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## Developing a Culturally Based Cardiac Rehabilitation Program: The HELA Study

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### Abstract

**Background:** Heart disease disproportionately affects Native Hawaiians and other Pacific people. In response, researchers proposed and communities endorsed, developing a cardiac rehabilitation (CR) program based on the hula, a Native Hawaiian dance form. The utilization of cultural practices in health interventions can improve outcomes and increase enrollment and retention, but requires sensitivity and understanding.

**Objective:** This paper provides the conceptual framework and methods used for integration of multiple communities' perspectives to inform the design of a hula-based CR intervention.

**Methods:** Specific strategies and processes were established to ensure the equity of scientific—clinical and patient—cultural knowledge and perspectives. Multiple methods were used and a flow diagram defined steps for the intervention development.

**Results:** Patient and cultural consultations provided information about the multidimensional benefits of hula and its use in a CR intervention. Clinical and scientific consultations provided specific guidelines for exercise prescription and patient monitoring. Integrating findings from all consultations identified important direction and requirements.

**Conclusions:** Community-based participatory research (CBPR) principles guided a complex collaboration of multiple communities; although time consuming, inclusive consultations provided valuable information and relationships.

### Keywords

Community-based participatory research, health disparities heart diseases, Native Hawaiian, Pacific Islander, rehabilitation health services, community health services world health population characteristics

Cardiovascular disease (CVD) is a leading cause of death and disability.<sup>1</sup> Substantial racial/ethnic disparities in CVD exist, with Native Hawaiians and other Pacific Peoples (NHPP) bearing a disproportionate burden of coronary artery disease (CAD) and its risk factors, including mortality rates that are among the highest in the United States.<sup>2,3</sup> In Hawai'i, cardiovascular mortality for Native Hawaiians, the indigenous people of Hawai'i, is almost twice other racial/ethnic groups.<sup>3</sup> Because of these disparities, CAD was identified as a top research priority in a needs assessment of 19 community-based health organizations serving NHPP.

After hospitalization for major cardiac events, including coronary artery bypass graft surgery and acute myocardial infarction, it has been well established that participation in CR improves functional status, quality of life, and long-term outcomes,<sup>4-10</sup> with a reduction in mortality by 20% to 32% when compared with medical therapy.<sup>7,9,10</sup> Despite these benefits, CR remains underutilized, with only 10% to 20% of eligible patients referred to CR<sup>11</sup>; there is evidence that this treatment gap is even wider for the elderly, women, and racial minorities.<sup>12</sup> Although lack of motivation, inconvenience, and physician support<sup>13</sup> are identified as common reasons for

CR underutilization, minority populations likely encounter additional barriers. Indeed, in a recent study of barriers to CR participation among racial minorities, several factors were identified: (1) Negative prior experience with healthcare professionals, (2) the need for support from social network and family to access the healthcare system, (3) fatalistic healthcare beliefs, (4) a poor understanding of CR, and (5) preference for stress reduction rather than traditional exercise methods.<sup>14,15</sup>

Culturally congruent CR programs that offer alternate forms of physical activity may be more attractive and familiar to patients than traditional exercise (e.g., treadmill, stationary bicycle) and may result in better adherence.<sup>16</sup> For example, Tai Chi and ballroom dancing, when utilized as a foundation for CR, improve exercise capacity and quality of life,<sup>17,18</sup> as well as utilization and adherence.<sup>18</sup>

Hula, an ancient dance form of Native Hawaiians, may be effective as a basis for CR. Originally performed to convey history and spiritual beliefs, hula is now commonly practiced as a form of cultural expression,<sup>19</sup> and is composed of specific controlled rhythmic movements that enhance or allude to the meaning or poetry of the accompanying songs or chants.<sup>19-22</sup> Although Native Hawaiians may have a cultural affinity for hula, dancers come from many different ethnicities, and hula is practiced by both men and women of all ages.<sup>20-22</sup> There are at least 174 *hālau hula* (hula schools) in Hawai‘i, and nearly 1,100 schools of dance teaching hula worldwide,<sup>23,24</sup> with enrollment ranging from a dozen to several hundred students. *Kumu hula*, recognized as guardians and educators of hula tradition and esteemed as cultural resources, lead hula students, who often bond and provide social support to each other—a factor found to positively impact recovery from heart surgery.<sup>25-27</sup>

