Evolving Palliative Care Practices among Marshall Islanders in Hawai'i: Generational Comparisons

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Abstract

Little is known about Marshallese palliative care practices. We explored traditional and contemporary Marshallese palliative care practices and examined generational differences. We performed three focus groups in 2011-2012 among Marshall Islanders in Hawai'i. A native speaking interpreter assisted group facilitators. Data were analyzed using classical thematic triangulation methods to identify specific Marshallese palliative care practices, the effect of economic and social challenges in Hawai'i, and generational differences comparing young and old. Nineteen persons (10 men and 9 women, youth aged 17-27 years, and elders as defined in Marshallese culture, aged 46-79) participated. A "good death" was defined as "peaceful and pain free," occurring from natural causes. Factors associated with a "good death" included gathering of family to absolve conflicts, and proper and timely cultural practices. Factors associated with "bad deaths" included young age, active suffering, accidents, suicides, "black magic/curses," or lack of timely or proper burial. Comparing generational differences, older Marshallese had differing opinions regarding preferred place of death, burial site, cultural practice preservation, artificial prolongation of life, and cremation. Barriers included mortuary fees, cost of transporting bodies, United States (US) government policies, and wait times for death certificates. Many cultural factors contribute to "good" or "bad" deaths. Attitudes toward palliative care practices differ by generation. Having previously documented different approaches by Yapese, a generalized "one size fits all" approach to Micronesians is inappropriate. Overcoming identified barriers may facilitate practices necessary for a good death in Micronesian populations in their home nations and as they migrate to communities throughout the US.

Keywords

Palliative Care, Marshall Islanders, Generational Comparison

Introduction

Death, for Micronesians, is one of the most important events in the life of the entire community. Traditionally, death not only unites the family, it initiates a complex series of reaffirmed interpersonal ties, rituals, and exchanges that refocus the entire community and create new social identities for everyone. In small island communities, traditional palliative care practices release the immediate family from daily chores to allow them to tend full time to the dying. Efforts are made to resolve all family disputes and inheritance issues while the dying person can still participate in the discussions. Our study examines ways that these practices are being reshaped due to new economic challenges and new social pressures faced by citizens of the Marshall Islands.[1]

The Republic of the Marshall Islands (RMI) is an island nation of two parallel archipelagic chains of 29 coral atolls comprising 1,225 islets, located in the Central Pacific, about halfway between Hawai'i and Australia (Figure 1).[2] In 2018, the population of the RMI was estimated at 75,684.[3] About 53% of the population is younger than 24 years and only about 10% are 55 or older.[3] In 2009, nearly half of the population lived in the capital, Majuro. Another 9,345 citizens resided on tiny (0.23 square miles) Ebeye Island—one of the most densely populated locations in the Pacific.[4]

The RMI became a sovereign, independent country in October 1986, ending over 125 years of foreign control. In 1986, a Compact of Free Association was signed between the RMI and the United States (US), granting the RMI sovereignty in domestic, foreign, and economic affairs, but granting the US defense rights. The Compact allows Micronesians to migrate freely between the nations without visas or time limits.[5]

Bikini and Enewetak atolls are former US nuclear test sites, where, between 1946 and 1958, the US detonated 67 nuclear devices equivalent to over 7,000 Hiroshima bombs. Radioactivity contaminated food and water.[4] Increases in leukemia, breast cancer, and thyroid cancer after radiation exposure have been clearly documented, especially in individuals exposed during childhood.[6] Many RMI citizens continue to suffer from medical conditions that can be traced to the adverse impact of the nuclear testing programs.[4]

Although traditional Marshallese diet consisted of fish and edible plants such as breadfruit, taro, and pandanus, at present, in urban areas, a large percentage of calories consumed are from imported foods.[7] Fresh food is limited and costly. As a result, non-communicable diseases are emerging as the leading cause of mortality. Diabetes-related diseases and cancer (all types) are the leading causes of death. Marshallese also have high rates of infectious diseases such as tuberculosis and leprosy.[4]

Many Marshallese suffer disproportionately from healthcare disparities and seek healthcare services in Hawai'i.[8] In one decade, the Micronesian population has more than doubled in the US, with the Marshallese population itself increasing from around 7,000 in year 2000 to more than 22,000 in 2010. In 2010, the largest percentage of Marshallese in the US lived in the State of Hawai'i.[9]

Little is known about Marshallese palliative care practices; there are no studies in the literature. This project is part of a greater

