian Researchers
 - Creation of Indigenous frameworks for programming and evaluation developed through qualitative methods
 - Example: Pilinahā (4 Connections)

Pilinahā Framework

4 Connections



(Odom et al., 2019)

- Connection to place—to have a kinship with ‘āina
- Connection to community—to love and be loved; to understand and be understood
- Connection to past and future—to have kuleana (a purpose in the world)
- Connection to your better self—to find and know yourself

Sections

- Section 2: Research Roles and Processes
 - **Researcher Self-Knowledge and Reflection**
 - Building Relationships and Entering the Community
 - Research Roles of Elders
 - Research-related Titles for Community and Kūpuna Partners

Researcher Self-Knowledge and Reflection

- Identity Questions
 - Where is “home” for me?
 - Who is my “community”?
 - Which social group(s) do I choose to affiliate with and why?
 - Who and what do societal institutions (schools, religious institutions, media, law) say I am?
- Power and Positionality Questions
 - What is my position based on my social indicators and titles?
 - What privileges do I hold?
 - How much power do I have in this world and in the context of this community?
 - How does my positionality and power affect how I interact with community members?
 - Why am I entering this community?
 - What is the purpose and objectives of my qualitative research project?
 - What steps do I need to take to ensure that the space I hold in this community does not lead to harm?

Sections

- Section 2: Research Roles and Processes (cont).
 - Use of 'Ōlelo Hawai'i in Research Projects
 - Developing Research Questions
 - Developing a Research Proposal
 - **Creating a Data-Sharing Agreement**
 - Community and Institutional Review Boards (IRBs)
 - Consent Forms

Creating a Data-Sharing Agreement

- How will you agree on what is collected?
- Who will collect the data, where will it be stored, and how will it be protected?
- How long will data be held? After the study is completed, will the data be destroyed or transferred to participants?
- How will you ensure that the data are not used in ways that can hurt individuals or stigmatize the community?
- If products are produced, who owns the patent and benefits from the sale of the product?

Sections

- Section 2: Research Roles and Processes (cont).
 - **Developing Interview Questions**
 - **Reciprocity and Makana (gift)**
 - Conducting Interviews with Kūpuna
 - Addressing Challenges and Setbacks
 - Dissemination of Findings
 - Community Benefit



Developing Interview Questions

Initial Proposal

60-90 minute interviews with elders, asking about their experience with health/elder care and advice for providers

Final proposal based on community feedback

Three 60-minute interviews, each a week apart:

1. Talk story – rapport building
2. Generational lessons of strength and resilience
3. Experiences with health/elder care and advice for providers

Reciprocity and Makana (Gift)

- Makana need to be negotiated with community and within budget and bureaucratic limits
- In our project, interview participants receive:
 - Audio and video interview recordings and transcripts
 - Personal stories for the interviewee to share with the family
 - 'Ai pono (healthy foods), like dried banana
 - Pa'akai (Hawaiian salt)
 - Māmaki tea
- Staff receive
 - *Nānā I Ke Kumu* (Look to the Source) book
 - Co-authorship on publications and presentations

