



# Sharing the Patient Experience: A “Talk Story” Intervention for Heart Failure Management in Native Hawaiians

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## Abstract

**Background:** Native Hawaiians (NHs) suffer disproportionately from cardiovascular disease morbidity and mortality. **Objective:** To test a narrative intervention of patient stories to support heart disease self-management in NHs. **Method:** Six NH storyteller videos were developed with community feedback following established methods. The NH participants with heart failure (N = 35) were recruited from a major medical center in Hawai'i. Participants completed demographic questionnaires, watched videos via iPad, and described experiences. Follow-up was 4 weeks later. **Results:** Mean participant age was 57.0 years (standard deviation [SD]:13.0) and 31% (11) were female. On a scale of 1 (worst) to 4 (best), respondents rated the videos 3.7 (SD: 0.5) in relevance for helping them manage their heart disease and 3.6 (SD: 0.5) in their experience using these videos. When asked what they liked best, the most common response was that they are “like me” (from 14 respondents, ranging from a 43-year-old woman to an 84-year-old man). Of those completing follow-up (n = 15), 87% said videos helped them. **Conclusion:** Our narrative “talk story” intervention showed promise as a culturally relevant method to share patient experiences and reduce health disparities.

## Keywords

patient-centered, narrative intervention, heart disease, Native Hawaiians, chronic care management

## Introduction

Native Hawaiians (NHs) suffer disproportionately from cardiovascular disease (CVD) morbidity and mortality and often lack access to effective chronic disease management and/or culturally appropriate care (1–3). This has significant consequences for health-care costs and outcomes. Native Hawaiians, both elderly and of working age, have higher rates of preventable hospitalizations for CVD than whites (4–6) and a higher cost burden for these hospitalizations (7). They are also hospitalized younger than other racial/ethnic groups for these conditions (4–6).

Narrative health interventions can be powerful tools to promote behavior change and patient education, allowing patients to share their experiences with other patients to both promote health and bring a sense of being understood (8,9). Storytelling interventions have shown considerable promise in reaching communities with high health disparities in

meaningful, effective, and culturally relevant ways (10,11). Such interventions have been used to improve chronic disease management (1,10). This storytelling model has been adapted internationally, with promising results related to the translatability, feasibility, and acceptability in a variety of

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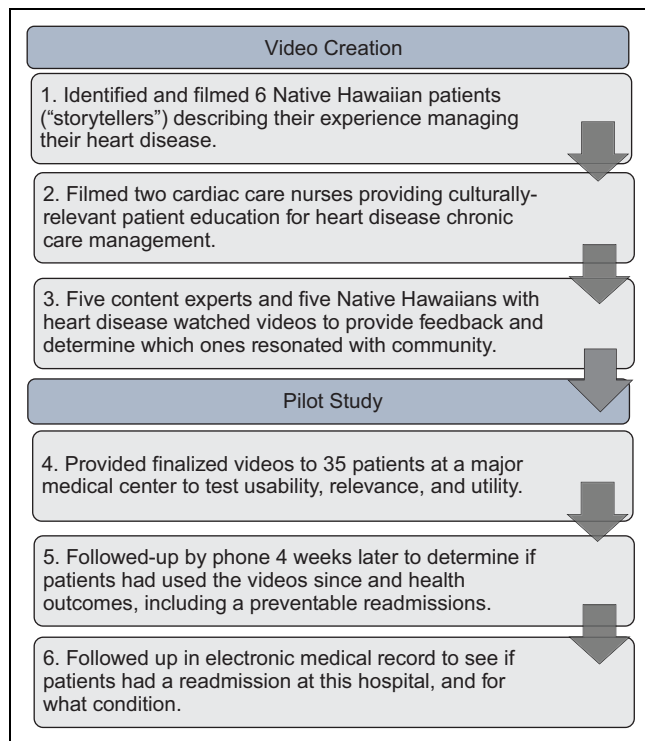
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**Figure 1.** Study flow diagram.

cultural contexts (12). Apart from offering potential to improve patient activation and empowerment through peer identification, the process of listening to the experiences of other patients from similar backgrounds is believed to not only give patients a sense of community but also make patients more receptive to health education (10).

Across generations, NHs have a powerful and vibrant tradition of oral history that continues to this day (13). Taking the time to “talk story” is also an important cultural value in many communities in the state of Hawai‘i (14,15). To our knowledge, storytelling health interventions have not been tested in NH patients, despite the high likelihood that this would be relevant and effective in this patient population with high health disparities. The study goal was to pilot test a video-based “talk story” intervention focused on CVD; specifically, we test its usability, relevance, and utility among NHs with preventable heart disease at a major medical center.

