Developing culturally relevant palliative care resources for health in the US Affiliated Pacific Islands

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Pacific CEED Team

Thanks to a great collaborative team!!

• Dept. of Family and Community Medicine, JABSOM
• UH Cancer Center
• Kokua Mau, Hawaii Hospice & Palliative Care Org.
• Comprehensive Cancer Control Programs in the USAPI
What and where are the USAPI?

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<thead>
<tr>
<th><strong>United States</strong></th>
<th><strong>Flag Territories and Commonwealth</strong></th>
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<tbody>
<tr>
<td><strong>Affiliated</strong></td>
<td>Guam</td>
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<tr>
<td><strong>Pacific Island</strong></td>
<td><strong>Commonwealth of the Northern Mariana Islands (CNMI)</strong></td>
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<td><strong>Nations and Jurisdictions</strong></td>
<td><strong>Freely Associated States</strong></td>
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<td>Federated States of Micronesia (FSM)</td>
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<td>Republic of the Marshall Islands (RMI)</td>
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<td>Republic of Palau (ROP)</td>
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INDIGENOUS PEOPLE OF THE US API

- Belauans
- Samoans
- Marshallese
- Kosraeans
- Chuukese
- Chamorros
- Carolinians
- Pohnpeians
- Yapese
Populations
most recent population estimates

• Am Samoa- 65K
• CNMI- 51 K
• Chuuk- 54 K
• Kosrae- 8K
• Pohnpei- 34K
• Yap- 12K
• Guam- 178K
• RMI- 64K
• Palau- 20K
• Total - 485K
GEOGRAPHICALLY DISPERSED

• Global Geography
  – 14 time zones between Wash DC and Palau (-05:00 to +09:00 UTC/GMT)

• Pacific Geography
  – International Date line
  – $3,500 round trip Yap to Hawaii
  – $1,000 round trip Hawaii to Wash DC

• Island Nation Geography
  – Logistics to get around within island nations
  – Boats
US-Pacific Thermo-Nuclear Weapons Testing Program

• Testing 1946-1958 : Above Ground
• Power of 7,200 Hiroshima Bombs
  – 1.6 Hiroshima bombs a day for 12 years
• Associated with 26 Cancers
• 2004 NCI Report - 530 excess cancers
• 250 to occur after 2004 (latency)
Factors influencing health system capacity

• Health workforce
  – Not enough
  – Inadequately prepared
  – Trained on the job by others who were trained on the job
  – No pipeline (difficulty completing 2-yr programs because of math, science and English skills)

• Quality assurance programs
  – Fledging efforts now in most USAPI
Health Indicators: Lifestyle Illnesses

• Diabetes - 75% of hospital days from DM
• 50% of people over 50 with DM
• 50% of men and women overweight
• Ischemic Heart Disease increasing
• Strokes increasing
• Cancer increasing
• Smoking/ alcohol high and increasing in girls and women
Where is care given?

Traditionally all care was given at home

Families still care for loved ones at home, but

• no caregiving training courses for families
• no palliative/eol training for professionals

In recent years, families take loved ones to the hospital shortly before death

- Appropriate use of scarce resources?
- Not clear where people want to die
What is Palliative Care?

- Specialized medical care for people with serious illnesses.
- Focuses on relief from symptoms, pain, & stress of serious illness - whatever the diagnosis.
- Goal is to improve quality of life for both patient & family.
Pal Care Definition (con’t)

• Team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support.

• Appropriate at any age and stage in a serious illness

• Can be provided together with curative treatment.

- Center to Advance Palliative Care (CAPC), 2011
Palliative Care an Important Issue

• USAPI cancer plans address continuum of cancer care incl. Quality of Life
• Cancer Leadership recognize Pal Care as an important issue
• Beginning in 2008, Pacific CEED addressing issue through a series of workshops in Honolulu, CNMI and Palau
• Developed resource & culturally appropriate Pal. Care Curriculum
Palliative Care Curriculum for the USAPI
Collaborators & Contributors:

• Kokua Mau - Hawaii Hospice and Palliative Care Organization
• Pacific CEED
• UH Cancer Center (formerly Cancer Research Center of Hawaii)
• CCPI, CCC Coordinators & palliative care staff – April, 2009 “Caring the Pacific Way” course
• Palau & CNMI palliative care trainings – Sept 2008 & July 2009
PC Curriculum Overview

8 Modules: The ‘basics’ of palliative care

• Each module:
  – Can be taught individually or as the full curriculum
  – Is 2 hours in length
  – Suitable for training entry-level students at a community college or health providers in the work setting as continuing education

• Blends lectures with small group work and self-reflection
PC Curriculum Overview (con’t)

• Each module contains
  – Powerpoint slides with extensive speaker notes
  – Background information for speaker
  – Pre/post test
  – Evaluation
  – Handouts
  – Bibliography of resources

• Curriculum is a DVD. Presenters can change and tailor the content & delivery for different participants, situations & education levels
Tailored for USAPI

The curriculum has been tailored in several ways to address cultural relevance and human resource demands:

• **Vocabulary** – Trainers are encouraged to stop and ask participants about the meaning of English words and to identify appropriate local language (e.g. to create a palliative care word list in language)

• **Resource appropriate** – Curriculum is designed for use in resource-challenged settings and can be adapted based on varied settings
Tailored to the USAPI (con’t)

• **Case studies** – Can be tailored to local situation

• **Cultural discussion** – Interactive sessions to engage students to discuss local implications (e.g. the meaning of food, the acceptability of pain, etc.)
Example - Module 1

Introduction to Palliative Care

Learning Objectives:

1. Describe what palliative care is
2. Describe the role of palliative care in the care of patients with cancer and other chronic diseases
3. Identify patterns of chronic and terminal disease and related issues of prognosis
4. Describe the financial impact of chronic disease and dying
Additional Modules

2. Pain Management
3. Symptom Mgmt – Constipation & Incontinence ( & Wound Care)
4. Symptom Mgmt- Anorexia and Shortness of Breath
5. Care Shortly Before Death
6. Essentials of Communication
7. Spiritual Care
8. Caregiver Issues
Implementation- FSM

FSM – 5 Day Train the Trainer workshop in Kosrae, May 2011

Clinicians from each state who commited to
- Educate colleagues on Pal. Care Curriculum
- Create Palliative Care Team at the hospitals
Implementation – FSM (con’t)

• Positive Feedback
  – Use English (build local lang. capacity; ex-pats)
  – Add in photos, data, local resources, available medicine
  – Create Action Plans
  – After staff trained, family caregivers

• Results: Kosrae and Pohnpei using materials.
• Political opposition in Kosrae – politicians who confuse palliative care with no care
• Access to opioids still an issue
Implementation - Guam

- June 2012 Training – Partnership btw ACS, UOG, Guam CC, Comp. Cancer (DOH)
- Train the Trainer 2-day workshop
- Palliative Care Curriculum in 3-day workshop for 120+ people
- Home for the curriculum at Guam CC
Future Plans

• Palau – Integration into College of Health
• RMI – currently conducting focus groups on death and dying that will be the basis for palliative care curriculum training
• American Samoa – group formed to discuss implementation
THANK YOU!

- Si Yu’us Ma’ase
- Olomwaay
- Fa’a Fetai Tele Lava
- Msuulaang
- Kulo Malulup
- Komagar
- Kalangan
- Kirissou Chapwur
- Kommol Tata

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