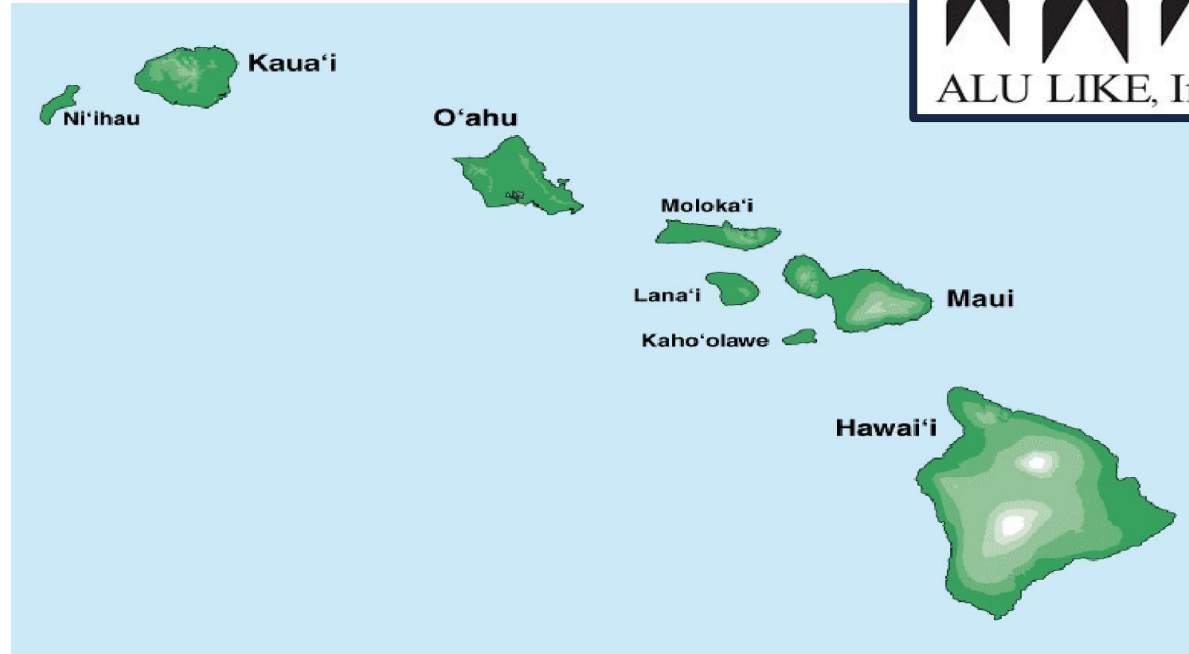
Healthcare Experiences

The Lives of Native Hawaiian Elders and Their
Experiences With Healthcare: A Qualitative Analysis

Kumu Kahi Title VI Program ALU LIKE, Inc.



- 14 sites on 5 islands
- Many associated with Hawaiian Homesteads
- Meals, education, activities, caregiver services, socialization



Project Details



- Community engagement with kūpuna
 - Partnership with Alu Like
 - Demographics
 - Age: 60 +
 - Native Hawaiian
 - Reside in rural areas
- Logistics
 - 3 Zoom Interviews (45 minutes - 2.5 hours)
 - Talk Story
 - Life Experiences
 - Healthcare
 - Makana (gift)
 - Digital and hard copies of Life Story, Recordings + Transcripts
 - Pa‘akai, māmaki tea and dried bananas and a personalized thank you card

Current Status



Year 1

- Completed 11 Interviews
 - 4 Moloka'i
 - 4 Kaua'i
 - 3 Hilo
- Healthcare Findings
 - APHA Presentation
 - Frontiers in Public Health Manuscript

Year 2

- Completed 9 Interviews
 - 2 Hilo
 - 3 Kona
 - 4 Maui
- Strength & Resilience Findings
 - APHA Presentation

Year 3

- 10 interviews planned
- Completed 7 interviews
 - 1 on Maui
 - 6 on O'ahu
- 3 more on O'ahu!

