The Process of Cultural Adaptation of an Evidence-Based Intervention with the Native Hawaiian Community

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ABSTRACT

Background: Culturally adapting evidence-based programs may increase effectiveness, but decreases in fidelity to the original intervention are possible.

Objective: We describe the process and lessons learned from the adaptation of an evidence-based intervention, the Savvy Caregiver Program (SCP), with a Native Hawaiian Community Action Board (CAB).

Results: We present three examples: retaining an existing activity, revising a core concept as a hybrid with a Hawaiian value/English term, and adapting a component of the curriculum with cultural foods.

Conclusions: We suggest researchers work with community to: articulate core components in evidence-based interventions, explicitly; adapt activities and content to include cultural practices and norms; engage in iterative adaptation processes to support cohort differences; emphasize the importance of an inclusive approach to cultural identity; consider potential benefits of culturally grounded interventions; and describe and report the processes used in cultural adaptation.

KEYWORDS: culture, adaptation, fidelity, Native Hawaiian, core components

Background

Native Hawaiians experience substantial health disparities including a high prevalence of chronic disease and multiple negative social determinants of health,[1] which can be attributed to the devastating impacts of colonization, oppression, and discrimination.[1,2] Contact with the West brought disease and cultural loss as missionaries established boarding schools, enforced Christianity and the English language, and removed children from their homes.[1,3] Hawaiian culture and language was distained as primitive, leading to the loss of agricultural ways of life, language, land, and access to native foods.[1,4] In the 1970s, there was a renewed pride in Hawaiian culture, language, and values. This movement included the creation of a public education system in ʻŌlelo Hawaiʻi (Hawaiian language) and increased participation in music, dance, arts, and crafts.[3] In alignment with this cultural resurgence, research suggests the promotion of culture or inclusion of cultural values and practices in evidence-based interventions reduces health disparities.[5–7]

Culture is a dynamic process, linking the past and present, including worldviews, and ways of living shared by groups in both physical and social environments; these worldviews and ways of living are passed from generation to generation and modified by social, historical, and political contexts.[8] Hawaiʻi's history and unique, blended culture are particularly important when culturally adapting programs to promote health. Cultural adaptation is often viewed as a continuum from surface to deep structural adaptation;[7] the process often beginning with surface or linguistic adaptations followed by deep structural adaptations that incorporate cultural, social, historical, and environmental aspects of population.[9] The reality that many Native Hawaiians do not speak ʻŌlelo Hawaiʻi fluently due to colonization, makes the cultural adaptation process with the Native Hawaiian community unique. Considering the limited number of fluent ʻŌlelo

Hawai‘i speakers, yet strong connection to cultural values, it may be more relevant to include deep structural adaptations before translation.

Objectives

We aimed to adapt the Savvy Caregiver Program (SCP) with the Native Hawaiian community as Alzheimer's Disease or related dementia (ADRD) is likely prevalent and there are unique cultural expectations for caregivers. Research suggests Native Hawaiian and Pacific Islanders experience a higher prevalence of cardiometabolic risk factors for ADRD and subjective cognitive decline,[13,14] are twice as likely to have ADRD,[15] and have higher rates of hospital readmission compared to people of other racial and ethnic identities.[16] Combined with the strong belief among the Native Hawaiian community that the failure to provide respectful care can lead to elders' loss of pride and that Native Hawaiian adults should care for their elders,[5,17,18] caregiving is common.

We describe our approach to culturally adapting an evidence-based intervention with the Native Hawaiian community and lessons learned. First, we describe the SCP and our approach to adapting it with the Native Hawaiian community. Next, we present three examples that illustrate how a Community Action Board (CAB) played an instrumental role in deep cultural adaptation of the SCP. To differentiate the two programs, we refer to the Savvy Caregiver Program as "SCP" and the adapted program as "'Auamo Kuleana," which is an abbreviation of: ‘Auamo Ke Kuleana O Nā Ma‘i Poina (Carrying responsibilities associated with dementia).

Methods

The Savvy Caregiver Program and Adaptation Process.