The Hula Empowering Lifestyle Adaptations (HELA) Study, funded by the National Institute on Minority Health and Health Disparities, is a randomized clinical trial evaluating the impact of hula-based CR, compared with usual care, on individuals recently hospitalized for a cardiac event. In this paper, we describe the cultural and conceptual framework and scientific methods used to formulate and design the program. We used a community-based participatory research (CBPR) approach to ensure the integrity of hula as an indigenous cultural practice, include patient perspectives, and retain the scientific rigor needed for a clinical trial.

## RESEARCH APPROACH AND METHODS

### Conceptualization of the Study

In response to the priority of CAD research identified by the NHPP community, scientists at the University of Hawai‘i’s Center for Native and Pacific Health Disparities Research, and *ka po‘e hula* (hula community) formed a CBPR partnership that included medical, Native Hawaiian cultural, and community expertise and participation. NHPP cardiac patient consultations were initiated to determine interest and preferences. Community resource relationships were established with selected *po‘e hula* to include *kūpuna loa hula* (respected elders of hula) and *hālau hula* (schools of hula). Similarly, collaborations were sought in the clinical community with cardiac surgeons, cardiologists, and CR nurses.

As shown in Figure 1, clinical consultations were conducted with clinical and scientific advisors with expertise in CVD, CR, and clinical research methodology. Formal and informal discussions were held to review the concept of hula-based CR and clinical considerations for its development and implementation. Establishing cultural and community consultations were more complex. Deliberate steps, with consideration to cultural and community protocol, were required, as well as knowledge about individual reputations and accomplishments in the Native Hawaiian community.<sup>28,29</sup> Meetings with cultural leaders and *kumu hula*, several who had heart disease, focused on the appropriateness of utilizing hula as a basis for a clinical intervention. These cultural and community voices unanimously endorsed the concept for the study. One cultural resource with a history of CAD articulated a common theme—hula-based CR would appeal to Native Hawaiians because of their familiarity and positive association with hula, and because it may offer an affordable alternative to traditional CR. Based on this strong endorsement, complemented by a review of the scientific and cultural literature, a study proposal was developed and funding was secured. The study was organized in two phases. The first phase involved the designing of the intervention, which is the focus of this paper. The second phase, the implementation of a randomized clinical trial, is presently ongoing and will be discussed in future publications. Approval was received from the institutional review board of the University of Hawai‘i.

### Establishing the Research Team and Advisors

In assembling the research team, it was important to establish equity in the spheres of expertise: community–cultural and clinical–scientific knowledge. The background of the investigators needed to include research and clinical knowledge, as well as community and cultural wisdom. The research team included investigators with expertise in clinical care, health intervention development, and research methodology. Several investigators and research staff had recognized expertise in the cultural practice of hula, Native Hawaiian language, and cultural protocols. In addition, several team members had personal experience with a close family member with CAD. The researchers’ ties to the indigenous, patient, and medical communities helped to attain the networks and community support needed for the development and implementation of the intervention.

