`Imi Hale
Native Hawaiian Cancer Network

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‘Imi Hale Native Hawaiian Cancer Network
A program of Papa Ola Lokahi
U01CA 114630, U54CA 153459
www.imihale.org
Native Hawaiians make up 20% of the state population

Major Ethnic Groups in Hawaiʻi
Hoʻokele i ke Ola
Navigating to Health
Cancer Patient Navigation Training Program
A Community-Driven Example
to Address Cancer Health Disparities in Hawaiʻi
Agenda

- Why we did it?
- How we did it?
- Where we are?
- What this means to our discussion today?
## Cancer Mortality, All Sites, 1998-2002
### Hawaii, U.S., and National Benchmarks

<table>
<thead>
<tr>
<th>All Race/Ethnicities, Both Sexes</th>
<th>Death Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hawai`i</td>
<td>155.2</td>
</tr>
<tr>
<td>U.S.</td>
<td>197.8</td>
</tr>
<tr>
<td>HP 2010 objective</td>
<td>159.9</td>
</tr>
<tr>
<td>ACS 2015 goal</td>
<td>101.2</td>
</tr>
</tbody>
</table>

Rates are average annual over a 5-year period.
Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.
Hawai`i Data: Hawaii Tumor Registry, Cancer Research Center of Hawai`i, University of Hawai`i.
# Underlying Causes of Death in Hawai‘i
## 2004 Resident Deaths by Ethnicity of Decedent
*(age-adjusted rates/100,000)*  
*Source: DOH – Hirokawa, R 5/2006*

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>NATIVE HAWN (percent)</th>
<th>TOTAL STATE (percent)</th>
<th>HIGHER/LOWER THAN STATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>218.3</td>
<td>145.4</td>
<td>50% Higher</td>
</tr>
<tr>
<td>Diabetes Mellitus</td>
<td>28.9</td>
<td>13.2</td>
<td>119% Higher</td>
</tr>
<tr>
<td>Heart Disease</td>
<td>305.5</td>
<td>164.3</td>
<td>86% Higher</td>
</tr>
<tr>
<td>Cerebrovascular Disease</td>
<td>75.6</td>
<td>46.0</td>
<td>64% Higher</td>
</tr>
<tr>
<td>Other Circulatory Diseases (Including HPT and atherosclerosis)</td>
<td>20.6</td>
<td>14.1</td>
<td>46% Higher</td>
</tr>
<tr>
<td>Nephritis, Nephrotic Syn. and Nephrosis</td>
<td>26.9</td>
<td>11.2</td>
<td>140% Higher</td>
</tr>
</tbody>
</table>

*a/ Causes of death coded according to ICD 10  
b/ Rates age-adjusted, based on 2000 US standard population  
c/ Rates calculated using HHS 2004 population estimates  
d/ Rates calculated using post-censal population est. from US Census*
Table 5. Average Annual Incidence & Mortality Counts & Rates for All Cancer Sites by Sex & Race/Ethnicities Combined, Hawai‘i, 2000-2005

<table>
<thead>
<tr>
<th></th>
<th>INCIDENCE</th>
<th>MORTALITY</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male Incidence Count</td>
<td>Male Incidence Rate</td>
</tr>
<tr>
<td>Native Hawaiian</td>
<td>369</td>
<td>479.6</td>
</tr>
<tr>
<td>White</td>
<td>980</td>
<td>542.4</td>
</tr>
<tr>
<td>Chinese</td>
<td>186</td>
<td>423.5</td>
</tr>
<tr>
<td>Filipino</td>
<td>403</td>
<td>466.8</td>
</tr>
<tr>
<td>Japanese</td>
<td>842</td>
<td>476.3</td>
</tr>
<tr>
<td>Total, All Races</td>
<td>2,967</td>
<td>485.7</td>
</tr>
</tbody>
</table>

Note: Invasive cases only, in-situ cases are excluded. Counts are 6 year average annual, rounded to the nearest whole. All Races include race/ethnic groups listed plus all other race/ethnic groups combined.