The SCP is a 6- or 7-week program for caregivers of people living with ADRD. The program aims to educate caregivers about dementia, assess the situation associated with

caregiving, and develop the skills and perspective to perform the caregiving role effectively while guiding the person living with dementia through days that are as safe, calm, and pleasant as possible.[19] The program is delivered in-person or online in a group setting by certified trainers. The SCP has shown effectiveness in promoting caregiver mastery, knowledge, confidence, and wellbeing[20–28] and adapted for virtual dissemination (Tele-Savvy online program),[22] Indian Country (The Savvy Caregiver in Indian Country),[29] Korean Americans,[23] and African Americans (the Great Village).[30]

A research fellowship provided fiscal support for the PI (first author), who organized and facilitated the project. To guide the adaptation process, the PI established two teams, a mentorship team and the CAB. The PI facilitated monthly team meetings for both the mentorship team and the CAB, incorporating the feedback provided and making the recommended revisions to the SCP. The mentorship team was formed to support the PI as an early career researcher. The primary mentor had recommended members, all of whom the PI reached out to and they agreed to serve as mentors on this project. Mentors had experience in the development of the SCP, informal caregiving, risks associated with unmet needs, the influence of geographic location on health and wellbeing, cultural understandings of ADRD, caregiving in Indigenous communities, and culturally adapting and evaluating programs with Native Hawaiian and Pacific Islander communities. One of the mentors had worked with three of the CAB members to implement the SCP in Hawai‘i prior to this project. The mentorship team met monthly to provide mentorship support to the PI and review all changes suggested by the CAB to ensure fidelity to core components of the SCP.

Mentors introduced the PI to three CAB members, two of whom, (second and third authors) are leaders in dementia care in Hawai‘i and have led a nonprofit serving a Native

Hawaiian homestead community for decades. The two CAB members had lived experience as dementia caregivers, previously taught the SCP, and were interested in implementing an adapted version of the SCP as a program in their community-based organization. During the first meeting with the two CAB members, three additional potential CAB members were identified. These potential members had complimentary expertise and relationships with the two CAB members; however, they had not formally worked together. The three additional CAB were approached by the PI about the project agreed to participate. As a group, the CAB was comprised of people who identify with Hawaiian culture, are master trainers and facilitators of the SCP in Hawai‘i, have lived experience caring for a Native Hawaiian adult living with ADRD, or have clinical training in gerontology or social work. CAB members worked for community-based organizations and/or medical clinics serving the Native Hawaiian community in Hawai‘i and on the continent.

The goal of the CAB was to provide oversight and guidance of the cultural adaptation process. Prior to joining the CAB, all members reviewed and approved a document outlining goals and expectations including the scope of work, timeline, deliverables, and expectations. CAB meetings were offered twice per month (12 meetings during the adaptation process) and scheduled for at least 1 hour, however, meetings often ran longer than the allotted time; members were offered $25 gift cards for attendance and were requested to attend at least once a month. At each meeting, the CAB reviewed the SCP materials session by session, while also reviewing the logic model for the SCP (See Appendix 1), core components, and discussing Hawaiian culture, language, and values.

Members of the mentorship team and CAB are recognized as authors on all presentations, publications, and community reports developed from this project. Additionally, all findings

generated from this project were shared with the CAB and community for their review and feedback prior to dissemination.

There were minimal conflicts among CAB members during the adaptation process. One of the most challenging decisions was agreeing on the name of the adapted version. First, we came up with a list of 5 potential names and translations. Then, the PI created a survey requesting CAB members anonymously rank the 5 potential names. Based on survey results, the CAB came to an agreement on: ʻAuamo Kuleana o Nā Maʻi Poina. The process of adapting an existing curriculum was not determined to be research as no data were collected from participants, thus, Institutional Review Board approval was not obtained. To illustrate the process of adaptation, we provide three examples and lessons learned.

Results and Lessons Learned

Retaining an Existing Activity

An activity in the SCP aims to help caregivers identify and classify feelings associated with caregiving, along with a process to change those feelings. The activity starts by showing participants the "four quadrants of feelings" (Figure 1). The facilitator then explains that this activity is based on prior research suggesting that feelings can be categorized along two dimensions: positive and negative, and powerful and powerless. The SCP trainer manual describes positive and negative as whether the feeling was a good or bad, while powerful and powerless can be attributed to the amount of control the caregiver feels they have over the situation and feeling. Participants are given examples of where common emotions fit in the quadrants and then asked to identify their own feelings and where those feelings fit. For example, feelings of sadness and depression are a negative and powerless feeling whereas anger is a negative and powerful feeling. Once caregivers identify and classify their feelings within the

four quadrants, the facilitator describes a process caregivers can use to change their negative and/or powerless feelings to more positive and powerful feelings.