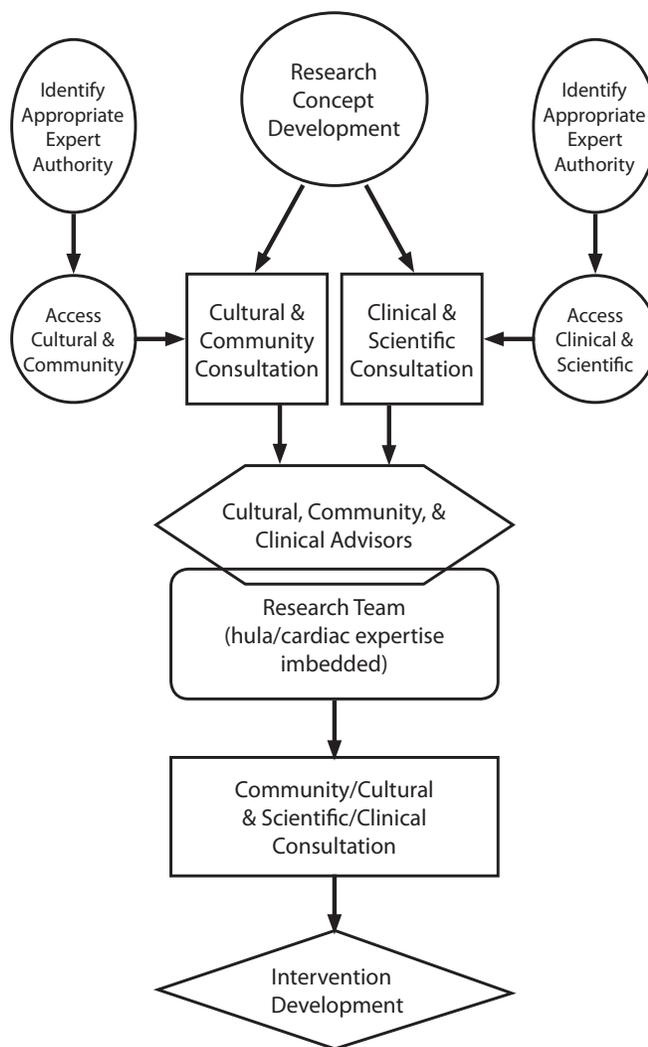
Cultural and clinical advisors, along with the patient community, provided guidance throughout the study. Cultural advisors with expertise in traditional knowledge were consulted on issues concerning cultural protocol and the use of hula as a modality for CR. Specific cultural advisors were included because they had experienced a CAD hospitalization and were, therefore, able to also provide a patient perspective. Clinical and scientific advisors with expertise in cardiology, CR, and clinical research with Native Hawaiian communities assisted in the study design and ensuring the intervention adhered to CR principles.

### Data Collection

*Community and Cultural Consultation.* To obtain community–cultural guidance on the development of a hula-based intervention, two qualitative methods were used. First, focus groups were conducted with 17 NHPP who were hospitalized for a cardiac event within the past year (Table 1). These men and women were questioned about hula as a CR modality and on the post-hospitalization recovery process. Focus group sessions are congruent with the Native Hawaiian tradition of storytelling and oral history and provided an open-ended venue for participants to share their opinions and thoughts. Second, to be consistent with CBPR principles<sup>28,29</sup> and Native Hawaiian cultural protocol, which necessitates the involvement of informed elders and those with specialized training,<sup>30</sup> six *kumu hula* (hula experts) were individually interviewed

for 60 to 90 minutes (Table 1). Key informant interview questions assessed the cultural appropriateness of the study and concerns regarding cultural integrity, and to solicit recommendations for intervention design.

Transcripts from focus groups and interviews were evaluated separately using a thematic analysis approach. First, investigators reviewed all transcripts and established five general domains determined from the context of the questions and the responses of the participants (Table 2). Then, two members of the research team independently reviewed the transcripts and identified repeating themes for each domain, and other themes that emerged with high frequency. Next, an investigator reviewed the transcripts to determine if additional themes or domains could be identified or clarified. Finally,



**Figure 1. Process flow diagram for a culturally based research intervention using CBPR principles.**

the frequency of the various themes was established through review of the transcripts.