## Methods

The study was based on methods developed by Houston et al (10) and designed to be effective and culturally relevant in the NH community. As demonstrated in Figure 1, we completed 6 steps as enumerated below.

### 1. Storyteller Videos

Six NH patients with heart failure who were known to the clinical staff to be engaging communicators were

approached to see whether they were interested in telling the story of their reason for hospitalization for a video to be shown to other NH patients with CVD. All were willing. Each chosen individual was given detailed information about the project and the videos and provided informed consent for participation.

Storytellers were 2 women and 4 men. Storytellers recorded their story at a location of their choice, either a public setting (beach, meeting room at the hospital) or at home. They told their story about finding out about and managing their heart disease, prompted by an interviewer who utilized a semistructured interview. This interview took between 30 and 60 minutes and was video-recorded. All storytellers received a stipend. Because storytelling interventions are deeply embedded in community participation, storytellers were also invited to attend a “launch party” to celebrate the completion of the final video tool (10) to build a sense of shared goals and community. A brief overview of video themes is attached as Appendix A. Videos were between 5 and 8 minutes long.

### 2. Patient Education Videos

Topics were based on a patient education booklet initially developed through the *Malama Pu‘u Wai* study to be culturally relevant to NH heart failure patients, which was in active clinical use at the pilot study site (16). The 11 patient education videos (fluids, medications, and what can damage the heart) were also developed from community and clinical experience and delivered by local cardiac care nurses at the pilot study site. Most videos were between 1 and 4 minutes long.

### 3. Storytelling Video Refinement

**Clinical stakeholders.** All videos were coded for themes for relevant topics based on previous research about pathways of relevance to self-management for communities in Hawai‘i (17). Videos were then shown in full to 2 (of a panel of 5) clinical stakeholders with experience in public health, NH communities, cardiac care and clinical management, and/or storytelling interventions. Stakeholders identified quotes from each storyteller that were particularly salient by rating each segment by theme on a scale. Using these ratings to guide editing, each video was edited to be between 5 and 8 minutes of salient clips.

**Community stakeholders.** Specific clips from each storyteller were shown to 5 NHs with heart disease at the pilot study facility who provided structured feedback. Videos were edited to reflect this feedback. Specifically, in response to feedback, we did the following: (1) removed the introductory personal stories that did not focus on heart disease; (2) added more information regarding challenges of drug, alcohol use, and smoking; and (3) added more tips around diet and exercise. Final videos are on YouTube under “Queens Heart Failure Stories” and can be found at the following link: <https://www.youtube.com/channel/UCAY33koZGiV8XFCuagGpW4Q>.

One interesting finding from the community was that they particularly enjoyed the scene with the ocean in the background, even though it introduced sound quality challenges. Respondents mentioned that this made them feel more peaceful. Also, women strongly preferred watching videos of women, while men didn't have a preference. Respondents also said they would like to show these videos to their families because it can be hard to communicate these issues.

#### 4. Study Recruitment

Patients aged 21 or older who self-identified as NH and had a primary admission diagnosis of heart failure were recruited from January 2017 to December 2017 from The Queen's Medical Center (QMC), the primary tertiary hospital for the Pacific Basin. Participants could have been hospitalized during recruitment or be attending the heart failure clinic following a past heart failure hospitalization. Potentially eligible patients were identified by 1 of 2 ways. The patients' attending physician could identify and refer potentially eligible patients to the research team, who could approach the patient to obtain informed consent, or nurse practitioners who were part of the care team, who could identify potentially eligible patients and notify the research team. Patients were then asked if they wanted to participate, screened to confirm study inclusion/exclusion criteria, and given informed consent. Of those who were approached and otherwise eligible, only 4 declined to participate stating that they felt too ill or were not interested. *Exclusion criteria included:* in intensive care unit or clinically unstable; non-English speaker; pregnant; memory loss or inability to participate in interview; non-Hawai'i resident; resident of nursing home, hospice, prison, or other similar institution.

Study screening, interviews, and interventions were administered by a trained research nurse. Following informed consent, patients were asked for self-reported sociodemographics, social network composition, health literacy, and health status. Patients were then shown the videos on the iPad and given time to watch what they wanted while being observed by the research nurse. When they indicated they were finished, they were given a brief questionnaire with both closed- and open-ended questions about their experiences. This took approximately an hour but varied considerably by patient health status and interest. Participants received a US\$20 gift card.