In discussing this activity with the CAB, a CAB member mentioned a Hawaiian value that they identified as indicative of positive and powerful: Hoʻoikaika, which means to make great effort, work hard, be strong, and be powerful.[31] Recognizing the opportunity to include Hawaiian language and values with the four dimensions, the PI (who is not fluent in Hawaiian language, but is familiar with Hawaiian culture) attempted to identify ʻŌlelo Hawaiʻi to align with the four dimensions: positive, negative, powerful, and powerless. After a review of ʻŌlelo Hawaiʻi resources, the PI was unable to identify ʻŌlelo Hawaiʻi for positive or negative. As such, the PI asked the CAB to review the activity at the following meeting and consider how to translate the terms used in the activity in ʻŌlelo Hawaiʻi. The CAB members who are fluent in ʻŌlelo Hawaiʻi confirmed there are no equivalent terms for positive or negative (in general). Realizing there was no direct translation, we revisited our broader goal: culturally adapting the SCP. The CAB members who had previously facilitated the SCP confirmed the activity was useful as it was originally designed and without a feasible direct translation, the original activity was retained in ʻAuamo Kuleana. As we moved forward, we focused on including common ʻŌlelo Hawaiʻi to ensure comprehension.

When reviewing the activity again, the CAB suggested placing greater emphasis on the feelings of others, specifically, how the feelings of a person living with dementia may influence the caregiver's feelings. The inclusion of others' feelings is in the SCP, although only briefly. Considering how maintaining relationships and ʻohana (family) are important Hawaiian values, we provided additional prompts for the facilitator of ʻAuamo Kuleana to ask participants to talk about how the feelings of others might influence their own feelings. These prompts included

recognizing that the kupuna's feelings may not align with the caregiver's feelings and taking time to reflect on how the kupuna feels.

Revising a Core Concept as a Hybrid with a Hawaiian Value/English Term

"Contented involvement" is a core component of the SCP, discussed in multiple sessions, and described as an important goal for caregivers. It is based on the premise that the basic human capacity for enjoying doing things persists, regardless of stage of dementia. In the SCP, knowing the person, structuring the task, and providing effective support can encourage contented involvement in the person living with dementia. This is presented as a dynamic process, requiring daily adjustments depending on the person living with dementia's abilities.

The CAB voiced two concerns with the concept of contented involvement. First, the term "involvement" implied the person must do something to be contented, suggesting that the caregiver needed to come up with tasks for the person to be "contentedly involved." While the SCP describes contented involvement as an active or a passive activity (e.g., contented involvement can occur while relaxing or watching TV), the CAB conveyed difficulty with the term "involvement." The second concern was that the caregiver needs to know what the person enjoys doing to promote it, which could add to caregiver burden, particularly for many Native Hawaiian caregivers who are asked to return home to Hawai'i to provide care.[32]

Instead, the CAB suggested dividing contented involvement into two related concepts: lōkahi and meaningful engagement. Lōkahi means balance, oneness, and harmony and is a commonly used term.[31] Lōkahi was recommended because it can be applied to helping the caregiver find balance within themselves, their relationship with the person living with dementia, and the family. The CAB suggested the phrase meaningful engagement to encourage caregivers to use structure and support to engage the person living with dementia in activities. This

suggestion was presented to the program developer, who agreed, yet suggested "comfortable engagement" to further remove the caregiver burden in knowing what the person living with dementia enjoys doing. Therefore, "contented involvement" was revised to: lōkahi and comfortable enagagement.

Adapting a Component of the Curriculum with Cultural Foods

The SCP includes two videos. One video demonstrates the stages of dementia by asking four participants at different stages to make a ham and cheese sandwich. The second video shows a healthcare provider helping a group of people living with dementia make a cherry tart. The healthcare provider tailors the necessary tasks to each person, illustrating the possibility of contented involvement (i.e., comfortable engagement) regardless of the stage of dementia.

