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# Colorectal Cancer Screening at the Nexus of HIV, Minority Statuses, and Cultural Safety

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# Abstract

**Background**—The incidence of non-AIDS-defining cancers has increased significantly among persons living with HIV (PLHIV). Screening education is recommended.

**Purpose**—Social learning, minority stress, and cultural safety theories informed this pilot to assess the feasibility of a colorectal cancer screening intervention targeted to PLHIV, with additional tailoring for relevance to Native Hawaiians, a group with low participation in cancer screening.

**Method**—The targeted education included behavioral modeling and barriers counseling in a culturally safe environment. Using a 2-group, pre/posttest design, AIDS service organizations were randomized to culturally responsive or standard education. AIDS service organizations consumers recruited through venue-based promotions were the unit of analysis. Knowledge–attitudes–practices, fecal occult blood test screening completion, and intervention feasibility were measured.

**Results**—Treatment arm participants, regardless of ethnicity, adhered to fecal occult blood test instructions and achieved increases in screening knowledge, attitudes, and practices. Relevance and acceptability of the educational intervention were endorsed.

**Discussion**—The culturally responsive intervention was successful in this group of PLHIV. Additional tailoring may be needed to reach PLHIV who do not participate in organizational activities.

**Conclusion/Translation to Health Education Practice**—This culturally responsive intervention shows promise for efficacy testing in a broader PLHIV population. Constituent-involving strategies were central to its development and delivery.

The increasing incidence of non-AIDS-defining cancers (NADCs) is of significant concern in the present landscape of cancer control for persons living with HIV (PLHIV).<sup>1–5</sup> NADCs are all malignancies other than invasive cervical cancer, Kaposi's sarcoma, and non-Hodgkin's lymphoma, the latter of which are defining conditions for a diagnosis of AIDS. Between 1991 and 2005, NADC cases in PLHIV increased 3-fold, whereas incidence of AIDS-defining cancers dramatically declined.<sup>5</sup> Ten NADCs appear to contribute substantially to the cancer burden among PLHIV, including anal, colorectal, liver, lung, mouth and throat, renal, skin, and vaginal cancers; Hodgkin's lymphoma; and leukemia.<sup>4</sup> As in the seronegative population, NADCs among PLHIV tend to be associated with older age. However, PLHIV are more likely to develop NADCs at a younger age than persons who are

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seronegative and may have atypically aggressive symptoms, higher tumor grades, and worse prognoses.<sup>3</sup> Treatment is complicated by a limited, albeit developing, body of knowledge on potential interactions between HIV and cancer treatments, as well as overlapping medication side effects.<sup>1</sup> Routine use of cancer screening tends to be less frequent in PLHIV than in individuals who are seronegative.<sup>1–3,5</sup> There is a growing need to proactively address NADCs through collaborations of PLHIV, social and health services providers, public health educators, and health researchers working together at the nexus of HIV and NADC screening.

This article describes results from a Hawai'i-based pilot intervention study designed to increase PLHIV's use of the fecal occult blood test (FOBT), a reasonably sensitive, first-line screen against colorectal cancer (CRC).<sup>6</sup> The primary purpose of the study was to test feasibility of a culturally responsive screening intervention, with attention to the viability of research protocols and educational strategies used. We speculated that in comparison to standard care (culturally neutral CRC screening print materials), the culturally responsive intervention (targeted print materials and face-to-face group education) would be more likely to suggest increases in CRC screening knowledge, attitudes, practices, and timely completion of FOBT.

Typically, researchers test feasibility prior to conducting a full-scale efficacy intervention trial. Feasibility studies provide preliminary evidence that an innovation and its research methods likely will be accepted by the intended population.<sup>7</sup> In addition, well-designed feasibility studies that meaningfully engage stakeholders as research partners may be especially important for historically marginalized groups; such engagement potentiates stakeholder support while at the same time informing intervention development and research design. In this feasibility study, a multidisciplinary research education team collaborated with AIDS services organizations and worked closely with a community advisory board to develop a CRC screening education intervention that was targeted to PLHIV residing in Hawai'i and tailored for relevance to Native Hawaiians, a group with low participation in cancer screening.<sup>8–10</sup> Study aims were to document and evaluate (1) feasibility of randomization, recruitment, retention, and data collection procedures; (2) feasibility of the educational innovation being positively received and culturally acceptable; and (3) whether positive effects of the educational innovation are suggested in CRC screening knowledge, attitudes, practices, and timely screening behavior.

# MINORITY STRESS, CULTURAL SAFETY, AND SOCIAL LEARNING THEORY

The literature on minority stress and health services utilization, cultural safety, and social learning theory provided the conceptual context for understanding the lived experiences of PLHIV and sensitizing educational approaches. *Minority* refers to a group with characteristics that prompt negative attributions from the social majority.<sup>11</sup> Moreover, the term connotes disadvantage in resource access and, concomitantly, might include lived experiences of persistent marginalization and individual and/or collective trauma.<sup>11–21</sup> Minority stress theory recognizes that persons with a sexual minority status (lesbian, gay, bisexual, transgender) often are the object of prejudicial attitudes, social stigma, and differential treatment by individuals, groups, and institutional systems; such attitudes and behaviors are associated with chronic strain and psychological distress.<sup>17</sup> Ethnic and sexual minority groups experience a disproportionate burden of HIV/AIDS, and microaggressions (intentional or unintentional verbal denigration, discrimination, or assaultive behavior) experienced by these groups in mainstream health care settings may cause avoidance or delays in seeking care.<sup>12–14,16,18,20,21</sup> In particular, these groups have noted refusal of

services, rough or inappropriate touching, negative and judgmental verbalizations, and non-acknowledgment of families of choice.<sup>16</sup>

