Palliative Care and Traditional Practices of Death and Dying in Wa'ab (Yap Proper) and in the Outer Islands of Yap

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Abstract

Background: *Death remains one of the most important and significant activities in Yap, an event that involves the entire island. A death of a Yapese not only unites the family, it initiates a complex series of reaffirmed kinship ties, rituals and exchanges that refocus the entire community and create new social identities for the participants. How these ties, exchanges, and identities are changing due to new economic challenges and new social pressures were the focus of this preliminary study, which sought to document the resiliency or fragility of traditional structures, measured in the efforts around death and dying in Yap and to identify ways that the health care system can intervene to improve palliative care.*

Methods: *226 persons (49 on Wa'ab - Yap Proper - and 177 on the Outer Islands) participated in 16 focus groups, of which eight were on Wa'ab and eight on four Outer Islands: Fais, Falalop, Fetherai, and Mogmog. We additionally conducted 6 semi-structured open-ended key informant interviews, added to capture more of Yap's enormous sociocultural diversity.*

Results: *The islands of Yap, particularly the Outer Islands, continue to support one of the world's best traditional palliative care involving the immediate family, more distant relatives and in many cases the entire community. However, participants showed considerable concern for ways that this system is weakening and offered numerous suggestions for improving and strengthening palliative care in Yap.*

Discussion: *Although caution must be exercised not to undermine the existing system, six recommendations on how the health system can intervene can be identified. These involve identifying a key resource person on each island; supplying small, practical "comfort care" kits; making more pain medication available; conducting regular home visits; improving patient-physician and physician-family communication; designing a suicide intervention strategy; and documenting existing variations of how the dying are cared for on the other Outer Islands of Yap.*

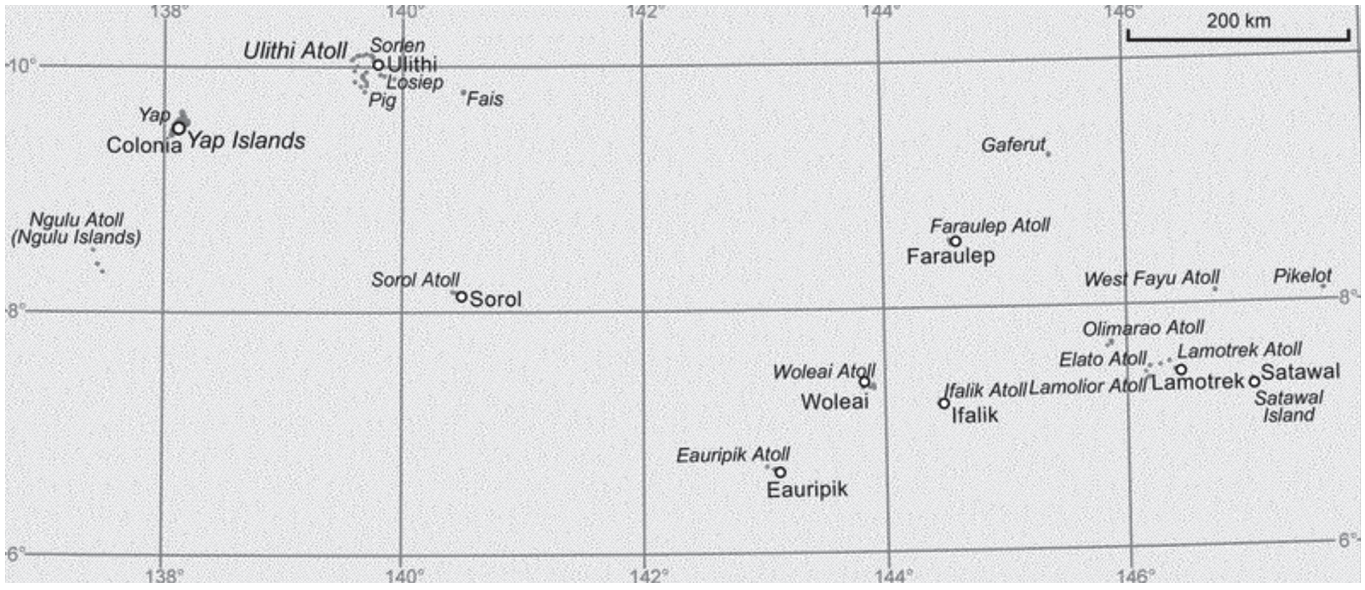
Background

Yap, the western-most state of the Federated States of Micronesia (FSM) is located in the western Caroline Islands midway between Guam and Palau. Yap has a population of approximately 11,200.[1] 65% of the population resides on Wa'ab (Yap Proper), which consists of four islands connected by roads, waterways and channels, and includes the town of Colonia, Yap's capital, whose population is about 1000. The population density is 243 per square mile and the median age is 20.9.[2]

Stretching 600 miles east of Wa'ab are 78 outer islands, of which 22 are inhabited. Including the outer islands, the state of Yap covers approximately 500,000 square miles of ocean yet consists of only 45.8 square miles of land area.