*Clinical and Scientific Consultation.* To obtain clinical and scientific guidance on the development of a hula-based intervention, we performed a detailed review of the CR published literature, including standard CVD and CR textbooks, guidelines from specialty organizations, and review of the peer-reviewed literature. We then convened two meetings, one with nine local clinical cardiologists and a separate key informant interview with a national CR leader. These consultations discussed the feasibility, scientific basis, and design of hula-based CR, including issues on the level of exercise intensity, monitoring of physiologic variables, safety, program duration, and goals of therapy. Recognizing the lack of post-hospitalization CR in the community, and the potential for culturally informed CR to improve adherence and clinical outcomes, the clinical cardiologists quickly reached a consensus on the potential benefit, feasibility, and general design of hula-based CR. Guidance from the informant interview was critical to ensure that the hula-based CR adhered to the highest scientific and safety standards. Important guidance was obtained from a Native Hawaiian scientist with extensive experience undertaking research in Native Hawaiians communities.

**Table 1. Enrollment Characteristics for CAD Patient Focus Groups and *Kumu Hula* Informants**

Characteristic	CAD Patients Focus Groups	Kumu Hula Informants
Age, years (range)	59 (38-72)	62 (50-80s)
Gender		
Male, % ( <i>n</i> )	65 (11)	17 (1)
Female, % ( <i>n</i> )	35 (6)	83 (5)
Ethnicity, % ( <i>n</i> )		
Native Hawaiian	62.5 (10)	100 (6)
Samoan	12.5 (2)	—
Other Pacific Islander	25 (4)	—
Clinical diagnosis, % ( <i>n</i> )		
Heart patients (with history of heart surgery)	31 (5)	—
Heart patients (no heart surgery)	44 (7)	—
Caregivers	25 (4)	—

## RESULTS AND DISCUSSION

### Conceptualization of the Study

The cultural–community and the scientific–clinical discussions informed several key areas, all consultations affirmed that a hula-based CR program was appropriate and they provided initial parameters for the development of the intervention. For example, clinical experts recommended that post-hospitalization CR included 1 hour sessions three times weekly for 12 weeks,<sup>31</sup> and highlighted the importance of social support in cardiac recovery. Studies have well-established that strong social support and group interventions positively effects recovery from cardiac-related hospitalization, specifically it has shown to improve physical functioning and activities of daily living, and to reduce depression, rehospitalization, cardiac event recurrence, and CAD deaths.<sup>25,26,32</sup> Although our cultural consultations conveyed that *hālau hula* classes were typically 1 hour weekly, more frequent sessions were sometimes organized depending on the objective of the class. The cultural–community consultations also noted the naturally occurring social support between members of a hula class and between the *kumu hula* and their students. Thus, the study had early determination of the intervention duration, and agreement that hula-based CR could provide social support in addition to improving physical functioning.

### Community Consultation: Qualitative Study Results

Table 2 provides a summary of the key findings from the CAD patient focus groups and *kumu hula* interviews. We identified five domains: Physical-medical, emotional-mental, social-interpersonal, cultural-spiritual, and logistical. The results were further categorized as “benefits” or “concerns” to using hula as the basis for CR. Overall, both patients and *kumu hula* believed that hula-based CR would be both culturally attractive and effective, based on its physical, emotional, social, and spiritual benefits.

The strongest benefit identified by *kumu hula* was the multidimensional nature of hula and its effects on health. Physical benefits of hula identified included an increased awareness of one’s body, and the feasibility of selecting dances to accommodate varying physical capabilities. The *kumu hula* noted the mental benefits of memorizing the words, meanings, and movement sequences. Interestingly, the *kumu hula* noted,