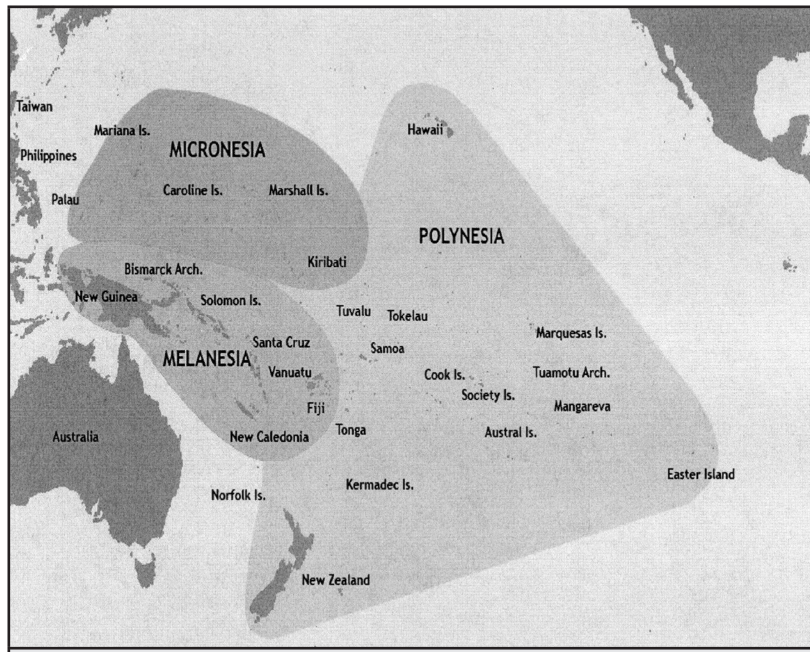

Figure 1. Map of Micronesia[2]

effort to improve end-of-life care for Micronesians, to learn more of traditional and contemporary Marshallese palliative care practices, to examine changes occurring as these migrants adapt to new social and cultural challenges, and to examine generational differences between young and old Marshallese.

Methods

We performed 3 focus groups in 2011-2012 among Marshallese living in or visiting the island of O‘ahu, Hawai‘i. Some were born and raised in the US, while others originated from Ebeye of Kwajalein Atoll and other outer islands including Likiep, Wotho, Ebon, and Jaluit (Figure 2).[10]

This study was declared exempt by the University of Hawai‘i Institutional Review Board, certificate CHS#18261. Subject recruitment was conducted by our interpreter. All participants provided written informed consent. No compensation was provided for participants; however, light refreshments were provided. Group facilitators were uniformly trained to conduct focus groups using a prepared script and a native speaking interpreter. Participants were asked the following open-ended questions:

1) What is a good death?
2) What examples can you give of a bad death?
3) How could the health care system improve its services to help make bad deaths better ones?
4) What traditional aspects of death and dying in your community are most important to preserve as the society and its healthcare system changes?

These questions were adapted from a prior study conducted by Maskarinec, et al, in the islands of Yap, Federated States of Micronesia.[11] All focus groups lasted 90-120 minutes. Participants were encouraged to speak either English or Marshallese. Sessions were audio-recorded with permission, transcribed, and analyzed by the facilitators. Data were analyzed using classical thematic triangulation methods to identify specific Marshallese palliative care practices, the effect of economic and social challenges in Hawai‘i, and generational differences comparing the young (17-27 years, n = 6) and the old (as defined in Marshallese culture, 46-79 years, n = 13).

Results

Demographic characteristics of participants in the focus groups are presented in Table 1. Four of six participants in the “young” group were born in the US, and only one had lived in the US for less than 5 years.

Six themes emerged as key concepts:

1) Pain Free Death
Both young and old Marshallese wanted a pain free death, both endorsing use of allopathic pain medications:

- “Just as Americans give pain medicine it is the same as giving herbal medicine in the Marshall Islands.”
- “Anything that can be done to take care of pain and suffering should be done by doctors and other medical personnel.”