#### 5. Follow-Up Interview

Patients were followed up at 4 weeks post interview with a brief (20 minute) telephone survey to ask again about their experience with the video, their health status, and their health services use (rehospitalization and emergency department [ED]). Participants were mailed a US\$20 gift card after the phone interview.

#### 6. Electronic Medical Record (EMR) Data

We also obtained EMR data regarding patient demographic information (zip code, health insurance) and whether they had a rehospitalization or emergency department visit at QMC within 4 weeks.

#### Data Analysis

Data were entered and stored in REDCap (18). STATA 15.0 (College Station, Texas) was used to analyze the usability, relevance, and utility of a "talk story" intervention. According to the pilot study goals, analyses were descriptive in nature. This study was approved by the University of Hawai'i CHS #23410.

### Results

In the 35 pilot study participants, the mean age was 57.0 years (standard deviation [SD]:13.0). Demographic details are shown in Table 1; 31% (11) were female; 100% were NH; and 47% had less than a high school education. A total of 74% self-reported low health literacy (ie, were not at all/not really/somewhat confident filling out medical forms by themselves).

Patients reported significant social challenges. For instance, 34% had housing challenges, 40% reported active substance use, 40% reported mental health issues, and 32% reported that health was secondary to other concerns. Also, 17% of the sample had no one in their social network, 31% had 1 person, 43% had 2 people, 6% had 3. Only 1 person had more than 3 (4 individuals) in their social network.

#### Video Engagement

All videos were watched on an iPad while sitting with the research nurse. During this time, 85.7% spontaneously told their own heart failure stories to the research nurse. Many patients were short of breath, sleepy, or coughing so much that it was hard for them to respond to interviewer question and watch many videos. Two respondents specifically stopped watching the videos early due to illness (eg, shortness of breath, tachycardia); 31% watched the videos less than 10 minutes, 20% watched them between 10 and 19 minutes, and almost half (46%) watched the videos for 20 minutes or more. Of our 17 possible videos, 3 participants watched 1 video, 20 watched 2 videos, 9 watched 3 videos, and 3 watched 4 or more. The shortest interview was about 30 minutes where the patient watched only 1 or 2 videos. The longest interview was about 2 hours. In this case, the patients told many stories of their own heart failure experiences while watching the videos.

Details around patient self-reported responses to the videos from interview questions are shown in Table 2. On a scale of 1 (worst) to 4 (best), respondents rated the videos 3.7 (SD: 0.5) in relevance for helping them manage their

**Table 1.** Descriptive Results for Native Hawaiian Study Participants With Heart Disease.<sup>a</sup>

| Demographics  | n (%)     |
|---|-----------|
| Education   |           |
| Less than HS  | 14 (46.7) |
| High school graduate  | 13 (43.3) |
| College graduate  | 3 (10.0)  |
| Age-group   |           |
| Working age (18-64)   | 25 (71.4) |
| Older adults (65+)  | 10 (28.6) |
| Gender  |           |
| Female  | 11 (31.4) |
| Male  | 23 (65.7) |
| Other   | 1 (2.9)   |
| Family income   |           |
| Under US\$20 000  | 20 (57.1) |
| US\$20 000-US\$40 000   | 7 (20.0)  |
| Over US\$40 000   | 3 (8.6)   |
| Missing   | 5 (14.3)  |
| Low self-reported health literacy   |           |
| Not at all/not really/somewhat confident filling out medical forms by self  | 26 (74.3) |
| Sometimes/usually/often have someone help read hospital materials   | 22 (64.7) |
| How strongly do you relate to the Native Hawaiian culture?  |           |
| A lot   | 34 (97.1) |
| Somewhat  | 1 (2.86)  |
| Member of a couple (unmarried, same sex, and/or married)  |           |
| Yes   | 22 (37.1) |
| No  | 13 (62.9) |
| Employment status   |           |
| Employed  | 3 (8.6)   |
| Retired   | 4 (11.4)  |
| Not employed/unable to work   | 28 (80)   |
| Report challenges in  |           |
| Housing   | 12 (34.3) |
| Not having enough money   | 14 (38.2) |
| Social support  | 11 (31.4) |
| Knowledge of illness  | 6 (17.0)  |
| Substance use (active)  | 14 (40.0) |
| Trouble with MH issues  | 14 (40.0) |
| Denial/not wanting to deal with illness at least "sometimes"  | 16 (45.7) |
| Health secondary to other concerns  | 11 (32.4) |
| Number in Social Network: "From time to time, most people discuss important matters with other people. Looking back over the last six months—who are the people with whom you discussed matters that are important to you?" |           |
| 0   | 6 (17.1)  |
| 1   | 11 (31.4) |
| 2   | 15 (42.9) |
| 3   | 2 (5.7)   |
| 4   | 1 (2.9)   |
| Relationships (of all 51 listed relationships)  |           |
| Daughter/daughter-in-law  | 12 (23.5) |
| Sister/sister-in-law  | 10 (19.6) |
| Spouse/partner/   | 9 (17.6)  |