Yapese is spoken by the inhabitants of Wa'ab, while the distinct Micronesian languages of Ulithian, Woleaian, and Satawalese are spoken in the Outer Islands; communication between the two groups most often takes place in English (understood by all islanders). According to the 2000 census, there were a total of 2,030 households in Yap, with a median of 5.4 persons per household. Some cash income was reported by 1,578 households (77.7%), with a mean household income of $8,300. Yap's literacy rate is 92%. Life expectancy at birth is 66.5 for males, 67.6 for females. In 2004, per capita expenditure on health was US$180, an increase from US$116 in 2002.[3]

Yap Memorial Hospital in Colonia is the only hospital in Yap and is directly accessible only to those residents who live in Wa'ab. Residents who live on the Outer Islands find access difficult due to limited transportation and rely on 17 Outer Island dispensaries[4] and on traditional practitioners. A field ship sails about every 6 weeks when in service. Other cargo ships that can also carry passengers sail



Map of Yap and its Outer Islands

infrequently. Only three of the Outer Islands (Woleai, Ulithi, Fais) have runways. These are serviced irregularly by Pacific Missionary Airways (PMA), which offers reduced fee medical evacuations.

The Outer Islands of Yap have been largely left to their own devices by the health services system. Not only are there cultural, social, political, and linguistic divides between the main islands and the Outer Islands, but the distance between islands and the poor transportation back and forth frustrate most attempts to provide help for the islands. Given the clear preference of outer islanders to die on their own island, ways to improve the situation certainly deserve attention.

A death of a Yapese not only unites the family, it initiates a complex series of reaffirmed kinship ties, rituals, and exchanges that refocus the entire community and create new social identities for the participants. However, new economic challenges in the form of a cash economy, heavier reliance on imported food, increasing use of tobacco and alcohol, new religious sects (including Mormons, Bahais, and various Christian fundamentalist groups), and the increasing possibility that death may take place in Yap Hospital rather than at home, or even at a hospital in Manila, Guam, or Honolulu, all place stress on the rituals and exchanges that traditionally characterized death in Yap.[5] Yap (like all of Micronesia) is undergoing an epidemiological transition,[6] in that the islands continue to face problems with infectious diseases, including tuberculosis, Hansen's disease, dengue, cholera, filariasis, STIs, and a recent outbreak of Zika virus,[7] while now experiencing a huge rise in chronic diseases including diabetes, hypertension, cardio-vascular diseases, and cancers. Maternal child health issues include pregnancy complications, low birth weight, high infant mortality rates, and low immunization rates. Malnutrition problems co-exist with chronic diseases linked to obesity. These problems all add stress to the traditional systems of care and exchange.[8]

How traditional ties, exchanges, and identities are changing due to new economic challenges and new social pressures was the focus of this study. We sought to document the resiliency or fragility of traditional structures, measured in the efforts around death and dying in Yap and to identify ways that the health care system can intervene to improve palliative care.

Methods

Discussions were initiated between Yap Comprehensive Cancer Control Program (Yap CCCP), the leadership of the Wa'ab Community Health Center (WCHC), Yap Department of Health Services (Yap DHS), and the Governing Board of Yap Area Health Education Center on how best to address the community-perceived need of improved palliative care. Exploring existing beliefs about death and dying utilizing focus groups was agreed upon as an appropriate strategy. The proposal was presented to the Council of Pilung and Council of Tamol (the Councils of Chiefs of Wa'ab and of the Outer Islands), as well as to the Yap Cancer Coalition, the Yap Medical Association and Yap Nurses Association. Once adjusted to include their recommendations, the proposal was submitted to the Pacific Center of Excellence for the Elimination of Disparities (CEED) which requested further modification that limited the number and scope of focus groups and reduced the budget while also requesting a review of a draft Pacific Palliative Care Curriculum prepared by Kokua Mau in Honolulu (see article in this issue). Approval from the University of Hawaii's IRB was obtained (CHS 18261) and the research was undertaken in April and May 2010.