**Table 2 Key Community Consultation Findings**

General Domains	Informant Interview Themes (Kumu Hula)		Focus Group Themes (CAD Patients)	
	Benefits	Concerns	Benefits	Concerns
Physical/medical aspects	Hula enhances health and well-being on multiple levels (physical, mental, spiritual)	Some dances or forms of hula would be too rigorous	Hula is a good physical activity option for CR	Ensuring that the intensity level is age-matched and noncompetitive
	Hula increases dancer's ability to tune in to his/her body Those with disabilities can return in phases, participating as able			
Emotional/mental aspects	Hula enhances health and well-being on multiple levels (physical, mental, spiritual)	Some students find it difficult to let go of their emotional stress with life during their time in class.	Hula as means of stress/negative emotion reduction/management	Can be too emotional so that no longer enjoyable
	Unconditional love (aloha) is established and expected between teacher and student and among students Understanding the meaning of the poetry of the song or chant is essential to the teaching and learning of hula			
Social/interpersonal aspects	Strong bond develops between class participants as well as with the teacher	Some may be embarrassed that they have not learned this cultural practice before	Hula classes can also serve as a social support group	More female participation
			Would appeal to people of different ethnic backgrounds	
Cultural/spiritual aspects	The longer one dances, the more spiritual health develops. It is also related to the meaning of the songs which often are about places or history that the dancer relates to.	It is not a required part of learning the dances; not all feel this type of connection	Hula is more than a dance also an expression of culture and life	Too deep in cultural aspect might take away from its enjoyment
Logistical aspects	Dance selection should relate to the class and determined by kumu hula		Best outdoors and on hospital grounds	
	A hō`ike (recital) at the end of the 12 weeks will serve to motivate continued participation Low-intensity dances are better, both `auana (modern) or kahiko (old) are appropriate.		Include group activities and opportunities to interact with other participants `Auana (modern hula) preferred. Learn the meaning of songs and dance	

as a concern, some hula students find it difficult to let go the emotional stress from their daily life while in hula class. The social benefits identified related to the strong friendship and bond students develop. Finally, the *kumu hula* believed spiritual benefits come through deeper understanding of the poetry in the songs or chants that hula accompanies, and the connection formed between the dancer and the places, people, and events they are dancing about.

The CAD patients' focus groups also believed hula had suitable physical and emotional benefits, including stress reduction and social support among dancers and with the *kumu*. Additionally, it was felt that hula-based CR would allow participants to express themselves through a cultural practice that would be of spiritual benefit. However, some participants commented that the spiritual side of hula may be "too deep," which might limit the enjoyment for some.

#### Clinical Consultation Recommendations

Clinical community interviews included guidance on exercise prescription, physiological goals, frequency and duration of exercise, and staffing and location of classes. Heart rate monitoring of participants was frequently raised during interviews, with general agreement that it could be done through continuous telemetry or periodic measurement.

The importance of CR participants learning to self-monitor levels of physical exertion was raised, as was the importance of warm up and cool down periods, and concerns about the stability of the sternum during exercise for post cardiac bypass surgery patients.

#### Integration of Community and Clinical Consultation Results

Table 3 illustrates the integration of community consultation findings with clinical recommendations to develop specific intervention design strategies. The left column of the table reports selections from the synthesis of findings from the two qualitative data sets. The center column provides clinical recommendations based on key informant interviews that parallel the patient community qualitative findings. The right column of Table 3 provides the resulting strategy of the integration of cultural–community and clinical–scientific findings into the hula-based intervention.

An example of how integration of cultural and clinical information informed the development of the CR program and randomized clinical trial is intervention staffing. The cultural and patient community viewed credentials for the instructor of hula important for authenticity and credibility. Although hula instruction is available from a variety of individuals, the clear preference from the community was for

**Table 3. Selected Recommendations and Application to Intervention Design**

Focus Group and Interview Findings	Clinical Recommendations	Resulting Intervention Design
A well-respected <i>kumu hula</i> (hula expert) should teach the class.	The level of medical supervision is based on the health condition and stage of recovery of the participant	<i>Kumu hula</i> , with 30+ years of teaching experience engaged as instructor. Minimum 1 nurse present during class, physician available.
Class should start off slowly and accommodate students with different levels of physical ability.	Assessments of physical conditions are made and individual exercise prescription developed. Classes should include warm-up, conditioning, and cool-down.	<i>Kumu hula</i> modifies movements to accommodate limited range of motion in beginning weeks. All classes include warm-up movement, conditioning (dancing), and cool-down. Participants use heart monitors and BORG scale for self-assessment
Participants should be encouraged by <i>kumu hula</i> to self-monitor their condition and adjust their exertion intensity.	Participants should be encouraged to self-monitor using specific physical exertion scales	
Social support that emerges in the class is culturally appropriate and key to motivation and retention.	A strong social support network reduces depression, stress and other risk factors and can improve the patients' physical outcomes.	The hula class incorporates group sharing, learning and naturally fosters social support. <i>Kumu hula</i> establishes value of <i>aloha</i> and mutual caring.
Cultural learning is a key component for hula.	Understanding the importance of physical activity, diet and other behaviors are important for heart health.	The <i>kumu hula</i> explains the poetry and history of the song or chant as well as the history behind each dance. All participants receive educational material about heart health.