(continued)

**Table 1.** (continued)

| Demographics         | n (%)    |
|----------------------|----------|
| Mother/mother-in-law | 6 (11.8) |
| Son                  | 4 (7.8)  |
| Niece                | 2 (3.9)  |
| Friend               | 2 (3.9)  |
| Granddaughter        | 2 (3.9)  |
| Grandmother          | 1 (2.0)  |
| Father               | 1 (2.0)  |
| Roommate             | 1 (2.0)  |
| Nephew               | 1 (2.0)  |

Abbreviation: HS, high school.

<sup>a</sup> N = 35.

heart disease and a 3.6 (SD: 0.5) in their experience using these videos.

When asked what they liked the most, the most common response (14 respondents) was they are "like me." Other responses included that the storytellers are: saying "the right things"/"the truth"/"like it is" (6 respondents); "you can learn from them"/"good reminder"/"good information" (6); they are all Hawaiian (3 respondents); "I know them"/"They remind me of someone I know" (2 respondents); "I like to hear everyone else's story (1 respondent). The things they liked the least were "nothing" or no response (19) or sound quality ("too noisy"/"hard to hear") (7 respondents). Comments are shown seen in Table 2.

In total, 75% of the sample said they would like to show them to someone else. Of those who said they had someone in their social network (20), 81.5% said they would like to show these videos to someone else, mentioning family members (especially daughters and sons), other people "like me", and friends.

### Usefulness of Videos

In all, 84% said they would like to watch them again. Respondents noted "it might be helpful to watch them all" (84-year-old man) or "I'd like to watch them all when I feel better" (56-year-old-woman). A 23-year-old woman noted the resonance with her own experience, "All of these should be on TV... I didn't know what was happening to me." Another 52-year-old male respondent noted "I know what they are all going through." Another (a 64-year-old man) said "It's hard to live like this, with this" and a 72-year-old who reported "other" for gender said the videos were "sad but interesting" and "they tell the truth."

When asked which video was their favorite, the importance of personal connection was clear, as individuals were drawn to others who had similar experiences to them. A 52-year-old man, a 52-year-old female, a 66-year-old man, and a 77-year-old-man all noted they like the video by the storyteller 3 (a middle-aged man) because he was "like me." A 71-year-old male noted he liked the story by storyteller 5 the best because "I have a pacer too." A 42-year-old male like

**Table 2.** Usability, Relevance, and Utility of a “Talk Story” Intervention From Patient’s Perspectives.

|   | n (%)     |
|---|-----------|
| How relevant do you think these videos are in helping you manage your heart disease?  |           |
| 1 (worst)   | 0         |
| 2   | 0         |
| 3   | 12 (34.3) |
| 4 (best)  | 23 (65.7) |
| How would you rate your experience with patient education videos?   |           |
| 1 (worst)   | 0         |
| 2   | 0         |
| 3   | 13 (37.1) |
| 4 (best)  | 22 (62.9) |
| What do you like best? (n = 32)   |           |
| I am like them/they are like me   | 14 (43.8) |
| They are saying the right things/the truth/like it is   | 6 (18.8)  |
| You can learn from them/good reminder/good information  | 6 (18.8)  |
| They are all Hawaiian   | 3 (9.4)   |
| I know them/They remind me of someone I know  | 2 (6.3)   |
| I like to hear everyone else’s story  | 1 (3.1)   |
| What do you like least? (n = 13)  |           |
| Sound quality (“too noisy” “Hard to hear”)  | 7 (53.8)  |
| I cannot follow anyone else’s program, I have to follow my own  | 1 (7.7)   |
| Too many  | 1 (7.7)   |
| I have to lose weight. I have a “hard head”   | 1 (7.7)   |
| “Reminds me of me.”   | 1 (7.7)   |
| “We Hawaiians are hard headed. It’s true.”  | 1 (7.7)   |
| Too repetitive/“same story”   | 1 (7.7)   |
| Would you like to watch them again? (n = 33)  |           |
| Yes   | 28 (84.8) |
| Maybe   | 3 (9.1)   |
| No  | 2 (6.1)   |
| Would like to take a copy home? (n = 30)  |           |
| YouTube   | 15 (50.0) |
| No  | 10 (33.3) |
| Other   | 4 (13.3)  |
| DVD   | 1 (3.3)   |
| Would you show them to someone else? (n = 32)   |           |
| Yes   | 24 (75.0) |
| No  | 8 (25.0)  |
| Who else do you think would enjoy these videos? (n = 15)  |           |
| Family members (ie, 2 daughters, daughters and sons, any family member who wants to help, my daughter, my son)              | 5 (33.3)  |
| Anybody, everybody with heart failure, anybody who is sick  | 3 (20.0)  |
| Other people like me, sick people like me   | 3 (20.0)  |
| Friend  | 1 (6.7)   |
| Other patients from Queen Emma clinic   | 1 (6.7)   |
| If you were going to watch videos as part of patient education here at QMC, how would you like to do this? (28 respondents) |           |
| Computer  | 9 (32.1)  |
| YouTube   | 7 (25.0)  |
| iPad  | 5 (17.9)  |
| Other   | 3 (10.7)  |