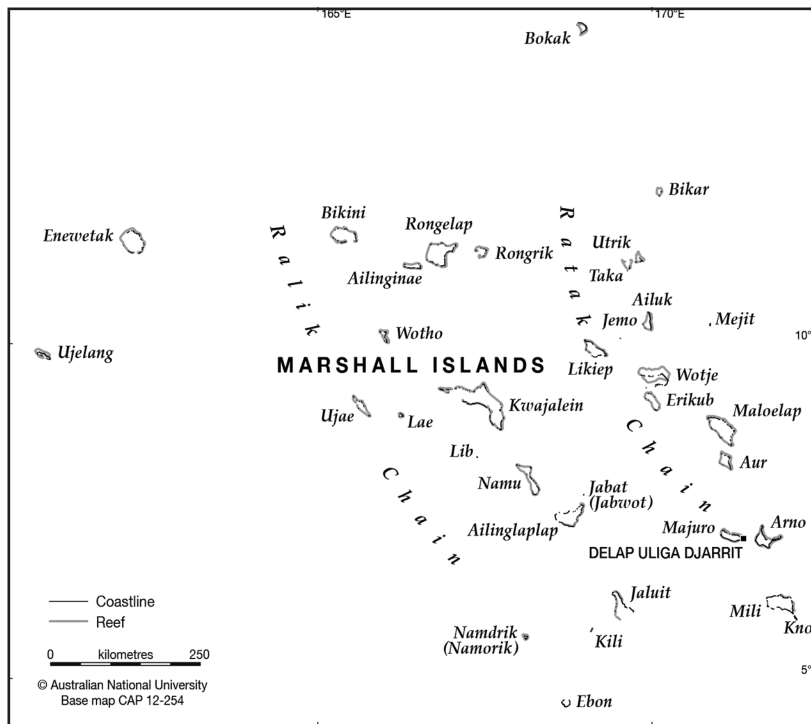

Figure 2. Map of the Republic of the Marshall Islands[10]

Table 1. Demographic Characteristics of Focus Group Participants

Characteristics	Group 1 n=6	Group 2 n=7	Group 3 n=6	All n=19
Age	**54.4 (46-63)**	**65.3 (54-79)**	**20.3 (17-27)**	**47.6 (17-79)**
Gender				
Male	4	3	3	10
Female	2	4	3	9
Time in US				
Since birth	0	0	4	4
< 5 years	0	2	1	3
5-10 years	2	0	0	2
11-20 years	2	1	1	4
> 20 years	2	4	0	6
Marital Status				
Married	4	2	1	7
Divorced/widowed	0	1	0	1
Single	0	0	5	5
Unknown	2	4	0	6

2) Life-Sustaining Interventions

Young and old had different views on the use of life-sustaining interventions in terminal illness. Elders equated a good death as one that is "peaceful and pain free," occurring naturally without artificial life prolongation. The young endorsed aggressive life-sustaining medical interventions.

Younger Marshallese stated:

- Hospitals "should do everything to keep [someone] alive…they have the expertise that the family does not."
- "If there is a way to live longer, they can go to the hospital, but if somebody wants to stay at home and die, it is the person's choice."

3) Place of Death

Preferred place of death differed depending on being in the RMI or in Hawai'i. Most respondents preferred to die in institutions while in Hawai'i. Young and old cited different reasons for this preference. According to elders, having people present that were "connected to" oneself was more important than the actual locale of death.

- "I would like to die at home if I were in Marshall Islands; If here, I [would] rather die…inpatient, hospice, or in some institution. While away [from Marshall Islands], hospice becomes like your home."
- "In the hospital, there's all these people really connected to you…a nurse or a doctor comes in…I [would] rather die in the hospital; if I were back home, I would choose to die with my family, but…here in Hawai'i…I would rather die in the hospital."

Younger Marshallese preferred to die in a hospital so that aggressive medical intervention can be provided.

- "Better [to die] in the hospital. They can help things until they can say they cannot help you anymore."

4) Cultural Practices/Family

Elders emphasized cultural practices surrounding death, while younger Marshallese discussed these practices in less detail.

Elders equated "good deaths" with family gatherings to absolve conflicts and with proper and timely performance of certain cultural practices such as the *ilomej (wake)* and *eorak* (post burial services). These cultural practices were important for understanding genealogic relations and for gathering extended family and friends. A death in the RMI is announced over public radio. In fact, a death that occurs in Hawai'i is still announced over public radio in the RMI. During the *ilomej (wake)*, the body may remain with the family for up to seven days, during which time extended family, friends, and community members pay their respects and bring condolence money and gifts.

The burial occurs after the *ilomej* and takes place on land owned by chiefs, free of charge after permission is granted. Clothing worn at the time of death and the mats used in the *ilomej* are buried with the deceased. Prior to conversion to Christianity, bodies were wrapped in mats and buried. Today, bodies, mats, and personal belongings are placed in coffins and entombed in cement.

Three days after the burial, a memorial service, known as *eorak*, is conducted at the burial site. Family members, dressed in white, place white stones on the grave, symbolizing resolution of conflict and forgiveness of sins. Graves are not touched or tended to until another death takes place to avoid "bwijerro," misfortune.