Cultural safety initially was developed to address health disparities in socioeconomically disadvantaged, yet culturally rich, Maori communities of Aotearoa (New Zealand).<sup>22</sup> The construct of cultural safety initially was coined by Maori nurses who observed tendencies in non-Maori providers to verbally and behaviorally denigrate indigenous cultural values and practices and to attribute poor health outcomes to cultural deficits.<sup>22-24</sup> In short, provider behavior fostered a sociocultural climate experienced by Maori communities as threatening and functioned as a potent barrier to Maori participation in health services. Cultural safety is intended to further the discourse on decolonization of knowledge development. The construct purposefully extends the definition of *culture* as values and practices to include group meanings as embedded in historical, social, economic, and political relationships and process, with emphasis on subverting relationships of unequal power.<sup>23,24</sup> Guidelines for cultural safety are premised on the recognition of a group's strengths in surviving cultural trauma, coping with ongoing marginalization, and making health services more welcoming. Providers practicing cultural safety do not assault or challenge consumers' cultural identities; rather, they demonstrate respect for all ways of knowing, strive for reciprocity in learning, and, importantly, continuously monitor for negative biases and judgments. The broad relevance of cultural safety guidelines has led to their adaptation and adoption by other indigenous and minority communities, including persons living with HIV.<sup>23,25–27</sup>

Educational approaches informed by social learning theory<sup>28</sup> are compatible with cultural safety guidelines. This theory posits that learning occurs in a social context. Participatory learning activities are understood to empower behavioral enactment. Self-efficacy (the belief in one's ability to perform a behavior) is a pivotal aim and facilitated by attitudes that a behavior is beneficial, as well as by knowledge and skills requisite to behavioral enactment. Learning strategies focus on attitudinal modeling and reinforcement, demonstration of behavior with learner observation, imitation (practice), discussion of barriers to behavioral enactment, and coaching with barriers counseling when indicated.<sup>29</sup>

#### LIVING WITH HIV

The demographics of PLHIV in Hawai'i impact the types of care that persons receive and barriers experienced.<sup>30</sup> In Hawai'i, the majority of PLHIV are of advanced ages with long durations of HIV infection, which increases the likelihood of being treatment experienced (extensive experience with medications is associated with high levels of drug resistance). This presents a particular challenge when PLHIV are diagnosed with advanced cancers and prompted this targeted CRC screening intervention for PLHIV. Persons of Native Hawaiian/Pacific Islander ethnicities have a higher prevalence of HIV/AIDS and poorer health outcomes than other ethnic groups in the state.<sup>31</sup> Fewer years in school, lower incomes, higher rates of homelessness, and other distal factors are associated with these disparities. For Native Hawaiians in general and for Native Hawaiian male-to-female transgender persons in particular, accessing curative and preventive care also may be influenced by additional sociocultural factors.<sup>13,14,18,32</sup>

Traditional Native Hawaiian culture favors collective well-being over that of the individual.<sup>32</sup> Though collectivism may motivate support (*kokua*) from blood-related and fictive kin networks, Native Hawaiians living with HIV may avoid care if disclosure of stigmatized statuses threatens family well-being or if treatment adherence interferes with performing family responsibilities (*kuleana*). Traditional culture held an honored social role for men who had sex with men (*na aikane*) and persons who were male-to-female transgender persons (*na mahu, na mahuwahine*), with the latter considered a third

gender.<sup>13,14</sup> However, in contemporary times tolerance for such persons has declined sharply; among underserved Native Hawaiians, those identifying as transgender or other sexual minority are the least likely to seek care and thus are medically underserved.<sup>14,18</sup> The complex interplay of these biomedical and sociocultural factors motivated the development of a culturally responsive educational intervention—one that was targeted to PLHIV, with attention to additional tailoring for Native Hawaiians.

# INTERVENTION

The research project was promoted as "*Na Pua o Ke Ola*" (*Na Pua*), which in Hawaiian means "the flowers of life" and, metaphorically, likens people to flowers that thrive and bloom when life-giving resources are available. In *Na Pua*, screening education was promoted as a vital resource. The educational innovation was culturally targeted on the lived experiences of PLHIV, with additional tailoring for PLHIV identifying as Native Hawaiian.

*Na Pua*'s culturally responsive intervention was informed by two social learning theory– inspired cancer screening intervention trials with Native Hawaiians, one focused on breast cancer screening with older women in rural churches and the other on CRC screening with older persons in civic clubs.<sup>33–35</sup> As in these earlier interventions, *Na Pua*'s education was manualized. There were 4 key components: (1) prepared testimonials on screening benefits as modeled by a cancer survivor and/or family member with sociodemographic characteristics similar to the target audience; (2) presentation of the evidence on cancer prevalence in the seropositive population, screening efficacy, and benefits of early detection, as presented by a health care provider/educator; (3) explication and demonstration of FOBT use with opportunities for behavioral imitation; and (4) throughout the educational session, purposeful review of learning with opportunities for discussion of biopsychosocial challenges to screening enactment, barriers counseling, and behavioral coaching.

As with the CRC intervention in Hawaiian civic clubs,<sup>33</sup> *Na Pua* provided participants in both study arms with screening resources and free FOBT home kits. However, age of screening was lowered from 50 years, as recommended by the US Preventive Services Task Force,<sup>6</sup> to 40 years because clinical findings suggest that CRC may develop at younger ages and be more aggressive in persons who are seropositive. The ColoCARE (Helena Laboratories, Beaumont, TX) FOBT kit was distributed to all participants. To use this, a pad made from biodegradable paper chemically treated with a chromogen is floated on the water surface in the toilet bowl after a bowel movement. If detectable blood is present, the hemoglobin reacts with the chromogen and a blue or green color reaction occurs. Participants were instructed to record the color of the pad on a card and return by mail to *Na Pua*. The project's community advisory board believed that adherence would be higher for this FOBT kit than for the FOBT kit requiring collection of stool samples and mailing to a laboratory for analysis.