After reviewing the videos with the CAB members, they strongly advocated for the development of new videos for three reasons. First, there is a lack of diversity among participants included in the videos both in gender and ethnicity (both videos included only women, and most participants were White). Second, the activities in the videos are not culturally relevant. CAB members stated that when they had previously shown the sandwich making videos (as part of the SCP), Native Hawaiian caregivers were distracted by the food products and said they rarely make sandwiches. When discussing the cherry tart video, all CAB members expressed they were unfamiliar with how to make a cherry tart and thus were unable to understand how the healthcare provider was structuring the task based on the participants stage of dementia (i.e., the aim of the video). Third, CAB members found the videos dated and the healthcare provider curt and unfriendly, which was offensive to the Native Hawaiian community who hold kūpuna (elders) in high regard.

To address these concerns, the CAB worked with the mentorship team to develop culturally relevant activities that mirror and uphold the aims of the original videos. The CAB assembled a group of four kūpuna living with different stages of dementia to participate in culturally relevant activities that were video recorded. Instead of a ham and cheese sandwich, participants were asked to make a spam musubi, a common food item in Hawaii with similar steps of assembly. Instead of the cherry tart, participants helped prepare lomi salmon and poi (made from taro, pounded and thinned with water) for a lūʻau (Hawaiian feast) by putting items in cups and covering them with a lid (i.e., the tasks directly mirrored the cherry tart activity). In addition to the activities, the healthcare provider referred to the kūpuna as "aunty" or "uncle," which is a common and respectful way to refer to older adults.

After filming the adapted activities, one of the caregivers brought her ukulele and began playing popular Hawaiian songs to entertain the kūpuna. The kūpuna spontaneously began dancing and singing along with the music. One of the kūpuna who was in a late stage of dementia and unable to make a spam musubi, was captured on video singing along with an old Hawaiian song. This impromptu celebration highlighted the deep connections to culture; it reinforced the concept that personhood persists, an important aspect of the SCP. The celebration videos were added to the curriculum to bolster the strengths-based view of people living with dementia.

Conclusions

Native Hawaiians have experienced substantial cultural and linguistic losses due to a long history of colonization and oppression, contributing to a unique, blended culture. We describe the importance of a community engaged approach to culturally adapt the SCP, an evidence-based intervention. Typically, models of cultural adaptation suggest incorporating surface structure

adaptations first, as deep structural changes involve modifying core components, which may change the program. However, we learned that linguistic translation (i.e., what is typically considered a surface structure change) could detract from the adapted program, as many Native Hawaiians are not fluent speakers. Instead, we maintained aspects of the program in its original form and included deep structural adaptations to include cultural values. However, with the growth of Hawaiian immersion schools (since 1987) and increasing number of fluent ʻŌlelo Hawaiʻi speakers, translation and further adaptation of the curriculum may be relevant for younger adults who are fluent in ʻŌlelo Hawaiʻi and appreciate the opportunity to engage with their culture and language in this program.

As we adapted the SCP, we also realized it was important to shift from asking how to adapt the program, to asking if an adaptation is needed, and if so, why. As illustrated in the "four quadrants of emotions" activity, we relied on the original activity, since a direct translation was not possible. In adapting "contented involvement," we relied on both Hawaiian values and an English concept, illustrating the blended nature of Hawaiian culture. Lastly, the creation of new videos was necessary, as CAB members indicated the original videos hindered the ability to understand and apply the content presented in the videos. We plan to evaluate the videos during the pilot test (ongoing) and anticipate the videos will be an important aspect of ʻAuamo Kuleana, as videos have shown promise with other rural Hawaiian communities.[33,34] When creating the videos, we also learned the importance of embracing a strengths-based approach. This is particularly salient in reclaiming Hawaiian culture, recognizing the strengths of Native Hawaiians, honoring kūpuna, and promoting wellbeing of the community.[35]

As research in cultural adaptation continues to expand, it will be increasingly important to: articulate core components of evidence-based interventions, describe the adaptation process,

include cultural norms in implementation, acknowledge cohort differences, and consider culturally grounded interventions instead of culturally adapted interventions. From our experience, clear identification of the SCP core components was essential; we worked directly with the program developer, which was necessary for maintaining fidelity to the program.