- "Everyone is welcomed to stay at the person's house day and night during this period, and people travel from the outer islands to pay respect."
- "The day of death, the day you see everybody, the day you understand your genes and relations."
- "In relation to death, the day of death, you will see everybody…you will get to meet everybody, regardless if you are related or not."
- "…after they're buried and after everything is said and done. You can't touch the grave or clean it until someone else dies and is buried in the cemetery. Otherwise, this will be bad luck."

Elders expressed belief in resurrection when speaking about practices that are important in preparation for this.

- "We put their clothing and belongings along with gifts in the coffin so they can come back."
- "Other people put magic, because they think that that person will come back to you to do whatever you want."

Elder participants also expressed concern about loss of their culture as the young become more and more acculturated in Hawai'i.

- "Younger generations do not know much about the culture. We are losing our custom, what we have."

The young focused on other details of the *ilomej* that had impressed them as children, such as having certain food items like ship biscuits available. Young participants said:

- "Every time we used to have a ilomej, we brought biscuits and everybody…would eat the biscuits. It is something you relate with death. It's always been biscuits."
- "I think the whole process is important. If the health care system changes, I don't think [the] culture would be able to keep things… It changes slightly to accommodate the change in the system, but ilomej and the whole process should be preserved."

5) The Body

Elders expressed clear opposition to cremation and wished to be buried on their island of origin. They preferred the body to stay intact for burial, preferring to ship the corpse back to the RMI as soon as possible if death occurred elsewhere.

One elder stated:

- "There was no such thing as cremation back home. People did not believe in cremation."

Younger participants were more accepting of cremation and felt that it was acceptable to hold cultural practices without the body present, stating:

- "Some [younger generation] might just want to be cremated and buried here [in Hawai'i]"
- "I think it is okay to have the wake and the process without the body present."

6) Bad Deaths/Barriers
Both young and old identified similar factors associated with "bad deaths," those from unnatural, abrupt, and unexpected causes, including suicides, stillbirths, accidents, shark attacks, or getting lost at sea. A "bad death" could also result from "black magic, curses, or witchcraft." Death at a young age from a non-communicable disease is viewed as bad.

- "Nowadays, most people die early from some disease [like] diabetes, cancer, or kidney disease. In the past, they [died] from old age."

Both groups identified lack of a timely burial or burial site as a bad death. They identified government policies, laws and regulations, and financial limitations as obstacles to a good death.

- "One of my family members died in Hawai'i. She was free from pain in the end. Bad thing was she spent months and months in the morgue because she didn't [have] enough money to go home right away."
- "Bad death is when you leave somebody unburied. For months, or until the government just cremates the person because there's no space."
- "When people die at home, all the family goes to the house and sleeps over. They stay in the person's house for whole 7 days. We cannot do it here, t hey will kick you out. Too much noise, too crowded. Here we cannot do that."
- "It is very different from our usual customs, we cannot even practice the wake, the white pebbles all that. Even coming to the house to do *ilomej*. In the Marshalls, your house is the morgue, so you can do whatever you want, when you want. It's 24 hours open. At home [in Marshall Islands], if they want, they can just bury right in front of their house. Free of charge. You don't have to pay for a grave."

Discussion and Conclusion

Many underlying cultural factors contribute to "good or bad" deaths. Although a well-developed traditional system of palliative care existed in the RMI, with traditional forms of respite care, bereavement care, estate planning, and even family counseling, all of these structures are threatened by modern social forces. Our study uncovered significant generational differences in attitudes and opinions, as discussed below. The health systems and providers who interface with Marshallese and other Micronesians in their home nations or as they migrate to other parts of the US, may be better able to provide appropriate and culturally relevant end of life care.

Pain Free Death

Participants desired a peaceful pain free death and were open to allopathic pain medications during the dying process. This differs drastically with another Micronesian culture, the Yapese, who indicated that pain while dying is desired and who refrain from using either allopathic or traditional medications to alleviate pain.[11]

Life-Sustaining Interventions

There were clear differences between young and old Marshallese regarding life-sustaining interventions in the setting of terminal illness. The young had conflicting views on palliative care, indicating a desire for a peaceful and pain free death yet still wanting aggressive medical care in terminal illness. Reasons for this difference may include limited exposure to traditional Marshallese practices, the availability of life prolonging medical technology, or the perception that people are dying from what are seen as unnatural causes: diabetes or kidney failure.