Unlike the church- and civic club–based interventions, *Na Pua* was aimed at a more socially vulnerable target audience, namely, persons living with HIV, which included persons of Native Hawaiian ancestry, as well as others of diverse ethnicities and cultural identifications. Guidance from *Na Pua*'s community advisory board and other constituent-involving strategies were used to customize this CRC screening intervention primarily on the experiences of PLHIV in Hawai'i and to tailor certain elements of the educational intervention for relevance to Native Hawaiians. Guidelines for targeting and tailoring included (*a*) acknowledgement of screening challenges (eg, HIV-related illness, discrimination, stigma, microagressions) with barriers counseling when indicated; (*b*) assurance of a culturally safe educational environment, with attention to confidentiality, privacy, and sensitivity to educator behaviors that demonstrated welcome and affirmation of

minority experiences; (c) use of only those Native Hawaiian practices (eg, lei greetings, oli or opening chant) and terms (eg, kokua or help) commonly included in multicultural gatherings in Hawai'i; and (d) use of English translations and explanation for all Hawaiian language terms and traditions used. Thus, all participants attending the culturally responsive educational session were welcomed with flower garlands and, as is customary in Hawai'i, time was taken to informally connect through "talk story" (ho'olauna). The formal presentation began with a welcome by the principal investigator (herself of Native Hawaiian ancestry) and a Hawaiian chant (oli) acknowledging gratitude for all sources of knowledge. The principal investigator encouraged the honoring of diverse experiences and invited all to share learning through group activities and discussion (*hui kuka*). Members of the purposefully diverse research education team were introduced prior to delivery of the intervention's 4 key components (ie, testimonial, evidential information, demonstration and practice in FOBT use, discussion with focus on addressing screening barriers). Throughout the educational session, research-educators purposefully used common Hawaiian language terms for words such as *help/support* (kokua). Print materials tailored on CRC at its nexus with HIV, with attention to inclusion of Native Hawaiian cultural elements, were distributed. Also disseminated were illustrative instructions for FOBT use and for returning results. Participants were encouraged to contact Na Pua with any further inquiries or concerns they might have. Follow-up contact was made within 7 days to inquire about any difficulties encountered in FOBT completion, to provide barriers counseling if needed, and to arrange a time for completion of the postintervention survey. This intervention was compared against standard education (a packet of culturally neutral print materials). A summary of strategies used, corresponding social learning theory concepts, and practice applications is provided in Table 1.

#### METHOD

A randomized 2-group pre-post control group comparison design was used. AIDS services organizations were randomized to condition. Data were collected and analyzed by client.

#### Measures

Five measures were used to evaluate feasibility. First, a project log was used to systematically document randomization, recruitment, retention, and data collection protocols, with attention to overall acceptability and to unanticipated challenges as reported by participants or observed by researchers. Log entries were discussed at weekly meetings, and next steps were finalized through consensus agreement. Second, a participant tracking log was used to record enrollment and to document study retention. Also documented were attempts made to contact participants about packet drop-offs, rescheduling of missed meetings, and reasons participants discontinued study involvement.

Third, a knowledge–attitude–practice (KAP) survey was administered at baseline and at 2week postintervention follow-up. For the purpose of our feasibility assessment, we wanted to determine whether the survey could be completed with relative ease and whether items captured information on participants' knowledge, attitudes, and CRC screening practices. The KAP survey developed by investigators of CRC screening with Hawaiian civic club members<sup>33</sup> was nominally revised for use. In addition to demographic items, there were 42 multiple-choice items (15 knowledge, 19 attitudinal, and 8 practice related). Scoring for 34 of the KAP items used a scale of 1 (*strongly disagree*) to 5 (*strongly agree*); scoring for 8 of 15 knowledge items offered the response choices of false, not sure, and true, which were postcoded as 1 = correct, 0 = not sure, or -1 = incorrect.

Fourth, all participants received 2 free FOBT kits (a second kit could be used to ensure accuracy or given to a family member), a results recording card, and an addressed, stamped

envelope for returning results. Participants were asked to return test results in 2 weeks. In the event of a suspicious or positive FOBT result, participants were encouraged to speak with their physician and/or AIDS services case manager to obtain additional screening. Participants in both groups were contacted 2 weeks post-baseline for a second KAP and evaluation survey, regardless of whether FOBT results were returned.

Fifth, an evaluation was used to assess participants' experiences with study involvement. Four open-ended questions were asked of participants in both study arms on aspects of the study they liked most and least, suggestions for study improvement, and whether they would recommend participation to a friend. Those in the treatment arm completed 9 additional multiple-choice items on the intervention.

#### **Recruitment and Sample**

Our objectives were to enlist the support of at least 4 AIDS services organizations willing to be randomized to condition and to enroll about 40 older (40 years) adults of diverse ethnocultural groups and genders. Although 40 is a small sample size, the literature suggested that few participants would have completed CRC screening at baseline, and the research team conjectured that 25% of control arm participants versus 75% or more of the experimental arm members would have completed the FOBT at posttest. With this large difference at posttest, a sample of 40 individuals ( $\sim$ 20 per arm) would be sufficient to suggest an effect (alpha = .05, power = 0.85).

We sought representation from urban and rural communities with attention to enrollment of Native Hawaiians because this group is historically underrepresented in cancer prevention studies and trials.<sup>36</sup> Five AIDS services organizations agreed to participate, with one organization providing services in 2 discrete locations for a total of 6 recruitment sites. Three programs were randomized to receive the treatment intervention (culturally responsive group education and print materials, free FOBT kits) and 3were randomized to receive the control intervention (culturally neutral print materials, free FOBT kits).