Resident

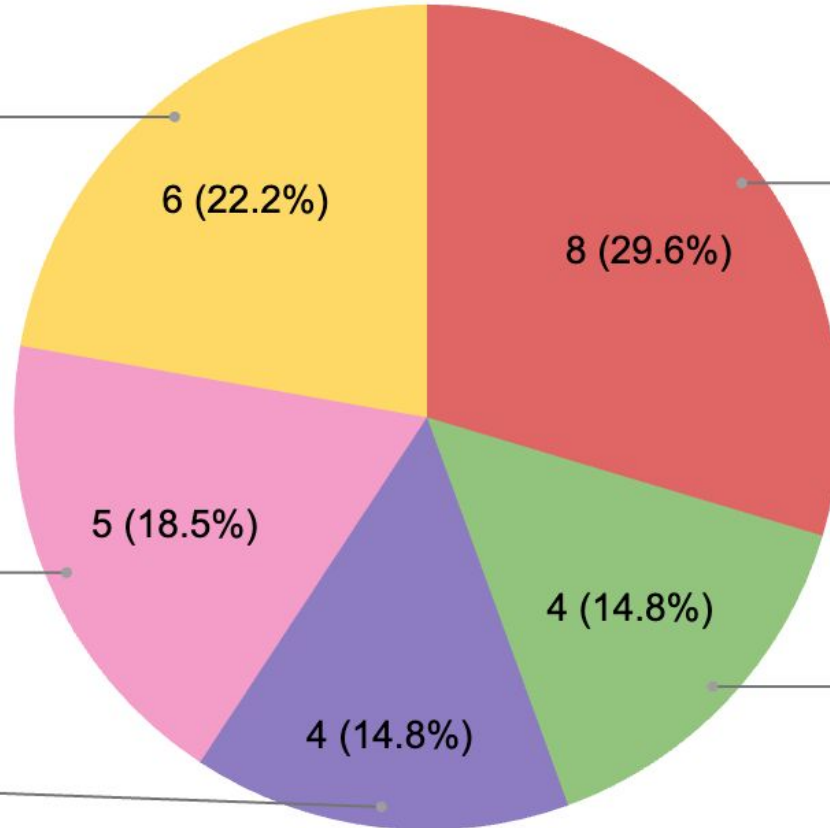
O'ahu
22.2%

Hawai'i Island
29.6%

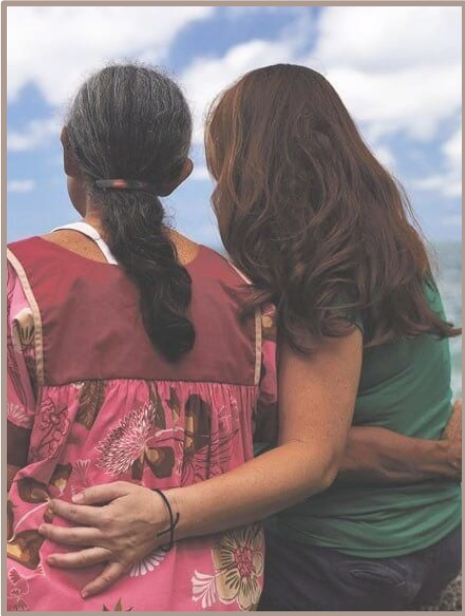
Maui
18.5%

Moloka'i
14.8%

Kaua'i
14.8%



Healthcare Experiences



- Early Life Experiences with Healthcare
- Positive Healthcare Experiences
- Negative Healthcare Experiences
- Experiences with Social Services
- Caregiving and Long-Term Care
- Advice for Providers

Early Life Experiences with Healthcare

Many participants said that they did not see a Western provider growing up unless it was for immunizations or a serious health issue

“The only kind of medical thing we had was to go to [hospital] whenever we needed shots.”

“Back then, I guess... you don’t go to the doctor because I guess maybe insurance or whatever... I don’t know if they had or was expensive... Got to be really serious before you go to the hospital.”

Early Life Experiences with Healthcare

All of the participants and their families successfully maintained their health and treated illnesses/injuries with Hawaiian health practices (ex. lā'au lapa'au, pule, ho'oponopono, lomilomi, & traditional diet)

"When you got burns, it wasn't run to the hospital... my tūtū man [grandfather] would go outside or my father would go outside, get aloe for the burns... put it on the burns. . . I remember one time I was in church... my son had a really high fever and they went and got ti leaf. One of the kupunas got ti leaf and put it on him to bring the fever down. So, it wasn't... run to the hospital, run to the doctor, it was always natural stuff.

Positive Healthcare Experiences



Majority of the kūpuna currently use both Western medicine and Hawaiian wellness practices.

"You got to take [Western] medicine that you swallow and then it works inside out. And that's what they say, "It needs to be healed... from the inside out." That's why [Hawaiians] drink a lot of different kinds of tea, it works from the inside out."