(continued)

**Table 2.** (continued)

|   | n (%)     |
|---|-----------|
| TV  | 3 (10.7)  |
| DVD   | 1 (3.6)   |
| Other notes about how would you like to watch? (14 people responded, categories not mutually exclusive) |           |
| You tube/on a computer  | 3         |
| “Any way/all ways”  | 1         |
| On a phone/cell phone   | 4         |
| TV  | 2         |
| Mentions no Internet and/or no computer   | 4         |
| Would you like to tell your story in a future video?  |           |
| Yes   | 5 (14.3)  |
| No  | 30 (85.7) |

**Table 3.** Four-Week Follow-Up.

|   | n (%)     |
|---|-----------|
| From phone interviews (N = 15)                      |           |
| Do you think the videos in the hospital helped you? |           |
| No  | 2 (13.3)  |
| Yes   | 13 (86.7) |
| Have you watched them again?                        |           |
| No  | 13 (86.7) |
| Yes   | 2 (13.3)  |
| Have you showed them to anyone else                 |           |
| No  | 14 (93.3) |
| Yes   | 1 (6.7)   |
| From EMR and self-report (N = 35)                   |           |
| Readmitted to hospital?                             |           |
| No  | 26 (74.3) |
| Yes, QMC  | 8 (22.9)  |
| Yes, other (Molokai)                                | 1 (2.0)   |
| Emergency department visit                          |           |
| No  | 24 (68.6) |
| Yes, QMC  | 10 (28.6) |
| Yes, other (Kuakini)                                | 1 (2.9)   |

Abbreviation: QMC, Queen’s Medical Center.

the story by storyteller 2 best because he was “trying to lose weight like him.” And a 57-year-old man liked storyteller 4’s story because he “has shortness of breath and fluid just like me.” The 3 people who liked storyteller 1 (a woman) best were women.

### Mode of Delivery

Of the 28 respondents who discussed how they would like to watch videos like these, if they were part of the patient education at QMC, they said the following: 32% (9) said on a computer, 25% (7) said YouTube, 18% (5) said iPad, and 11% (3) said TV. Of note, 4 participants mentioned specifically that they have no computer or Internet access.

## Follow-Up

Follow-up detail is shown in Table 3. We completed the QMC EMR follow-up for all patients and the 4-week telephone follow-up with 15 patients (42.9% of the study sample). For 9 patients, we were able to learn from family members or EMR why they could not be reached for follow-up: 4 patients died in the 4-week follow-up period; 5 were otherwise unavailable (ie, hospitalized, in drug treatment, in hospice); 11 could not be contacted after 3 follow-ups for various reasons likely related to social challenges (ie, homeless and no phone, all phone lines disconnected, in jail). From the QMC EMR and the report, 26% had been readmitted to the hospital (all but one at QMC) and 31% had gone to an ED (again, all but 1 at QMC). Of the 15 individuals reinterviewed, 87% said they thought the videos helped them.

## Discussion

Our study goal was to create and evaluate the suitability and utility of a narrative-focused, community-, and culturally-relevant intervention to share patient experiences among NHs. The “talk story” videos were relevant and useful to study participants. Respondents liked the videos and identified with the storytellers. The narrative intervention also opened up a dialog with the nurse researcher, which could build trust and strengthen relationships to support clinical care.