Place of Death

The ideal place of death differed depending on whether death occurred in Hawai'i or back home. Similar to Chuukese and Yapese customary practices, dying at home is the norm among people in the RMI where traditional Marshallese end of life practices involve extended family and community.[11] To our surprise, most participants preferred institutional deaths while living in Hawai'i. Elders appeared to value relationships with people surrounding them more than the actual locale of death, stating that in Hawai'i, doctors and nurses "become like your family." Since there are fewer family members in Hawai'i, medical personnel may serve as fictive family members. The young favored institutional deaths for a different reason, as a means for obtaining more aggressive medical care. Understanding these preferences may be especially helpful for palliative care providers who are assisting Marshallese at the end of life.

Cultural Practices/Family

Much like the Chuukese and Yapese, timely and proper performances of cultural practices emerged as an important component of a good death. Marshallese view death as a time to learn their genealogy.[11,12] Important cultural practices like *ilomej* and *eorak* are vital to a good death.

The Body

Our findings show clear generational differences regarding cremation. Marshallese traditionally bury their dead intact. Elders expressed desires for a traditional burial and wished

their bodies to be shipped back intact to the RMI for burial. This practice is so important that the US Embassy published a memorandum regarding shipment and disposition of remains.[13] Belief in resurrection could explain this desire to keep the body intact. In contrast, many younger participants felt cremation was acceptable. As Marshallese are dying abroad, shipment of the body back to the RMI is difficult and costly, and cremation may be a suitable alternative for the young.

Bad Deaths/Barriers

Both young and old participants shared similar perceptions of what are bad deaths and on barriers to a good death. Abrupt and unexpected deaths such as from shark attacks or getting lost at sea were considered bad.

Suicide is another bad death. In 2003, suicide was noted to be the leading cause of death among Marshallese aged 15-44 years. A reported increase in suicide is attributed to the breakdown of family structures and the lack of education and employment opportunities. Rapid urbanization and strong identification with American culture may contribute to a confused sense of identity.[14] Our groups included as bad deaths those from non-communicable disease, like cancer, diabetes, and kidney failure, regarding these deaths premature.

Both groups identified government policies, laws, regulations, and financial limitations as obstacles to a good death. The gathering of family and friends for the *ilomej* is important for a good death, however, visiting hours and rules at hospitals and noise-limits in residential areas limit these important cultural practices. Department of health regulations allow only licensed funeral directors/embalmers to prepare, house, and transport dead bodies, while traditional practice allows Marshallese to prepare the dead and bury them free of charge. Financial constraints along with high mortuary and burial fees are obstacles to proper and timely burials. Participants shared painful stories of bodies of loved ones left in the morgue for months while cultural practices and funerals were either postponed or held without the body present. Cost and regulations governing the shipment of bodies back to the RMI are also barriers.

Study Limitations

As originally conceived, this study was one component of a larger project with initial plans to repeat this exercise in Majuro and Ebeye in the Republic of the Marshall Islands, with Chuukese in Honolulu and in their home islands, including Weno, Fefen, Faichuuk, and the Mortlocks, as well as in Pohnpei and Kosrae, for a more complete understanding of the differences in Micronesian attitudes toward death and dying. Unexpected financial barriers made the aforementioned impossible to complete. Additionally, more attention could have been paid to differences among Catholic, Protestant, Evangelical, Latter-day Saints (Mormon), and Baha'i faith groups, as religious orientation could have a major influence on beliefs and practices. Attitudes among the growing expatriate communities of Micronesians in Guam, Oregon, and Arkansas would have also enriched the findings presented here. In this study, elders were defined in Marshallese culture as aged 46-79, differing from the traditional western definition of 65 and above. Study participants were recruited by word of mouth primarily by Marshallese medical professionals on O'ahu. Due to the utilization of focus groups rather than a population-based sample, there may have been selection bias in those who agreed to participate.

Conclusions

Many underlying cultural factors contribute to "good" or "bad" deaths. Attitudes toward palliative care practices differ by generation. Having previously documented different approaches by Yapese, a generalized "one size fits all" approach to Micronesians is inappropriate. Characterization of a good/bad death is dynamic: death can be good, peaceful, and pain free but turn bad if certain cultural practices cannot be performed. Overcoming identified barriers may facilitate cultural practices necessary for a good death.

Conflict of Interest

None of the authors identify any conflicts of interest.

Presentation at Meetings

This study was presented as a poster at the Annual Meeting of the American Geriatrics Society in May 2014, and as an oral presentation at the 3rd Cross Cultural Health Care Conference in Honolulu, Hawai'i in August 2013.

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