All organizational partners allowed the researchers to provide study information through newsletter articles and announcements, posters, flyers, and intercept recruitment at organizational venues. Because inclusion of Native Hawaiian clients was emphasized, researchers communicated with case management units specializing in practice with Native Hawaiian and Pacific Islander persons. Targeted intercept or venue-based sampling methods were used to provide general information about the study.<sup>37</sup> Informational tables were set up at AIDS services activities (eg, food pantry pickups) where interested individuals could easily visit with the study team. If wishing to enroll, a team member met with the individual in a private area, obtained signed written consent, had the individual complete the baseline KAP, and provided information on future contact. Recruitment closed when all sites appeared to be saturated (ie, researchers encountered individuals who had already enrolled or had declined participation). At baseline, 45 individuals were enrolled and completed the first KAP survey.

#### **Data Analyses**

Participant and project tracking logs and evaluation data were managed in Microsoft Office Excel 2007. To analyze qualitative data, 2 researchers trained in content analysis<sup>38</sup> independently coded all open-ended responses from the evaluation and log narratives. Acceptability, recruitment, retention, and other feasibility domains were used as a priori categories. Preliminary analyses from the evaluation and logs were graphically juxtaposed, and the study team examined text data with a view toward obtaining an integrative description of all qualitative findings. Summary findings were finalized through discussion

and consensus agreement. As indicated, frequencies were calculated and compared by study arm, ethnicity (Native Hawaiian, non-Native Hawaiian), and/or wave (baseline, postintervention).

Timely completion of the FOBT and KAP surveys was used to evaluate whether positive treatment effects were suggested. As a pilot study, results were analyzed at the individual level, although study randomization was by recruitment site (discrete AIDS services program). These data were managed in IBM SPSS Statistics, version 20 (IBM SPSS Statistics, Armonk, NY). Demographic data were summarized by study arm and ethnic group (Native Hawaiians, non-Native Hawaiians). Fisher's exact test was used to evaluate between-group differences on categorical variables (eg, age group, prior use of FOBT, timely completion of FOBT on this study). The independent-sample *t* test was used for continuous variables (eg, agreement level on KAP items toward screening). Repeated-measures analysis was used to compare changes across data waves.<sup>39</sup>

# RESULTS

#### **Response to Research Design and Participation**

**Randomization**—Randomization was generally accepted by AIDS services organizations and individual participants; no negative comments were indicated in either the project log or the participant evaluations. The project log indicates that 15 participants freely mentioned their familiarity with study arm assignment and research protocols through their participation in other studies.

**Recruitment**—Though agency policies do not allow staff to actively assist in study recruitment, AIDS service organizations facilitated study promotion by giving researchers access to group activities and communication channels (eg, newsletters). An ethnically diverse sample of 45 participants (Caucasian, including white Hispanics = 20, Native Hawaiian = 17, Asian = 4, African American = 1, Arabic American = 1, Native American = 1) was enrolled. About 37.7% of the baseline sample reported Native Hawaiian ethnicity and indicated that Hawaiian was their primary cultural identification. Native Hawaiians and other Pacific Islanders comprise about 9% of persons known to be seropositive and living in Hawai'i; thus, Native Hawaiians were overrepresented in the sample. However, the intercept method was less successful in enrollment of other Pacific Islanders who have low/no participation in AIDS service organization-sponsored group activities. The project log reports relevant communications with staff from AIDS service organizations and Pacific Islander-specific community-based agencies; communications indicate that HIV remains a highly stigmatized condition among Pacific Islander migrants (Micronesians from nations having Compact of Free Association treaties with the United States that allow for establishing residence as nonimmigrants). Agency personnel explained that individuals fear deportation or other negative consequences and thus take extraordinary care in not being seen at events of AIDS services organizations.

Table 2 details sample characteristics at baseline. The treatment and control groups were equivalent on all major sociodemographic variables. Fisher's exact test was used to compare age distributions. In the treatment arm, 10 participants were 40 to 49 years of age, 13 were 50 to 59, and 4 were 60 + years. In the control arm, 9 participants were 40 to 49 years of age, 3 were 50 to 59, and 6 were 60 + years. Differences were not significant (P = .077).

**Retention**—A participant was determined to have been successfully retained if she or he completed the baseline and postintervention KAP. Researchers were especially interested in learning whether participants in both study arms could be equally retained; of concern were control arm participants whose contact with researchers was more limited and who might

perceive fewer benefits to involvement. Retention did not vary by study arm or ethnicity. Eight individuals discontinued participation for reasons of relocation (3), illness (3), death (1), lack of interest (1). (Table 3 displays recruitment and retention of study participants by study arm and Native Hawaiian/non-Hawaiian ethnicity.)

**Measures**—In both arms, participants completed all KAP items. There was no missing quantitative data and no apparent difficulties with understanding Likert-scaled items, including those items stated in the negative. Evaluation data indicates that the KAP was about the right length, straightforward, and easy to understand. Also indicated was appreciation for the convenience and privacy afforded by the home kit.