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

(1) What is a good death?
(2) What examples can you give of a bad death?
(3) How can the health care system improve to help make bad deaths better ones?
(4) Are there traditional practices of which we should be aware before advocating any changes?

Groups included a youth group, a cancer survivor group, a group of widows, a group of community leaders, two community groups on Yap, physicians of Yap Hospital, and groups divided by gender on four outer islands. Altogether 226 persons (49 on Wa'ab and 177 on the Outer Islands) participated in 16 focus groups, of which eight were on Wa'ab and eight were on four Outer Islands: Fais, Falalop, Fetherai, and Mogmog. We additionally conducted 6 semi-structured open-ended key informant interviews. These informant interviews were added to capture more of Yap's enormous sociocultural diversity.

Results

The islands of Yap, particularly the Outer Islands, continue to support one of the world's best traditional palliative care systems (known on Ulithi and Fais as *hachou*–care for the dying, with cognates in the other languages and dialects of the Outer Islands), involving the immediate family, more distant relatives, and in many cases the entire community. However, participants showed considerable concern about the way this system is weakening and offered numerous suggestions for improving and strengthening palliative care in Yap.

Traditional practices release the immediate family from their daily chores to allow them to tend full time to the dying (shifts are assigned throughout the night, a process known as *yach metmat lobong*). Attendants are expected to be quiet, subdued, and cheerful, taking care not to excite the dying patient. Food, supplies, and labor are provided by the extended kin network and wider community. Special food offerings and daily garlands of flowers are brought to the dying person, and efforts are made to resolve all family disputes and inheritance issues while the dying person can still participate in the discussions. As one elder explained: "When we take it [food and supplies] to the sick person's house, then we have to call out the names. We have to make a relationship on the person's father's side and on the person's mother's side." That is, the visitor's geneology and relation to the patient is explicitly articulated as part of the visit. Christian families perform bedside prayers and sing hymns, and all community members are expected to visit the dying person. Whenever possible, relatives from other islands also visit the dying and bring supplies to the family.

In some communities, a "question medicine" is prepared to give to the patient, to determine whether or not they may survive or cannot. Divination by palm knot tying is still sometimes practiced for this purpose, too, and knot tying is also used to identify who is

the right person to do local medicine. A yes or no question is posed, then knots are tied in four coconut fronds and the numbers in each counted, with the final number providing the code for the answer to the question.

At a typical funeral, distant relatives announce their kinship ties to the deceased, orally tracing the lineage through both parents of the departed, ties that in some cases are otherwise nearly forgotten and sometimes require genealogical consultations to prepare. On some of the more remote islands "wailing," is still performed at the funeral, ritual lamentations addressed directly to the newly dead, although this practice is actively discouraged by Christian religions. Coffins are laden with *lavalavas* (locally woven cloth worn as a skirt) and monetary offerings. In many communities, the grave site is watched for three days in expectation of signs that the spirit of the departed is still hovering there, and conversations with the dead take place. Personal property of the deceased not disposed or willed before death is burned, to dissuade the spirit of the departed from remaining near the home.

After a death, the family remains at home for four days. Catholic Yapese conduct a nine day novena at their home, with all work obligations suspended; more distant relatives tend their fields and perform other chores for the family. Work on some taro fields or on small non-inhabited but cultivated atoll islands closely associated with the deceased may be suspended for up to six months as a sign of respect. After the funeral, the name of the deceased is no longer uttered, until a suitable descendant is born to whom the name is given, along with expectations that the newborn will grow up to develop the same character as his namesake.

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

(1) To some Yapese, pain while dying is desired. Although not as prevalent as the almost universal opinion that experiencing pain during labor and delivery is a necessary part of being a complete woman, it was considered to be a strong argument against pain medication. All agree there is no local medicine used only to control pain. Much more than a simple test of strength or will power is involved, but the issues of ethical subjectivity and moral identity involved are too complex to fit within the current paper.[9]

(2) Family members never want to give up hope of cure. They always want something 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 unacceptable.

(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 whether the patient is at the hospital or at home. Local medicine practitioners generally hold much better rapport with the patient and their families than do western trained physicians.

(6) Yapese both on Wa'ab and on Outer Islands would prefer to die at home.