Importantly, these narrative videos engendered a sense of community and/or recognition. Respondents in both the community pretesting and in the intervention group noted that they would like to show these videos to their families because it can be hard to communicate these issues. Similar responses were seen for a similar intervention in Vietnam where people invited neighbors and family to watch (12). The Vietnam context had an element of sharing the information with others and, at the same time, seemed to offer an indirect form of recognition as being important members of the community at large, despite having chronic disease.

Loneliness is a significant health risk factor, and 17% of sample had no one they talked to regularly. Social networks are important. In a recent study of Medicare beneficiaries, not only were minority racial/ethnic groups more likely than non-Hispanic whites to have someone accompany them to the doctors’ appointment but also were individuals in groups more likely to experience disparities in health outcomes and access (including those with lower education, the dual eligible) (21). Thus, a greater consideration of the social network in the clinical encounter may also help address other health disparities beyond race/ethnicity (19,21-23).

We learned some important information to help us refine our videos. Most of the research participants were more interested in the “lived experiences of the storytellers” versus watching any of the educational videos. In future

interventions, we would consider coupling narratives with relevant patient education to ensure that patients watch these or would directly embed personal narratives within the content and context of an educational video. This would allow us to hopefully leverage the greater openness to patient education after watching storytelling videos noted in previous research (10).

We learned other important practical lessons for future research. This patient population had significant and multifaceted social challenges. Many did not keep appointments or have homes, making recruitment and follow-up more challenging. Also, this patient population was quite ill, and a number of participants died before follow-up. As a pilot project, we did this filming and editing on a minimal budget. In the future, it would be ideal to use outside technical expertise and to film in more outdoor settings, as this was appealing to our community. Women preferred watching videos of women who are underrepresented in heart failure.

This study has many strengths and some limitations. As a pilot study, our sample size was small, and our sample was disproportionately lower in socioeconomic status than would be expected in this clinical setting. Similarly, we did this work in a particular hospital in Hawai‘i and findings may not be relevant to other settings. Nevertheless, this study provides useful baseline information to justify such an intervention and to guide, in a practical way, the design and planning.

The high risks for hospitalizations for NHs are likely multifaceted, including practical challenges, such as limited access to care generally and limited access to culturally or linguistically relevant care specifically, as well as underlying social determinants, such as higher poverty, that can compromise preventive health care and disease management (1,2,24,25). This study cannot address the social factors. However, seeing similar challenges, and navigation tips, from others may be helpful. This can engage social networks (26,27) to support health and reduce health disparities in NHs, a group for whom communal values and *ohana* (family) are important community strengths (20).

## Conclusion

The narrative “talk story” intervention provided a patient-centered feasible way to communicate health issues among NH patients, showing promise as a culturally relevant method to reduce health disparities in chronic disease management. Such a video intervention built a sense of shared experience and of not being alone in their struggles and provided an opportunity for many patients to spontaneously share their own stories, challenges, and experiences. This can build a sense of community among those with an impactful chronic disease that demands significant self-management and, often, behavioral changes in nutrition, fluids, and substance use that many patients struggle to achieve. This could also build trust in other health conditions, including those that are more stigmatized than heart disease but also show significant health disparities, such as HIV.

## Appendix A

### Video Descriptions/Themes

#### Storyteller 1 (female)

1. Name
2. Finding out about heart problem
3. Challenges with medication
4. Caregiving role
5. Have to have a good mind-set
6. Exercise
7. Ideas for resources
8. Message if have new diagnosis
9. Message if have new diagnosis
10. Final thoughts

#### Storyteller 2 (male)

1. Name
2. Finding out about heart problem
3. Adjusting to heart disease
4. Small steps
5. Trying to manage, in denial
6. Diet
7. Diet
8. Hard head

#### Storyteller 3 (male)

1. Name
2. Finding out about heart disease
3. How it feels to have congestive heart failure
4. How it feels to have congestive heart failure
5. Managing fluid intake
6. Diet
7. Taking medicines
8. Listen to doctor—Will feel difference

#### Storyteller 4 (male)

1. Name
2. Finding out about heart problem
3. Surgery
4. Drugs, heart disease, and denial
5. How to get off drugs—Have to do it yourself
6. If I can do it, anyone can
7. Hawaiians have the highest heart conditions
8. How to cook/exercise
9. Changed diet
10. Talk story at QMC