Rates are average annual and are per 100,000 population, age-adjusted to the 2000 U.S. standard population.

Source: Hawai‘i Tumor Registry, Cancer Research Center of Hawai‘i, University of Hawai‘i

HAWAI‘I CANCER FACTS & FIGURES 2010

21% higher

37% higher
# Prevalence of Recommended Cancer Screenings - 2010

<table>
<thead>
<tr>
<th>SCREENING</th>
<th>NATIVE HAWN (percent)</th>
<th>TOTAL STATE (percent)</th>
<th>HIGHER/LOWER THAN STATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mammogram (&lt; 2 yrs)</td>
<td>45.2</td>
<td>53.0</td>
<td>15% Lower</td>
</tr>
<tr>
<td>Mammogram (ever had)</td>
<td>60.6</td>
<td>66.7</td>
<td>9% Lower</td>
</tr>
<tr>
<td>Clinical Breast Exam</td>
<td>48.4</td>
<td>52.3</td>
<td>7% Lower</td>
</tr>
<tr>
<td>Pap Smear (&lt; 3 yrs)</td>
<td>79.4</td>
<td>77.2</td>
<td>3% Higher</td>
</tr>
<tr>
<td>Colorectal Ca – FOBT</td>
<td>18.5</td>
<td>15.5</td>
<td>19% Higher</td>
</tr>
<tr>
<td>Colorectal Ca – Flex Sig/Colonoscopy</td>
<td>54.3</td>
<td>61.4</td>
<td>12% Lower</td>
</tr>
</tbody>
</table>

Why we did it?

• Higher cancer mortality rates for Native Hawaiian and Pacific Islanders

• Fractured and disjointed health care system

• The Communities asked for help. Expressed need from Community Outreach Staff, particularly those from the neighbor islands
How we did it

Involved community – Hawaiian and Clinical

Looked to our ancestors (Wai`anae, NACR,Freeman)

Looked to the source of issues

Built on community strengths and values

Promote co-learning and capacity building

Provide tangible benefits
Research to develop Curriculum

• Extensive review of Navigator programs elsewhere
• 86 Key Informant interviews and surveys
• Focus groups with cancer survivors and their family on 5 islands
• Mentors from Native American Cancer Research and NCI

‡ We discovered 3 truths about cancer care

Kaohimanu Dang, NH Intern launched this initiative.
We learned that cancer care is complicated and fractured.
Regardless of where people are in the continuum, they need:

- Information
- Access to services
- Emotional and cultural support
- Confidence and assistance to manage their care

Kehau Matsumoto and Ann Jones, Breast Cancer Survivors
Patients face barriers both in the community **AND** in the healthcare setting.

**Access Barriers**
- High costs
- No insurance
- Few providers & services
- Long distance to care
- Too busy to seek care
- Stressed support system

**Systems Barriers**
- Running between providers
- Lost referrals and paperwork
- Not knowing who is in charge
- Not knowing what to ask
- Feeling intimidated
- Providers’ lack of sensitivity, time to answer questions, or knowledge of resources
**Imi Hale Patient Navigator Model**
Cancer navigation through the cancer-care continuum

<table>
<thead>
<tr>
<th>Clinical Cancer Patient Navigator</th>
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</thead>
<tbody>
<tr>
<td><strong>Community Cancer Patient Navigator</strong></td>
</tr>
<tr>
<td>Screening</td>
</tr>
<tr>
<td>Provide education on cancer</td>
</tr>
<tr>
<td>Link clients to cancer screening</td>
</tr>
</tbody>
</table>

Link clients to health information, cancer care, insurance, financial assistance, transportation, housing, food, counseling, and other services.
Findings Shaped the Purpose and the Format

**Designed to:**

- Increase cancer knowledge
- Increase awareness of cancer services and providers
- Strengthen communications
- Build on Hawaiian values