#### **Response to the Intervention**

Based on postintervention evaluation data, all participants, regardless of study arm or ethnicity (N = 37), indicated that the research intervention was acceptable and that they would recommend participation to a friend. Approximately 51% (n = 19) named one or more specific benefits derived through participation, including the opportunity to increase awareness and knowledge of important health issues (n = 10); convenience and privacy afforded by FOBT home kit (n = 6); experiencing the researchers or educational environment as kind, sensitive, approachable, easy to talk, respectful, and honoring of diversity (n = 6); and incentives such as cash, meal, and/or free FOBT (n = 5). The benefit of increasing awareness and knowledge was expressed in comments, such as very informative, it helped me be aware that cancer screening is important, it gave me the chance to check out my colorectal health and gave me relief, the thing I liked most is to know where I'm at with my body. Among those in the treatment arm (n = 22), all found the face-to-face education to be thorough, yet easy to understand; this was credited to researchers' understanding and knowledge of the population and HIV/NADC (14), use of demonstration (14), and opportunities for group discussion in which participants "learned from each other" (10). Among those in the control arm (n = 15), about 66% suggested one or more ways in which the intervention might be improved, including simplification of print materials (10), more illustrations (8), and demonstration of home kit (8); notably, these all were elements of the treatment condition.

A secondary aim of our study was to assess the cultural acceptability of the educational innovation that was tailored on Hawaiian cultural and linguistic practices. Results from participant evaluations indicate that Native Hawaiians in the treatment arm (n = 7) gave higher ratings than their non-Native Hawaiian counterparts (n = 15) on the culturally tailored aspects of the educational innovation, including taking time to "talk story" prior to receiving education, t (20) = 2.11, P = .049, opening the educational session with chant/spiritual acknowledgement, t (20) = 2.45, P = .024, and integrating Hawaiian language terms and sayings in the educational presentation and print materials, t (20) = 2.43, P = .025. Non-Native Hawaiians indicated acceptance or neutrality to these tailored elements.

#### Suggested Treatment Effects

A tertiary study aim was to assess whether the educational innovation suggested positive treatment effects. At baseline, no significant differences were detected in the overall means for CRC-relevant knowledge, attitudes, and practices at baseline. Analysis of postintervention data suggests a significant main effect of the treatment intervention (see Tables 4 and 5).

A comparison of overall mean scores across study waves and between study arms yielded significant differences on knowledge, F(1, 35) = 6.33, P = .017, attitudes, F(1, 35) = 7.53, P = .009, and practices, F(1, 35) = 10.04, P = .003. At baseline, ethnocultural differences on a

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few of the KAP items were observed. Specifically, Native Hawaiian participants, regardless of study arm, were more likely to agree that "colorectal cancer screening involves giving something from my body which may lessen my mana [spiritual power]" and were less likely to agree that "colorectal cancer is a problem for people living with HIV." We were concerned that these beliefs might disable screening use. At postintervention, differences by ethnic group were not significant. Agreement on the belief about *mana* was less strongly endorsed by Native Hawaiians, t (35) = -1.451, P = .156, and belief about CRC as problem in seropositive population was more strongly endorsed by treatment arm participants, t (35) = 2.337, P = .025.

A 2-sided Fisher's exact test was used to compare FOBT use among participants retained to the study (N = 37). First, treatment and control groups were compared on use of FOBT prior to study participation. The association between study arm and FOBT use was not statistically significant (P = .107). Results of the Fisher's exact test indicate that at postintervention, those in the treatment arm were significantly more likely to complete the FOBT in a timely manner than those in the control arm (82% or 18/22 versus 40% or 5/15, respectively, P = .014).

The project and participant tracking logs document that 16 participants anticipated barriers in accessing a toilet with chemical-free water (12 rural dwellers had home catchment water collection systems and added varying amounts of bleach to purify water, 1 person lived in a transitional situation) and/or with occasional illness- or medication-related diarrhea (3 persons). Barriers counseling was provided either during or after the educational session; 100% (16/16) of barriers counseling participants completed the FOBT in a timely manner, whereas only 33.3% (2/6) of those who completed the FOBT in a timely manner did not participate in barriers counseling (Fisher's exact test, 2-tailed, P = .0021).

#### DISCUSSION AND CONCLUSION

This study addressed 3 feasibility questions that were answered in the following ways. First, the culturally responsive educational innovation was positively received by those in the treatment arm. Participants, regardless of ethnicity, expressed appreciation for knowledge and awareness gained, as well as appreciation for the researchers' sensitivity and approachability in communications. Second, procedures for randomization, recruitment, retention, and data collection were acceptable to AIDS services organizations and PLHIV. Third, positive effects of the educational innovation were suggested, with significant gains in CRC knowledge, attitudes, and practices and higher frequency of timely adherence to FOBT completion in the treatment group.

Several methodological issues inherent to our pilot limit generalization of results and point to considerations for future research. First, the sample was drawn from a self-selected client population. Though use of a client sample facilitated participant access to resources if abnormal or positive screening results were detected, the nature of the sample likely advantaged the perspective of those already inclined to service utilization and predisposed to participation in research trials. Intercept strategies for study recruitment limited our interface with individuals who might fear discrimination and thus not enter conventional service and research venues (eg, transgender persons, Pacific Islander migrants). Respondent-driven sampling that uses "seeds" (study participants who recruit a fixed number of additional respondents from their respective social networks) should be considered.<sup>40</sup> In deliberating upon ways to extend access to those who might need more assurance of confidentiality, privacy, and cultural safety, the researchers surmise that additional tailoring of study promotions may be indicated. Second, KAP survey administration introduced a potential confound. At study onset, a significant minority of PLHIV in transitional living situations

was anticipated; thus, we chose to personally deliver study materials to all participants (versus sending them out through the postal service). Personal connection may have exerted a stronger influence on social approval needs, thereby functioning as a screening reminder. Our choice highlights the challenge of balancing methodological rigor against best community-based practice with vulnerable persons. Third, the study assessed short-term gains only and it is possible that screening knowledge and behavior may decline over time.<sup>41</sup> Future research should consider additional educational efforts (booster sessions) to facilitate routine participation in screening, as well as use of other CRC detection procedures (ie, sigmoidoscopy, colonoscopy, double barium enema) possibly perceived as more intrusive, time intensive, and/or not covered by all insurances.