#### Storyteller 5 (male)

1. Name
2. Finding out

3. Pacemaker
4. Managing disease (Pacemaker gave confidence)
5. Low salt diet
6. Had to cut salt
7. Medication
8. Believe in the culture of Hawai'i
9. Thank god for the life and the people
10. Diet

#### Storyteller 6 (female)

1. Name
2. Finding out about heart problem
3. Heart attack experience
4. Didn't know had heart condition
5. Smoking
6. Nurse and patient education
7. Challenges, especially cigarettes
8. Managing stress
9. What gives her strength

#### Tips: Drinking

1. Storyteller 3 (male)
2. Storyteller 3 (male)
3. Storyteller 2 (male)
4. Storyteller 2 (male)

#### Patient Education

1. Introductions
2. The heart
3. What is heart failure
4. What can damage the heart?
5. Stretched heart
6. How to manage my heart disease
7. What can I eat?
8. Fluids
9. Medications
  - a. Types of medicine overview/side effects—Call doc
  - b. Anti-rhythmic medication/blood thinning
  - c. Provider needs to know about how you are taking
  - d. Diuretic medications
  - e. What about alternative medicines? Should I tell my doctor?
10. Exercise
  - a. Can I exercise? What kind can I do? Take is slowly; tips (buddy, cell phone); walking, swimming pool, hula; talk it over with provider if want to do big activities
  - b. Can I have sex?

11. Living as a whole person
  - a. This is an overwhelming time, Living with joy important along with other things. Can feel depressed?
  - b. Resources
  - c. We wish you well in the journey

### Author Contributions

All authors have approved the final article. Individual roles are as follows: Tetine Sentell: conception and design, analysis and interpretation of data, drafting article; Fiona Kennedy: conception and design, acquisition of data, analysis, and interpretation of data, revising article for critically for important intellectual content. Todd Seto: conception and design, acquisition of data and interpretation of data, revising article for critically for important intellectual content. May Vawer: conception and design, acquisition of data and interpretation of data, revising article for critically for important intellectual content. Germán Chiriboga: conception and design, interpretation of data, revising article for critically for important intellectual content. Coraleen Valdez: conception and design, acquisition of data and interpretation of data, revising article for critically for important intellectual content. Lisa M. Garrett: conception and design, acquisition of data and interpretation of data, revising article for critically for important intellectual content. Diane Paloma: conception and design, acquisition of data and interpretation of data, revising article for critically for important intellectual content. Deborah Taira: conception and design, acquisition of data, analysis and interpretation of data, revising article for critically for important intellectual content.



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### Supplemental Material

Supplemental material for this article is available online.