**Format:**

- 48 hour training
- 2 days/wk over 3 wks

Also a 3 credit community college class
Findings identified 14 Core Competencies

1. Describe the role of a Cancer Patient Navigator
2. Explain the importance of maintaining confidentiality of the people you help
3. Describe barriers to cancer care and ways to overcome them
4. Identify unique risk factors, tests and treatments of cancer. (focus on 8 types)
5. Identify related physical, psychological and social issues likely to face people with cancer and their families
6. Demonstrate the ability to gather data and create a “Patient Record”
7. Demonstrate ability to find reliable cancer info from agencies and on the Web.
8. Describe cancer-related services available in your community.
9. Describe the advantages of participating in clinical trials and barriers to participation.
10. Define palliative care and hospice care.
11. Assist patients in completing an advance directive.
12. Demonstrate the ability to work through “mock” cancer cases.
13. Demonstrate ability to organize a resource binder
14. Describe ways to care for yourself
Incorporated Multiple Training Methodologies

- Lectures
- Class Activities
- On-site tours
- Role Play
- Networking
- Writing
- Developing Resource Binders

Strong Emphasis on
- Communication Skills
- The Navigators Role – Boundaries
- Relationships
We developed materials to support Navigators

• CPN Training Curriculum
  - Piloted - January 2011
  - Field tested - May 2011

• Revised Existing Materials
  - End-of-life series
  - Managing your cancer care records

• New training units developed
  - Clinical Trials Unit
  - Nutrition Unit
  - Genetics

• New materials
  - CPN brochure
  - Questions booklet
  - Nutrition Eating Hints
  - CPN Quick Tips
Leveraged Funding to Support Training and Positions

- Office of Hawaiian Affairs - Grant 2005-2007
- CMS Grant 2006-2010
- ARRA Grant 2009-2011
- NCCCP Contract for QMC 2009-2013
- HRSA Grant 2010-2013
- Komen Foundation – Hawai‘i Chapter
- Intercultural Cancer Council
The importance of developing relationships

- 30+ faculty for each 6 day training
  - Provide time pro-bono
- 1-2 faculty for each continuing education session
- Training provided at no cost to individual and agency
- Survivors and previously trained navigators serve as trainers
- All training facilities have been provided in-kind
Where are we now?

- Conducted 11 – 48 hr trainings on 4 islands (O‘ahu, Moloka‘i, Maui, Hawai‘i)
- 146 Graduates
- Over 30 Continuing Education Sessions
- 5 Annual Conferences
- Trainees have changed over time based on increased interest
- Expansion to screening navigation in CHC setting
- 3 publications, multiple national presentations
Statewide interest and investment in Navigation

QMC-NCCCP

UH – OPHS & DNHH

Community Health Centers

Dept. of Health

Moloka‘i Gen Hosp

Maui Memorial

Hilo MedCtr
2005
- Interviews & focus groups with over 300 stakeholders
- OHA Grant $80,000
- MGH wins CMS grant

2006
- 1st Training on O'ahu
- 1st Neighbor island training on Moloka'i

2007
- Training expanded to Maui & Hawai'i Island
- Two 48hr-training

2008
- Developed 3-credit MCC Curriculum
- 1st Annual Ho'okele i ke Ola Conf.
- One 48hr-training

2009
- Received ARRA grant to continue & expand Ho'okele activities
- ARRA Grant $450,000
- $20,000 Komen Grant

2010
- 3-yr HRSA Grant to QMC ($1.2 mil) for Nav in 3 rural hospitals
- Two 48hr-training

2011
- Two 48-hour trainings & 1 two-day Intro CPN training
- 5 Cont Edu Sessions
- Pilot Screening Nav project w/WHC

2012
- One 48-hour training
- 2 Cont Edu Sessions
- Pilot Screening Nav project w/WHC

2005-2012:
- 21 N avs
- 60 N avs
- 73 N avs
- 83N avs
- 105 N avs
- 130 N avs
- 146 N avs
Where are the Navigators?