Negative Healthcare Experiences

The participants attributed their negative experiences with providers to poor communication

"...be understanding to us, just give us a chance and let us say things -- but sometime they just cut us short, you know? Let us finish our sentence, even if it take long. Sometimes, we get hard time talk. We share, but once you cut, 'oki us, all pau. We no like say nothing, we pa'a ka waha [shut our mouth]."

Experiences with Social Services

The primary social service that the participants were familiar with was the ALU LIKE program, and the comments were overwhelmingly positive

“ALU LIKE... would have presenters... And it’s so interesting because you get one. . . for diabetes, you have all the cancer programs, and all where you can seek help... Malama Na ‘Oiwi [community clinic]. . . and then your insurances. . . Your VA for hearing aids. So, you just have to tap your resources and pay attention.”

Caregiving and Long-Term Care

Participants talked about services they knew about that could help kūpuna age in place, the importance of documenting their wishes, and/or the services their private or public insurance plans might cover

“Hospice would come and help us... and give us a chance to rest... I thought hospice nurses was one of a kind... I would have a hard time because they get so close to you. They treat the patient like that’s their mom... their grandma.”

Advice to Providers

Take the time to talk-story and get to know the kūpuna as people and community members.

“I would rather have a doctor who can see me eye to eye and we can talk. “Oh, how are you?” or “What can I do for you today?” Or, you know, “Pehea kou ‘ohana?” [How’s your family?] That’s how you relate and get closer...”

“It’s not just about the medicine, it’s just not about why am I sick... Gee, I stay with [the doctor] half an hour to an hour, we just wala’au and we kūkākūkā [talk story]. That sometimes is good, it’s healthy!”



Advice to Providers

Learn about and acknowledge Hawaiians' experiences with colonization; respectfully approach the traditional health practices of your patients.

“You learn and treat the whole person, not just a symptom. And you got to understand where the genesis of that system comes from and treat that instead of just giving a drug to numb... you got to treat the root of it. And they don't ... teach that much in medical schools.”

“I think I would like to see Hawaiian medicine, along with regular American medicine. I think that would really help in introducing Hawaiian medicine. Because it works! It's just getting it and doing it... and taking it. But it works. I've seen it work.”

Advice to Providers

Communicate directly, clearly, and patiently.

“If you’re gonna tell me something, tell me straight. I said, “Doc, just tell me the true facts. She was straightforward and I liked that.”

“What made it positive is that the communication was clear on both sides. And if I didn’t quite understand, they would show me pictures or diagrams. And ... they would tell me what they’re going to do through the whole process, what’s gonna happen after I’m done, and then from there, the follow up with more literature or whatever needs to be done.”

Advice to Providers

Love what you do and show your passion in your work.

“Be patient, be respectful, have a sense of humor, don't show disdain, do your best, or else don't go into that kind of work unless you can be supportive and respectful of the patient. Don't go into it if you're just doing it for the money. Because it's more than that.”

“Put your heart in it. Whatever, you do, do it from your heart. And don't judge who they are, where they come from, this can be a homeless person, can be a rich person. They're still a human being... the main thing for me is to really aloha, take care with your heart.”



Appreciation for the Project

“Mahalo for all what you’re doing for us kūpunas to share all this knowledge with my grandchildren. It’s so nice to leave something back for them like this. Where they can see me. Where I can say to them no matter what in life, mai poina ke Akua ‘cuz he’s the only one can do what you need in life. Yeah, kēlā wale. Mahalo nui and always love each other.”

“I just want to say mahalo to both of you for taking your time for doing things like this. For kupunas. I really, really appreciate it, and I'm sure I'm speaking on behalf of all the kupunas that you guys are interviewing, so I just wanted to say, mahalo, mahalo, mahalo.”

Implications

- Research with Indigenous communities has evolved, and researchers need to disclose their positionality, respect Indigenous frameworks, engage partners in research design and dissemination, and negotiate data sovereignty and incentives
- Our qualitative guide may serve as a model for protocol development with other Indigenous and minority communities



Thank You

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HĀ KŪPUNA

National Resource Center for Native Hawaiian Elders



UNIVERSITY of HAWAII' I at MĀNOA*

THOMPSON SCHOOL

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