an experienced, well-respected *kumu hula*. Correspondingly, although CR could be conducted in a community setting, clinical experts generally agreed that the program should be held on hospital grounds to provide appropriate access to emergency equipment and personnel. As a result, the study engaged a well-respected *kumu hula* who was conferred her status through traditional protocol and had over 30 years' experience as an educator of hula and Native Hawaiian culture. Additionally, all classes would be held in a hospital setting and monitored by a registered nurse, with immediate access to emergency equipment and personnel. Following recommendations from CAD patients, initial sessions started with slower and less complex dances, with the *kumu hula* encouraging participants to self-monitor levels of exertion. Insights from the clinicians determined that the Borg Ratings of Perceived Exertion (BORG) scale would be posted around the classroom as a tool and reminder for self-monitoring.

At times, decisions about the integration of information were not clear. For example, should the warm-up and cool-down periods of the hula-based CR intervention be based on clinical or cultural/hula preferences? Is it possible to have an integration of preferences and retain the rigorous standards of each expertise? Although there was agreement from both cultural and clinical experts that the warm-up and cool-down periods are important, there were differences about the specific design. By allowing time for a thorough and balanced discussion that was inclusive of investigators, scientific-clinical, and community-cultural expertise, a more comprehensive understanding of objectives for CR and for hula education was communicated. By providing the opportunity for the cultural consultant to formulate and evaluate different activities for the warm-up/cool-down component, in consultation with the CR expert, the resulting intervention design innovatively addresses the physical limitations of participants and follows the medical recommendations, but also incorporated aspects of cultural education that is important to the dance training.

## LESSONS LEARNED

To combine the scientific and clinical standards for CR with cultural and patient communities' knowledge, we consulted extensively with a variety of experts. Utilizing an indigenous cultural practice as the basis for a clinical intervention increased both the complexity of the consultation process

and the integration of varying information. It required the investigators to be cognizant of expectations from both the scientific and community stakeholders regarding content and context. There were several lessons learned about collaboration, specifically for developing a culturally based clinical intervention to be evaluated through a randomized clinical trial. At times, multiple perspectives provided valuable insight. For example, patient preferences for lower intensity dances and the importance of social connections guided the study's cultural consultant on dance selection and identifying ways to facilitate relationship building. In contrast, balancing the competing priorities of science and culture were occasionally challenging. The investigators, advisors, and study consultants found that foundational values of mutual trust, respect, and the practice of continual communication were essential in dealing with disagreements, recognizing that conflict can occur when there is differing expertise and high levels of commitment to excellence. Collateral damage from conflicts within this study was minimized with early identification of important disagreements and by taking time to ensure respectful, inclusive, and thorough discussion. Disagreements such as the design of the warm-up and cool-down periods could have become divisive and eroded important research collaboration efforts. We believe the ability to find an acceptable resolution was, in part, because all of the investigators, consultants, and advisors had a fundamental understanding of both clinical and cultural practices.

For our study, CBPR guided a complex collaboration of multiple communities to form the intervention design. The consensus of the study team is that the efforts to be inclusive in consultations and facilitate a collaborative process required significant time and effort, but are worthwhile. Also valuable was providing time to work through differences in respectful ways that would ensure important product and process foundations.

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