### References

1. King GL, McNeely MJ, Thorpe LE, McNeely MJ, Thorpe LE, Mau ML, et al. Understanding and addressing unique needs of diabetes in Asian Americans, Native Hawaiians, and Pacific Islanders. *Diabetes Care*. 2012;35:1181-8.
2. Mau MK, Sinclair KA, Saito EP, Baumhofer KN, Kaholokula JK. Cardiometabolic health disparities in Native Hawaiians and other Pacific Islanders. *Epidemiol Rev*. 2009;31:113-29.
3. Aluli NE, Reyes PW, Brady SK, Tsark JU, Jones KL, Mau Met, et al. All-cause and CVD mortality in Native Hawaiians. *Diabetes Res Clin Pract*. 2010;89:65-71.
4. Sentell TL, Ahn HJ, Juarez DT, Tseng CW, Chen JJ, Salvail FR, et al. Disparities in diabetes-related preventable hospitalizations among working-age Native Hawaiians and Asians in Hawai'i. *J Med Public Health*. 2014;73:8-13.
5. Sentell T, Miyamura J, Ahn HJ, Chen JJ, Seto T, Juarez D. Preventable hospitalizations for congestive heart failure in Native Hawaiian, Filipino, and Japanese adults compared with whites. *J Immigr Minor Health*. 2015;17:1289-97.
6. Moy E, Mau M, Raetzman S, Barrett M, Miyamura JB, Chaves KH, et al. Ethnic differences in potentially preventable hospitalizations among Asian American, Native Hawaiians and other Pacific Islanders: implications for reducing health care disparities. *Ethn Dis*. 2013;23:6-11.
7. Sentell TL, Ahn HJ, Miyamura J, Juarez DT. Cost burden of potentially preventable hospitalizations for cardiovascular disease and diabetes for Asian Americans, Pacific Islanders, and whites in Hawai'i. *J Health Care Poor Underserved*. 2015;26:63-82.
8. Perrier MJ, Martin Ginis KA. Changing health-promoting behaviours through narrative interventions: a systematic review. *J Health Psychol*. 2016;23:1499-517.
9. De Graaf A, Sanders J, Hoeken H. Characteristics of narrative interventions and health effects: a review of the content, form, and context of narratives in health-related narrative persuasion research. *Rev Communicat Res*. 2016;4:88-131.
10. Houston TK, Allison JJ, Sussman M, Horn W, Holt CL, Trobaugh J, et al. Culturally appropriate storytelling to improve blood pressure: a randomized trial. *Ann Intern Med*. 2011;154:77-84.
11. Gucciardi E, Jean-Pierre N, Karam G, Sidani S. Designing and delivering facilitated storytelling interventions for chronic disease self-management: a scoping review. *BMC Health Serv Res*. 2016;16:249.
12. Nguyen HL, Allison JJ, Ha D, Chiriboga G, Ly HN, Tran HT, et al. Culturally adaptive storytelling intervention versus didactic intervention to improve hypertension control in Vietnam: a cluster-randomized controlled feasibility trial. *Pilot Feasibility Study*. 2017;3:22.
13. 'Ike' Āina: Native Hawaiian culturally based indigenous literacy. 2008, Retrieved August 6, 2018 from: [kamehamehapublishing.org/\\_assets/publishing/hulili/Hulili\\_Vol5\\_6.pdf](http://kamehamehapublishing.org/_assets/publishing/hulili/Hulili_Vol5_6.pdf).
14. Hu-pei Au K, Kawakami AJ. Research currents: talk story and learning to read. *Language Arts*. 1985;62:406-11.
15. JMcMullin J, Bone M, Pang JK, Pang VK, McEligot A. Native Hawaiian voices: enhancing the role of cultural values in community based participatory research. *Calif J Health Promot*. 2010;8:52-62.
16. Mau MKLM, Lim E, Kaholokula JK, Loui TMU, Cheng Y, Seto TB. A randomized controlled trial to improve heart failure disparities: the Mālama Pu'uwai (caring for heart) Study. *Open Access J Clin Trials*. 2017;9:65-74.



17. Sentell TL, Young MM, Vawer MD, Quensell ML, Braun KL, Taira DA, et al. Pathways to potentially preventable hospitalizations for diabetes and heart failure: patient perspectives. *BMC Health Serv Res.* 2016;16:300.
18. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research Electronic Data Capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform.* 2009;49:377-81.
19. Black S, Maitland C, Hilbers J, Orinuela K. Diabetes literacy and informal social support: a qualitative study of patients at a diabetes centre. *J Clin Nurs.* 2017;26:248-57.
20. Look MA, Trask-Batti MK, Agres R, Mau ML, Kaholokula JK. Assessment and priorities for health & well-being in Native Hawaiians & other Pacific peoples. 2013. Retrieved September 30, 2018, [https://www2.jabsom.hawaii.edu/native/docs/community/DNHH\\_Assessment&Priorities\\_Report\\_2013.pdf](https://www2.jabsom.hawaii.edu/native/docs/community/DNHH_Assessment&Priorities_Report_2013.pdf).
21. Sentell TL, Shen C, Landsittel D, Mays MH, Southerland J, King MH, et al. Racial/ethnic differences in those accompanying Medicare patients to the doctor: insights from the 2013 Medicare Current Beneficiary's Survey. *J Immigr Minor Health.* 2018;20:776-83.
22. Wolff JL, Roter DL. Family presence in routine medical visits: a meta-analytical review. *Soc Sci Med.* 2011;72:823-31.
23. Piette J. Editorial: moving beyond the notion of 'self' care. *Chronic Illn.* 2010;6:3-6.
24. Poureslami I, Nimmon L, Rootman I, Fitzgerald MJ. Health literacy and chronic disease management: drawing from expert knowledge to set an agenda. *Health Promot Int.* 2017;32:743-54.
25. Bernheim SM, Ross JS. Hospital discharge and the transition home for poor patients: "I knew I couldn't do what they were asking me." *J Gen Intern Med.* 2014;29:269-70.
26. Valente TW. *Social Networks and Health: Models, Methods, and Applications.* Oxford England: Oxford University Press: 2010.
27. Vassilev I, Rogers A, Kennedy A, Koetsenruijter J. The influence of social networks on self-management support: a metasynthesis. *BMC Public Health.* 2014;14:719.

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