



Pacific CEED Promising Practices & Progress Report Form

Project Name/Title: Exploring Yapese Beliefs on Death and Dying

Project Date/Duration: Spring 2010-present

Jurisdiction/Island/Village:
Yap

Audience Reached:

Who benefits from this project?
-Everyone who needs palliative care or home care for any other reason.

How many participants are there?
-226 persons participated in the 16 focus groups, 49 on Yap and 177 on the outer islands

Groups included a youth group, a cancer survivor group, a group of widows, a group of community leaders, two community groups on Yap and groups divided by gender on four outer islands.

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Photo:



Participant Quote: “A death in Yap brings the family together.” Petra Tun (quoted with permission).

History/Background:

✓ What is the identified need for this project?

Too many unsatisfactory deaths in Yap hospital, causing unnecessary suffering for patients and their families, poor quality of life at the end of terminal illnesses, along with avoidable expenses.

✓ Does the project build on an existing project?

Project complements Kokua Mau’s draft curriculum for palliative care and the workshop that was offered in Honolulu in the spring of 2009.

✓ Was the project adapted from a model used elsewhere?

No.

✓ What is the history of the project?

Yap AHEC was interested whether hospice care would be appropriate in Yap, and if so, how best to

develop an acceptable program and curriculum. This question led to needing to know more about current and traditional approaches to palliative care in Yap and its outer islands

Goal and Objectives:

- ✓ What is the overall goal of this project?

Gain an understanding of Yapese beliefs about Death and Dying in order to improve Palliative Care in Yap.

- ✓ What are the project's priority objectives?

Develop preliminary guideline for conducting focus groups in Yap Proper and the Neighboring Islands.

Conduct at least 7 Focus Groups on Death and Dying in the Neighboring Islands and Yap Proper

Complete analysis of Focus Groups Data and Effectiveness of Focus Group Guidelines.

Provide recommendations to improve Palliative Care in Yap based on findings from focus groups.

Use results to work toward preparing a culturally relevant palliative care curriculum for physicians, health assistants, and palliative care workers in Hawaii and in Micronesia, one that reflects local sensibilities and respects traditional practices.

- ✓ Which Comprehensive Cancer Control Plan objective does this project address?

This program addressed the Goals, Objectives and Strategies for Quality of Life/Survivorship in the Yap CCC plan.

Specifically it addressed Objective 2: By 2012, develop a program to support and guide cancer patients, survivors, family and friends to address physical, mental, spiritual and practical issues. Strategy 2.1: Encourage the Yap State Department of Health Services to provide regular refresher training for all physicians and nurses on the six cancer sites identified in Yap, the risk factors and available treatment options.

By making recommendations on how to improve end-of-life care in Yap, and laying the ground-work for a Palliative Care Curriculum fit for Yap, the program will help improve the training of physicians in providing palliative care to patients. Although this is only one aspect of strategy 2.1, appropriate palliative care is essential to a patient's quality of life.

Planning & Development:

- ✓ What data or reports were used to help plan the project?

Yap Cancer Control Plan

- ✓ Who are the project partners and what are their roles?

- 1) Yap Comprehensive Cancer Control Program- Yap CCCP provided leadership in making sure the grant fits in the Yap CCCP.
- 2) Yap Comprehensive Cancer Coalition- Provided leadership/guidance in caring out a CEED Legacy Grant

- 3) Waab Community Health Center- liaised with local health councils for permissions and focus group development. WCHC will also help provide venues for some focus groups.
- 4) Yap Department of Health Services- provide venues for focus groups in Yap Proper and the Neighboring Islands. Also liaised with Neighboring Island Dispensary Managers to organize Focus groups on Neighboring islands.
- 5) Council of Pilung- Granted permission and advice on how to perform project on Yap Proper.
- 6) Council of Tamol- Granted permission and advice on how to perform project on Neighboring Islands.
- 7) Yap Women's Association- Identified members of focus groups and offer advice to carry-out project.
- 8) Yap Medical Association- Provided expertise in current palliative care available in DHS. Also provided members for focus groups.