146 graduates as of March 2012.
13 CPN positions established

• 6 Queen’s Cancer Center
• 3 Moloka‘i General Hospital
• 1 Hilo Medical Center
• 1 Maui Memorial Medical Ctr
• 1 Hawai‘i County
• 1 Pali Momi Medical Center

Majority of graduates report using patient navigation skills in their jobs as community outreach workers and health care providers. (Source: 2010 Annual CPN Survey)
Active Community and Clinical Navigation in Hawai‘i

2 Active Navs: 1 Community, 1 Clinical
Kaua‘i
Wilcox Memorial Hospital, Lihue

29 Active Navs: 15 Community, 14 Clinical
O‘ahu
The Queen’s Medical Center, Honolulu

5 Active Navs: 4 Community, 2 Clinical
Moloka‘i
Moloka‘i General Hospital, Kaunakakal, Moloka‘i
Maui Memorial Medical Center, Kahului, Maui

8 Active Navs: 7 Community, 1 Clinical
Maui
Lana‘i
Kaho‘olawe

21 Active Navs: 17 Community, 4 Clinical
Hawai‘i
Kona Community Hospital, Kcälakekua
Hilo Medical Center, Hilo

66 Active Navigators who use patient navigation skills in their jobs as community outreach workers and health care providers as of June 2012.
Accountability

- Navigation training & curriculum
- Navigator network
- Data from navigation programs
- Patient satisfaction
Training & curriculum evaluations

Daily Evals of Modules

<table>
<thead>
<tr>
<th>MODULE</th>
<th>VERY USEFUL</th>
<th>SOMEWHAT USEFUL</th>
<th>NOT USEFUL</th>
<th>THIS MODULE CAN BE IMPROVED BY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung Cancer</td>
<td></td>
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<tr>
<td>Survivorship</td>
<td></td>
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<tr>
<td>Talk Story about Clinical Trials</td>
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</tr>
<tr>
<td>Physical Therapy for Cancer Patient</td>
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</tr>
<tr>
<td>Talk Story with a Navigator</td>
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<td></td>
</tr>
<tr>
<td>Colorectal Cancer</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Social Work with Cancer Patient</td>
<td></td>
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<tr>
<td>Unit Resource Activity</td>
<td></td>
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<tr>
<td>“What will you take on your 9:45” activity</td>
<td></td>
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</tr>
</tbody>
</table>

1. What did you like best about the training today?

2. How could the training be improved?

Pre/Post Test of Trainees

[Image of a computer screen showing a test form with questions and options for responses.]
2011 Survey of the Navigator Network

• n=84 (73 were graduates of our training program)
• 76% reported that they use CPN skills in their work
• 56% reported that CPN duties are in their job description
• 43% have navigated cancer patients for 2 or more years
• Most commonly see each client 4-8 times
• Most keep cases open 6 months or longer
• Most common pt. request for assistance:
  - Health or cancer information
  - Financial help
  - Emotional Support
Rural Scenario: MGH Demographics

The majority of cancer care is on O‘ahu.

- Native Hawaiian, 53.50%
- Filipino, 25.70%
- Caucasian, 8.90%
- Chinese, 0.30%
- Japanese, 8.60%
- ANAI, 0.60%
- Southeast Asian, 0.30%
- Unknown/Refused, 0.90%
Moloka‘i General Hospital – Rural Island Population

- 2 navigators assisted 327 clients over 1 year
- 1,130 total contacts, average 22/client
- Avg time per contact is 15 minutes
- 64% occurring by phone
- 84.4% of pts. Have at least 1 comorbidity
- Population dependent on off-island referrals for cancer care.
Navigation interactions MGH