Limitations notwithstanding, this pilot is consistent with the major emphases of health education science in the area of colorectal cancer screening. Findings from a systematic review of CRC screening interventions commissioned by the Agency for Healthcare Research and Quality underscore the need to develop evidence-based practices using educational strategies that are (*a*) targeted/tailored to specific populations, (*b*) provide demonstration of screening procedures, and (*c*) employ the efficacious, yet somewhat underused, strategy of face-to-face discussion with barriers counseling when indicated.<sup>42</sup> Our intervention aligns with these recommendations and our results suggest that the culturally responsive educational pilot shows promise for efficacy testing among PLHIV, a population at elevated risk for colorectal cancer and other non-AIDS-defining malignancies.

# TRANSLATION TO HEALTH EDUCATION PRACTICE

In translating our research to health education practice, we highlight the centrality of constituent-involving strategies in intervention development and delivery. In intervention development, our community advisory board members and AIDS services organizational partners played a vital role in providing assessment data from specific geographic communities, ethnic, and/or sexual minority groups. Community advisory board members offered thoughtful and practical guidance on linguistics, sociocultural relevance, and other tailoring domains. Their advice was helpful in tailoring the intervention to an especially vulnerable ethnic group (Native Hawaiians) while at the same time addressing elements of appeal and relevance for all participants. We recommend convening a community board or similar advisory mechanism, with attention to diverse representation and integration of cultural safety guidelines in board processes, and with members being the final arbiters of what is culturally safe.<sup>26,43,44</sup>

Use of constituent-involving strategies in education delivery is consistent with social learning theory.<sup>29</sup> Participants in this pilot endorsed the benefit of group education through which they were able to learn with and from each other. The value of behavioral modeling and barriers counseling were noted as helpful to screening enactment. Barriers counseling has been provided in other CRC screening interventions but has not always been accessed by participants.<sup>33</sup> In some situations, low/no use of barriers counseling is associated with high levels of health literacy. However, the desire for social approval also may be at play. By extension, persons marginalized by a stigmatized illness and/or other minority statuses may feel neither comfortable in disclosing their personal challenges nor confident in making suggestions to others. In such situations, fostering an interpersonal climate of cultural safety becomes especially imperative to use of barriers counseling that may increase the likelihood of behavioral enactment and thereby offer the prospect of health for all.

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# REFERENCES

- 1. Deeken JF, Tjen-A-Looi A, Rudek MA, et al. The rising challenge of non-AIDS-defining cancers in HIV-infected patients. Clin Infect Dis. 2012; 55:1228–1235. [PubMed: 22776851]
- Engels EA. Non-AIDS-defining malignancies in HIV-infected persons: etiologic puzzles, epidemiologic perils, prevention opportunities. AIDS. 2009; 23:875–885. [PubMed: 19349851]
- 3. Mitsuyasu RT. Non-AIDS-defining malignancies in HIV. Top HIV Med. 2008; 16(4):117–121. [PubMed: 18838745]
- Patel P, Hanson DL, Sullivan PS, et al. Incidence of types of cancer among HIV-infected persons compared with the general population in the United States, 1992–2003. Ann Intern Med. 2008; 148:728–736. [PubMed: 18490686]
- Shiels MS, Pfeiffer RM, Gail MH, et al. Cancer burden in the HIV-infected population in the United States. J Natl Cancer Inst. 2011; 103:753–762. [PubMed: 21483021]
- 6. US Preventive Services Task Force. Screening for Colorectal Cancer: U.S. Preventive Services Task Force Recommendation Statement. Rockville, MD: Agency for Healthcare Research and Quality; 2008. AHRQ Publication 08-05124-EF-3. http://www.uspreventiveservicestaskforce.org/uspstf08/ colocancer/colors.htm. [Accessed January 2, 2013]
- 7. Thabane L, Ma J, Chu R, Cheng J, et al. A tutorial on pilot studies: the what, why and how. BMC Med Res Methodol. http://www.biomedicalcen-tral.com/1471-2288/10/01.
- Pasick RJ. Response to Kreuter and Skinner. Health Educ Res. 2001; 16:503–505. [PubMed: 11525396]
- Pasick RJ, D'Onofrio CN, Otero-Sabogal R. Similarities and differences across cultures: questions to inform a third generation for health promotion research. Health Educ Q. 1996; 23(suppl):142– 161.
- Office of Minority Health. [Accessed April 20, 2012] HIV/AIDS and Native Hawaiians/Other Pacific Islanders. http://minorityhealth.hhs.gov/templates/content.aspx?lvl=3&lvlID=7&ID=7602. Published 2012.
- Barzailai, G. Communities and Law: Politics and Cultures of Legal Identities. Ann Arbor, MI: University of Michigan; 2003.
- Balsam KF, Molina Y, Beadnell B, Simoni J, Walters K. Measuring multiple minority stress: the LGBT People of Color Microaggressions Scale. Cult Divers Ethnic Minor Psychol. 2011; 17(2): 163–174.
- Ellingson L, Odo C. HIV risk behaviors among mahuwahine (Native Hawaiian transgender women). AIDS Educ Prev. 2008; 20:558–569. [PubMed: 19072530]
- 14. Ikeda LL. Who counts? Hawaii's mahuwahine (male-to-female transgenders) and vulnerability to HIV/AIDS. Intersections: Gender and Sexuality in Asia and the Pacific. [serial online]. http://intersections.anu.edu.au/issue26/ikeda.htm.
- Ka'opua LS, Braun KL, Browne CV, Mokuau N, Park CB. Why are Native Hawaiians underrepresented in Hawaii's older adult population? Exploring social and behavioral factors of longevity. J Aging Res. 2011; 1:1–8.
- 16. Lambda Legal. When Health Care Isn't Caring: Lambda Legal's Survey of Discrimination Against LGBT and People With HIV. New York, NY: Lambda Legal; 2010. http://www.lambdalegal.org/ publications/when-health-care-isnt-caring. [Accessed November 15, 2012]
- Meyer IH. Minority stress and mental health in gay men. J Health Soc Behav. 1995; 36:38–56. [PubMed: 7738327]
- Odo C, Hawelu A. E o na mahu o Hawai'i: the extraordinary health needs of Hawai'i's mahu. Pac Health Dialog. 2001; 8:327–334. [PubMed: 12180512]
- 19. Sotero M. A conceptual model of historical trauma: implications for public health practice and research. J Health Dispar Res Pract. 2006; 1:93–108.