✓ What was the planning process?

Discussions were initiated with Yap Comprehensive Cancer Control Program (Yap CCCP), the leadership of the Waab Community Health Center (WCHC) and Yap Department of Health Services (Yap DHS), and the Governing Board of Yap AHEC. Initial plan to address palliative care through exploring existing beliefs about death and dying was identified as a need. Proposal utilizing focus groups was drafted. This was represented to the Yap CCCP, WCHC, Yap DHS, and the Yap AHEC Governing Board. Proposal we adjusted per their recommendations, then shared with the Council of Pilung and Council of Tamol, as well as the Yap Cancer Coalition, the Yap Medical Association and Yap Nurses Association. Proposal completed and put into CEED grant application. Proposal was then adapted per CEED's requests including- number and scope of focus groups, reduced budget, and inclusion of a review of the Pacific Palliative Care Curriculum.

✓ What 'evidence' or models or theories of change influenced the project design?

Socio-ecological model of health.
SMART Objectives

Implementation:

✓ What are the project's primary activities?

Conducting focus groups in death and dying on Yap Proper and the Neighboring Islands.

✓ How were the activities carried out?

Facilitators for the focus groups were identified and trained. The facilitators organized focus groups composed of representative adult volunteers. Focus groups were scheduled and conducted where the participants were asked their opinions on four related topics:

- 1) What is a good death?
- 2) What is a bad death?
- 3) How can the health care system improve to help make the bad deaths better ones?
- 4) Are there current features of traditional practices that we should be aware of before advocating for any changes?

✓ Who implemented the project activities?

Yap AHEC

✓ What partners were involved?

Yap DHS, Waab CHC, Council of Tamol, Council of Pilung

- ✓ How did the community participate?
Provided housing and food for facilitators on Neighboring Islands. Helped to spread the word about the focus groups. Assisted each other with transportation.

- ✓ What materials or products or deliverables were created? (i.e. brochure, video, PSA, etc.)

Focus group guidelines, draft paper on key findings, Pacific Palliative Care Curriculum Module Review Tool, and presentation for CCC Coalition on findings.

Evaluation:

- ✓ What are the key results and/or outcomes.

Death remains one of the most important and significant activities in Yap, an event that involves everyone. It is clear that, particularly on the Outer Islands, Yap has one of the world's best traditional palliative care systems (known on Ulithi and Fais as *hachou*—care for the dying), involving the immediate family, more distant relatives and in many cases the entire community. There are ways this system can be supported and strengthened by the health services, though caution must be exercised not to undermine it.

While there were many points brought-up in the discussions on death and dying, some of the more pertinent points to developing a palliative care program include:

- 1) To some Yapese, pain while dying is desired. Although, this is not a prevalent as the almost universal opinion that experiencing pain during labor and delivery is a necessary part of being a complete woman.
- 2) Family members never want to give up hope of cure. They always want something being done for the patient that is working for a cure (usually this is local medicine). Acceptance of imminent death can and does occur, despite the continuation of local medicines targeted to cure the disease.
- 3) Autopsies are culturally taboo.
- 4) Never speak the name of the dead. "To discuss death, you are calling upon death."
- 5) Local medicine is almost always being given, regardless if the patient is at the hospital or at home. Local medicine practitioners generally hold a better report with patient and their families than western trained physicians. All agree there is no local medicine used only to control pain.
- 6) Yapese and neighboring islanders would prefer to die at home.
- 7) A good death occurs when one dies having met obligations, fulfilled responsibilities, and resolving disputes.
- 8) A quick death is not always a good death.
- 9) There are active systems of traditional palliative care in Yap. These traditional systems include respite care, hygiene practices, feeding, and even estate planning.
- 10) A hospice house would be inappropriate for Yap, as it would indicate that the family is not meeting their obligations to their loved one.
- 11) Yap has a very complex system regulating actions after a person's death. This includes notification of the death, funerals, dividing the estate. This varies significantly between the different culture groups of Yap.