(7) A good death occurs when one dies having met obligations, fulfilled responsibilities, and resolved disputes. A quick death is not always a good death.

(8) There are active systems of traditional palliative care in Yap. These traditional systems include respite care, hygiene practices, feeding, and even estate planning.

(9) A residential palliative care facility such as a hospice house would be inappropriate for Yap, as it would indicate that the family is not meeting their obligations to their loved one. This point was agreed upon in every group despite awareness of situations of neglect in which families were unable to meet those obligations.

(10) Yap has a very complex system regulating actions after a person's death. This includes notification of the death, funerals, and dividing the estate.Systems vary significantly between the different cultures of Yap. New disputes tend to arise after the funeral, criticizing the way the dead was prepared, the way people were notified, that people who thought they should be involved were left out.

Discussion

Although caution must be exercised not to undermine the existing system, six recommendations on how the health system can intervene can be identified.

1) A key resource person should be identified, most likely a member of the Outer Island dispensary staff or the Wa'ab Community Health Centers, to receive basic palliative care training. These individuals can then show families the safest and most suitable ways to care for the dying; particular instruction should include how to move the patient safely, how to prevent falls, wound care, bathing, hygiene, how to feed the patient, and help the patient sit up, simple methods that might relieve breathing difficulties or swallowing difficulties, and discuss ways to address dehydration, constipation, and incontinence. Laminated flip-charts would be suitable to teach local families basic care procedures.

This effort will require a glossary of appropriate words to be prepared, given, for example, that there is no local word for "incontinence" or "constipation," and that the same word is used not only for dementia and delirium but also for schizophrenia, psychosis, and other mental conditions, simply meaning "crazy."

2) If possible, a small, practical "comfort care" kit should be assembled and given to the families when they receive the training outlined above. This kit could include very basic supplies such as a bar of soap, a towel and wash cloth, a razor, reusable pampers, rubber gloves, a sheet, hydrogen peroxide, and chlorine bleach to disinfect bedding. Gradually, if resources permit, it might be possible to expand these basic supplies to include a set of more durable equipment, including a bed, walking cane, wheelchair, commode, but the reuse of these items might be problematic. Now that the hospital in Yap is manufacturing oxygen, it may be possible to have oxygen available on the Outer Islands, and this should be included in planning.

(3) Somehow, pain medication must be made available to those dying at home, but Yap's health services will have to decide the most practical way to address this serious need. With the morphine supply at Yap hospital sometimes running out, and none available on the Outer Islands, the timely supplying and stocking of pharmaceutical supplies throughout Yap still needs to be improved.

(4) Regular home visits, such as those conducted by physicians from the CHCs for the mentally ill, should be instituted, with families fully informed of their availability, for the terminally ill, which could address issues of dehydration, delirium, breathing difficulties, and other palliative care issues requiring more than the family's basic intervention. This could be combined with the practical at home teaching suggested above.

(5) Doctor-patient, doctor-family communication and communication between all members of the health team, especially doctors and nurses, with patients and their families, needs to be improved urgently. Outer islanders invariably reported unsatisfactory visits to Yap Memorial Hospital, with poor communication clearly the source of much of the dissatisfaction. Elders in Yap with long experience with the hospital also report that the situation is deteriorating. With the one remaining Yapese doctor at the hospital preparing to move to the CHCs, this problem may require more than additional training of staff. Yap Hospital may need to designate persons fluent in Yapese, Ulithian, Woleaian, and Satawalese to be responsible for communicating with patients (not just the terminally ill) and their families, as a first step to addressing this worsening situation.

(6) Suicide Intervention. An expert such as Fr. Fran Hezel[10,11] should be contacted to assess whether there are ways to design culturally appropriate workshops on suicide prevention and on family counseling following suicides, as deaths from the pandemic of suicide continues to plague Yap. Again, a glossary of terms used to speak of "suicide," for which there is no single one-word translation in any of the four local languages, might be a useful first step to prepare for such a workshop. It is noteworthy that the absence of a single term for suicide (as affirmed by the co-authors of this paper), unlike in Chuukese or Pohnpeian, suggests that suicide may be a more recent phenomena in Yap than in other parts of Micronesia.

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 should be made to extend this project to the 18 islands our research team was unable to visit. A sample of interviews of individuals from Ifaluk, Elato, and Lamotrek confirms this variation and it needs to be thoroughly documented.

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