- Whetten K, Reif S, Whetten R, Murphy-McMillan LK. Trauma, mental health, distrust, and stigma among HIV-positive persons: implications for effective care. Psychosom Med. 2008; 70:531–538. [PubMed: 18541904]
- 21. Wilkinson, W. LGBT-TRISTAR, Best Practices Series. New York: LGBT Tristar Publications; 2010. Culturally Competent Approaches for Serving Asian and Pacific Islander Lesbian, Gay, Bisexual, and Transgender Populations in California. http://www.lgbttristar.com/resources/ lgbttristarpublications.html. [Accessed November 15, 2012]
- Anderson J, Perry J, Blue C, et al. Rewriting cultural safety within the postcolonial and postnational feminist project: toward new epistemologies of healing. Adv Nurs Sci. 2003; 26(3): 196–214.
- Browne AJ, Smye VL, Varcoe C. The relevance of postcolonial theoretical perspectives to research in Aboriginal health. Can J Nurs Res. 2005; 37(4):16–37. [PubMed: 16541817]
- 24. Williams R. Cultural safety—what does it mean for our work practice? Aust N Z J Public Health. 1999; 23(2):213–214. [PubMed: 10330743]
- 25. McCubbin LD. Indigenous values, cultural safety and improving health care: the case of Native Hawaiians. Contemp Nurs. 2006; 22(2):214–217.
- 26. National Aboriginal Health Organization. Cultural Competency and Safety: A Guide for Health Care Administrators, Providers, and Educators. Ottawa, Ontario: National Aboriginal Health Organization; 2008. http://www.naho.ca/documents/naho/publications/culturalCompetency.pdf. [Accessed April 20, 2012]
- Smith, PS. master's thesis. Spokane, WA: Washington State University; 2010. Cultural Safety in Nursing Education: Increasing Care for LGBT Individuals. https://research.wsulibs.wsu.edu/ xmlui/bitstream/handle/2376/3442/P\_Smith\_011018665.pdf?sequence=1. [Accessed April 20, 2012]
- 28. Bandura, A. Social Learning Theory. New York, NY: General Learning Press; 1977.
- 29. Ormrod, JE. Human Learning. 3rd ed.. Upper Saddle River, NJ: Prentice-Hall; 1999.
- Marten LR, Chow DC, Valcour NA, Shikuma CM. Assessing the needs for HIV medical care in Hawaii. Hawaii Med J. 2009; 68(4):74–78. [PubMed: 19583108]
- 31. Hawai'i State Department of Health STD/AIDS Prevention Branch. Integrated Epidemiologic Profile of HIV/AIDS in Hawai'i. Honolulu, HI: Hawai'i State Department of Health; 2005. http:// hawaii.gov/health/healthy-lifestyles/std-aids/aboutus/prg-aids/aids\_rep/1h2005-1.pdf. [Accessed November 15, 2012]
- Ka'opua LS, Mueller CW. Treatment adherence among Native Hawaiians living with HIV. Soc Work. 2004; 49(1):55–64. [PubMed: 14964518]
- Braun KL, Fong M, Kaanoi ME, Kamaka ML, Gotay CC. Testing a culturally appropriate, theorybased intervention to improve colorectal cancer screening among Native Hawaiians. Prev Med. 2005; 40:619–627. [PubMed: 15850857]
- Ka'opua LS. Developing a culturally-responsive breast cancer screening promotion with Native Hawaiian women in churches. Health Soc Work. 2008; 33(3):169–177. [PubMed: 18773792]
- Ka'opua LS, Park SH, Ward ME, Braun KL. Testing the feasibility of a culturally tailored breast cancer screening intervention with Native Hawaiian women in rural churches. Health Soc Work. 2011; 36(1):55–65. [PubMed: 21446609]
- 36. Bantum EO, Cheng I, Cassell K, Ka'opua LS, Yamato R, Berenburg J. Cancer clinical trials in Hawai'i: who's being represented?.
- Muhib FB, Lin LS, Stueve A, et al. A venue-based method for sampling hard-to-reach populations. Public Health Rep. 2001; 116(suppl 1):216–222. [PubMed: 11889287]
- Krippendorff, K. Content Analysis: An Introduction to Its Methodology. Thousand Oaks, CA: Sage; 2012.
- Keselman HJ, Algina J, Kowalchuk RK. The analysis of repeated measures designs: a review. Br J Math Stat Psychol. 2001; 54:1–20. [PubMed: 11393894]
- 40. Salganik MJ, Heckathron DD. Sampling and estimation in hidden populations using respondentdriven sampling. Sociol Methodol. 2004; 34:193–240.