This project is not without limitations. While our CAB holds cultural, caregiving, and dementia knowledge, we were unable to include caregiver perspectives in the initial adaptation process. We did not prospectively use an adaptation framework, such as the Framework for Reporting Adaptations and Modifications - Expanded (FRAME),[36] nor did we systematically document or evaluate all modifications. Documenting changes and understanding decisions made in the adaptation process may assist with enhancing the efficacy of culturally adapted interventions. While there were minimal conflicts among CAB members, prospectively identifying processes to resolve conflicts may be important in the facilitation of community-led work. Lastly, it would be beneficial to elucidate what active ingredients, or how core components relate to expected outcomes (i.e. how activities may improve caregiver burden).

As stated by Trickett (2011), "culture is not only out there 'in our communities'; it is reflected in the ways in which we go about trying to understand and be helpful in those communities" (p. 60). From our experience with the process of cultural adaptation, we encourage researchers to dedicate time to building relationships with the communities with which they work. As researchers, it is our kuleana, or responsibility, to understand the core components of our interventions and have (or gain) a genuine understanding of the people and cultures we are working with to adapt interventions.

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Declaration of interest. We have no conflict of interest to declare.

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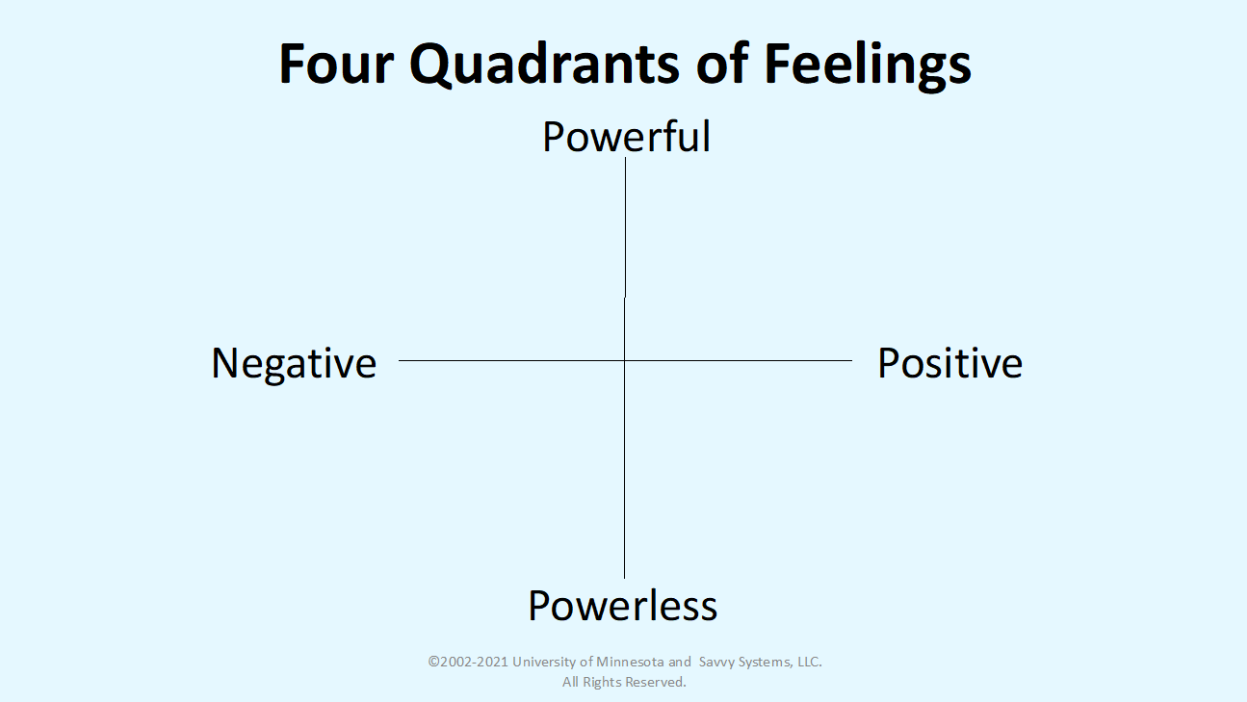
Figure 1.

The Savvy Caregiver Four Quadrants of Feelings Activity



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