- ✓ What evaluation data collection methods were used to measure the change?

Focus groups and individual interviews

Lessons Learned:

- ✓ What are the strengths and weaknesses of the project?

Given that Yap has 22 inhabited outer islands whose inhabitants speak three distinct languages (Ulithian, Wolleaian, and Satawalese) with many dialects, and given that both contemporary and traditional attitudes, beliefs, and practices vary enormously from island to island, an effort still needs to be made to extend this project to the 18 islands our research team was unable to visit during this project. A sample of interviews of individuals from Ifaluk, Elato, and Lamotrek confirmed this variation and it needs to be thoroughly documented.

- ✓ How could this project be improved?

Larger sample on more islands.

- ✓ What recommendations do you have for others who want to replicate the project?

- 1) Try one pilot group, with just four questions:

Q1: What is a good death?

Q2: What examples come to mind of deaths that were not good deaths?

Q3: How can the health care system improve to help more making the bad deaths better ones?

Q4: What traditional aspects of death and dying in your community are most important to preserve as the society and its health care system changes?

- 2) A second set of recommendations from this project concerns how to conduct focus groups with Micronesians. While developed for Yap, other jurisdictions may also consider some or all of these recommendations useful:

- 1) Oral or written consent should be obtained from every participant, and participation from local authorities, such as the chiefs' councils in Yap - Council of Pilung (Yap Proper) and the Council of Tamol (Neighboring Islands).

- 2) Always speak slowly and softly - really softly - never raising one's voice even to the cadence normal in Hawaii, even if background noise exists.

- 3) Always begin and end with a formal apology, it is part of discursive ritual and is much appreciated; one should apologize for wasting people's time, for possibly offending them, for asking obvious questions and not knowing about the culture, etc. Many speakers begin and end by saying: "I'm sorry..."

- 4) Never interrupt a speaker, or risk them choosing to be silent the rest of the much session. Practice with a timer how long 4 seconds really is; every time you are waiting for a response from a participant wait at least 4 seconds before intervening with a prompt.

- 5) For Micronesians there are no easy questions, so don't try to "soften up" the group with supposedly simple opening questions. However, do start with easier topics and progress systematically to harder topics. Emphasize at the beginning that there are no "right or wrong" answers to the questions.

- 6) Keep the number of different questions minimal – never more than 6 for a two hour session. Allow for long periods of silence and respect digressions as their relevance may only gradually (or much later) become apparent.

- 7) Politely ask that questions be saved to the end, but if someone asks something timely and

simple to answer, answer it to avoid seeming rude.

8) Encourage turn-taking and full group participation but be sensitive to the inner hierarchy of the group, with younger members deferring to elders, wives to husbands' sisters, nieces to aunts (in Micronesian kinship an aunt can sometimes be younger than a niece) and subtle clan and political hierarchies that will influence who speaks the most with the most authority.

9) There should always be refreshments.

3) The final recommendation is to carefully pick and train your facilitators. Having the right facilitators will enable the focus groups to be easily coordinated and conducted. Some characteristics a good facilitator we felt were important:

1) Respected member of the community, but not intimidating (for instance a health care worker, but not a chief)

2) Well-liked by the community.

3) When possible match age, gender, language and culture of the facilitator with the focus groups.

Funding for this conference was made possible by a cooperative agreement from the Centers for Disease Control and Prevention, REACH US through Pacific CEED, Department of Family Medicine and Community Health, JABSOM, University of Hawai'i, award number 5U58DP000976. The views expressed in the materials or publications or by speakers and trainers do not necessarily reflect the official policies of the Department of Health and Human Services; nor does mention of trade names, commercial practices, or organizations imply endorsement by the U.S. Government