- Shediac-Rizkallah MC, Bone LR. Planning for the sustainability of community-based health programs: conceptual frameworks and future directions for research, practice, and policy. Health Educ Res. 1998; 13:87–108. [PubMed: 10178339]
- 42. Holden, DJ.; Harris, R.; Porterfield, DS., et al. Enhancing the Use and Quality of Colorectal Cancer Screening: Evidence Report/Technology Assessment No. 190. Rockville, MD: Agency for Healthcare Research and Quality; 2010. AHRQ Publication No. 10-E-0002.
- 43. Fong M, Braun K, Tsark J. Improving Native Hawaiian health through community-based participatory research. Californian J Health Promot. 2003; 1:136–148.
- 44. McMullin J, Bone M, Pang K, Pang V, McEligot AJ. Native Hawaiian voices: enhancing the role of cultural values in community based participatory research. Californian J Health Promot. 2010; 8(suppl):52–62.

#### Tailoring Strategies, SLT Concepts, Practice Examples<sup>a</sup>

Type of Strategy	Social Learning Concepts	Tailoring Examples
Peripheral. Print and other educational materials use visual images to enhance appeal and support health message	Expectations. Participant believes that proposed action will benefit health Credible messengers may influence perceived benefit	Project logo uses both HIV red ribbons and culturally familiar image of native flowers known to grow in challenging terrain Photograph of Native Hawaiian–Pacific Islander health care provider featured on print material Print materials are illustrated with text written at about fifth- grade reading level Ethnically and gender-diverse training team
Evidential. Print material and presentation slides provide epidemiological information and screening facts	Expectations. Participant believes that health issue is relevant and health behavior is of benefit	Presentation of CRC prevalence among PLHIV Educational session includes slides with simple bar charts depicting prevalence rates FOBT and CRC screening methods illustrated in slides and print materials
Linguistic. Words and phrases common to native language and patois of local group are purposefully used, with attention to cultural norms and values	Reinforcement. Use of familiar terms clarifies and supports learning gleaned through modeling, observation, and practice Self-efficacy. Participant exposed to learning activities that facilitate behavioral enactment	Hawaiian folk wisdoms reinforce messages on cultural safety (eg, honor all experiences) Discussion uses "talk story" (informal sharing in Hawai'i- regional patois) approaches, with emphasis on practical suggestions for overcoming screening barriers Emphasize importance of information and apologize if information/words offend individual sensibilities
Constituent-involving. Education draws upon group experiences	Modeling. Personal testimonials on benefit of health behavior Observational learning and self-efficacy. Behavioral demonstration and opportunity for practice provided	CAB provides input on design and implementation of all activities and materials. NHPI/LGBT CRC survivor offers personal testimonial on value of screening FOBT kit demonstrated; participants use bed pan and imitation stools to practice use of FOBT kit
Sociocultural relevance. Recognizes, affirms, and works from group values, beliefs, behaviors, and context	Reciprocal determinism. Motivation to change results from interaction between people and social environment. Materials and education consider social context	CAB advises on critical sociocultural issues and ways to address <i>Lei</i> greeting and native chant used in welcome Discussion considers context of lived experiences (eg, HIV in pre- and current antiretroviral eras, management of HIV as chronic disease, minority stressors, needs for to protect self and family from discrimination) Presentation emphasizes that home kit supports health and need for privacy, which may address disclosure of HIV and other statuses.

<sup>a</sup>PLHIV indicates persons living with HIV; FOBT, fecal occult blood test; CRC, colorectal cancer; CAB, community advisory board; NHPI/ LGBT, Native Hawaiian–Pacific Islander/lesbian, gay, bisexual, and transgender.

# Sample Characteristics at Baseline

	Treatment $(n = 27)$	<b>Control</b> ( <i>n</i> = 18)
Age group		
40-49 years	10	9
50-59 years	13	3
60 + years	4	6
Gender		
Male	23	16
Female	4	1
Transgender	0	1
Ethnicity		
Native Hawaiian	10	7
Non-Native Hawaiian	17	11
Education		
Less than high school	4	3
High school or GED	3	6
More than high school	20	9
Health care insurance	26	17
Yes	1	1
No		

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Recruitment and Retention by Study Arm and Native Hawaiian Ethnicity

ve Ha	waiian	Non-Native Hawaiian	Total	Native Hawaiian 7	Control Arm Non-Native Hawaiian 11	Total	Total 45
<u>@</u>		15 (88%)	22 (81%)	6 (86%)	9 (82%)	15 (83%)	37 (82%)

# Change Scores by Study Arm

		Treatment Arm	Control Arm	Total
Average knowledge scores*	Pre-intervention	6.59 (SD = 4.58)	8.00 (SD = 4.34)	7.16 (SD = 4.48)
	Postintervention	9.00 (SD = 3.15)	7.80 (SD = 4.57)	8.51 (SD = 3.78)
Average attitude scores $*$	Pre-intervention	64.91 (SD = 4.50)	67.33 (SD = 5.58)	65.89 (SD = 5.04)
	Postintervention	68.95 (SD = 5.08)	65.73 (SD = 7.74)	67.65 (SD = 6.40)
Average practice scores*	Pre-intervention	28.45 (SD = 3.50)	30.27 (SD = 4.64)	29.19 (SD = 4.04)
	Postintervention	30.00 (SD = 4.70)	28.47 (SD = 4.53)	29.38 (SD = 4.63)

\* Significant group differences at .05 level.

# FOBT Return Rate by Study Arm $(N = 37)^a$

	Treatment Arm	Control Arm	Total
Ever done FOBT*	7 (32.8%)	9 (60%)	37 (100%)
FOBT timely return**	18 (81.8%)	6 (40%)	37 (100%)

<sup>a</sup>FOBT indicates fecal occult blood test.

\* Fisher's exact test, 2-tailed, P = .107.

\*\* Fisher's exact test, 2-tailed; significant group difference at .01 level.