**Most frequent barriers to cancer care**

1. Poor access to services
2. Lack of cancer care providers and services on island
3. Financial issues in accessing care

**Most frequent navigator actions**

1. Completing assessments
2. Helping patient obtain assistance from community organizations
3. Providing patient with support by listening
4. Helping patients with arranging travel
Patient Satisfaction Survey MGH

Patients strongly or somewhat agree that Navigators:

- recommend that navigation should be available to all cancer patients: 100.0%
- helped patient and their family through their cancer journey: 100.0%
- provided support and resources to complete treatment goals: 96.6%
- helped make sure they miss very few appointments: 89.7%
- helped get answers to their cancer care questions: 100.0%
Urban Scenario – Largest Tertiary Hospital in Hawai‘i

- Interacts with 40% of all cancer patients in the state
- 5-6 navigators provided services to 835 clients over 1 year.
- Average number of actions per patient was 9.49
- 56.5% of interactions occurred over the phone.
- 80% of patients were from O`ahu and 20% were from a Neighbor Island.

(Findings based on a medical record review of 120 randomly selected cancer patient records over a 1 year period)
Navigation actions for QMC

Most frequent barriers to cancer care

1. Transportation
2. Scheduling
3. Inter-island travel

Most frequent navigator actions

1. Assistance with appointments
2. Coordinating social services
3. Linking to cancer organizations
Patients strongly or somewhat agree that Navigators:

- Recommend that navigation services be available to all cancer patients: 90.3%
- Helped patient and their family through their cancer journey: 80.1%
- Provided them support and resources to complete treatment goals: 80.1%
- Helped make sure that they missed very few appointments: 68.0%
- Helped get answers to their cancer care questions: 85.4%
Future Goals of Cancer Patient Navigation

- Development of Navigation programs in more clinical settings – Community Health Centers, other hospitals
- Strengthen Navigation at both ends of the spectrum – Screening and Survivorship
- Third party payor support for Navigation services
- Report and publish outcomes data for the state of Hawai`i.
Reduction Disparities in Breast Cancer Screening among Micronesians in Hawai`i

Partners - `Imi Hale, Micronesians United, DOH-BCCCP

Intervention – Lay Health Navigators from Marshallese, Chuukese, Pohpeian, and Kosrean communities in Hawai`i

After 18 Months:
- 16 Micronesian Lay Educators trained
- 567 women outreached and educated
- 166 (82%) of 202 women aged 40+ eligible for mammography had never had one
  - 146 (88%) of 166 screened
  - 10 (6.8%) cancers diagnosed

14,000+ Micronesians in Hawai`i
- 7% speak English at home
- 12% unemployment
- $4.5K per capita income (vs. $30K for state)

Incorporating Navigation into the State Agenda
Hawaiʻi State Cancer Plan 2010-2015

- Reduce financial, geographic and cultural barriers to appropriate cancer treatment
- Increase the number of cancer patient navigators statewide
- Increase the number of hospitals and clinics offering patient navigation services
- Establish the discipline of Certified Patient Navigator as a reimbursed service in Hawaiʻi
Goal 3: Equitable Access to Care

- Increase the number of cancer patient navigators statewide
  - 146 completed navigation training
  - 12 established CPN positions
  - Majority using navigation skills in their current positions

Cancer Patient Navigation services are no longer a NICE to have, it is a MUST have in the cancer service line.
Goal 3: Equitable Access to Care

- Increase the number of hospitals and clinics offering patient navigation services
  - The Queen’s Medical Center
  - Moloka‘i General Hospital
  - Hilo Hospital
  - Maui Memorial
  - Waimanalo Health Center
  - Hui Malama Ola Na ‘Oiwi
  - Hui no ke Ola Pono
Goal 3: Equitable Access to Care

- Reduce financial, geographic and cultural barriers to appropriate cancer treatment
- Establish Cancer Patient Navigation as a reimbursed service in Hawai‘i
Na Ho`okele
Everyone, paddle the canoes, bail and paddle, paddle and bail
and the shore will be reached.
Mahalo!