
Cultural Issues in Death and Dying

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Although all of us experience death, not all of us think about death or respond to death the same way. This study begins to explore how cultural traditions, education, and tenure in Hawaii impact views of advanced directives, organ donation, suicide, and euthanasia. This information is useful to physicians who need to engage patients and families in discussions about death and end-of-life decision making.

Introduction

All people have, and will, experience death. But not all people view death or respond to death in the same way. As we increase our life expectancy¹ and our ability to prolong life artificially, issues surrounding death and dying become more controversial. How do different cultures look at death? What factors, besides culture, impact one's perceptions of issues like advanced directives, organ donation, suicide, euthanasia? These questions were asked in a qualitative study of death and dying in Honolulu among five Asian and Pacific Islander (API) groups—Chinese, Filipinos, Japanese, Native Hawaiians, and Vietnamese.

Expanding knowledge of cultural issues in death and dying is important for two major reasons. First, as health care professionals, we need to understand and respect cultural differences if we hope to provide care that is relevant and acceptable to our clients. Second, as educators, we need to encourage individuals to share their differences with each other as our society develops policies and social structures related to end-of-life decision making. This is especially crucial given the recent decisions by the 2nd and 9th Circuit Courts supporting the right to physician-assisted suicide. Although the Supreme Court has issued a stay on these decisions, many feel it is only a matter of time before assisted dying is legalized in the United States.²⁻³

Literature Review

Literature and educational materials on cultural-specific responses to death and dying among API Americans are scarce. Even where literature exists, it most often focuses on Japanese Americans and

show generational differences in response to death, with *issei* (first generation) respondents more likely to practice customs and traditions of Japan compared to *sansei* (third generation) and *yonsei* (fourth generation).⁴⁻⁵ Students of traditional Chinese culture have reported that Chinese are often hesitant to talk about death, as this is considered bad luck.⁶ Other reports describe the importance of funeral rituals in Chinese culture, from determining the right day of burial, to burning paper money to send with the deceased on his/her journey.⁶⁻⁷ If a person is buried without strict adherence to proper funeral rites, a hungry ghost may return to plague the living.⁸ The carrying-out of traditional death rituals is considered the most important act of filial piety among Vietnamese, from the rite of feeding the deceased to the rite of reburial, where bones of the deceased are collected, washed and preserved in a sacred jar for reburial.⁹ Ancestor worship is also important, and many Vietnamese Americans tend ancestral altars at home.⁹⁻¹⁰ Very little literature appears about Filipino Americans. Several cross-cultural studies of suicide, however, suggest that suicide rates among Chinese, Japanese, Filipino, and Vietnamese Americans are lower than suicide rates of Caucasian Americans and lower than those of their compatriots at home.¹¹⁻¹²

In summary, while some information is available about traditional death rituals, literature on how these traditions are practiced in the U.S. and on views of suicide, euthanasia, advanced directives, and organ donation is limited. This study begins to fill the gap by presenting information from interviews on death and dying practices with five Asian American and Pacific Islander groups in Hawaii—Chinese, Filipinos, Japanese, Native Hawaiians, and Vietnamese.

Method

Data were gathered from July 1995 to February 1996 through in-depth interviews with individuals of Chinese, Filipino, Japanese, Native Hawaiian, and Vietnamese descent. From each of the ethnic groups studied, two key informants (a religious leader and a bilingual health/social service professional) and five to eight focus group participants were interviewed. Key informants were selected because of their level of knowledge about their community's practices in this area; they were generally older adults who were well educated, bilingual, and respected by their communities as experts. Focus group members were identified by key informants and were affiliated with the religious and/or social service groups represented by the key informants. Because focus group members in the Chinese, Filipino, and Vietnamese groups were first-generation immigrants to the U.S., many were interviewed with the assistance of bilingual students.

The study's interview questions explored six broad areas including: 1) the underlying philosophy/religion influencing death and dying in the culture; 2) burial, memorial services, and bereavement; 3) suicide and euthanasia; 4) advanced directives and organ donation; 5) how beliefs/practices have changed over time; and 6) advice for health care professionals working with dying patients from the culture. Transcripts of the interviews were analyzed for common

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and differentiating themes. An initial draft of the summary of findings for each group was sent to one or more of the key informants, who were asked to provide corrections and/or to validate that the information contained therein was accurate to the best of their knowledge.

The study identified a number of differences among and within the ethnic groups, a full description of which is provided elsewhere.¹³ The current paper presents information from the study that is relevant to the more controversial aspects of death and dying—advanced directives (e.g., will, living wills, and documents giving power of attorney for health care decisions), organ donation, suicide, and euthanasia (e.g., withholding treatment, withdrawing treatment, and aiding death).

Findings

Historical Background of the Five Ethnic Groups

The Native Hawaiian people (or *kanaka maoli*) are indigenous to the islands of Hawaii, establishing their arrival as early as 100 A.D. They are of Polynesian extraction, sharing a common ancestry with the indigenous people across the South Pacific. Following contact with the West, the native population was reduced drastically as Native Hawaiians contracted and died from newly imported infectious diseases. This loss of cheap labor led to the “importation” of labor from Asia and this, in turn, helped contribute to the erosion of Native Hawaiian traditions and customs. Since the 1960s, the state has seen an increased appreciation of Hawaiian heritage and a resurgence of the traditional language and cultural traditions. In 1990, Native Hawaiians comprised about 19 percent of the state’s population.^{14,15}

The Chinese were the first of the Asian groups to immigrate to Hawaii in significant numbers, arriving in the mid-to-late-1800s to work on sugar plantations. Fears about loss of jobs for Caucasians stimulated a series of laws that substantially reduced Chinese immigration, including the Chinese Exclusion Act of 1882 and the Oriental Exclusion Act of 1924. Immigration restrictions began to relax in the 1940s, in part to recognize China’s position as a U.S. ally in World War II. Since the Immigration Act of 1965, which allowed 20,000 immigrants per year per country, Chinese immigration from Taiwan, mainland China, and Hong Kong has greatly increased. In 1990, about 6 percent of Hawaii’s population was Chinese.^{14,16-17}

The first major wave of Japanese immigration started after the Chinese Exclusion Act of 1882 when Hawaii sugar plantations looked to Japan for a new source of cheap labor. Almost 150,000 Japanese came to Hawaii between 1882 and 1908, when the Gentlemen’s Agreement restricted immigration from Japan to wives of Japanese men already in the U.S. All Japanese immigration was effectively halted in 1924 with the Oriental Exclusion Act. It restarted in the 1950s with the immigration of Japanese wives of U.S. servicemen. Although the Immigration Act of 1965 allowed 20,000 per country to immigrate to the U.S., fewer than 5,000 Japanese nationals have chosen to immigrate each year. Today, two-thirds of all Japanese Americans are U.S. born, compared to about 37% of all API Americans, and about half marry non-Japanese. In 1990, about 23 percent of the state’s population was Japanese.^{14, 18}

Filipino immigration began following U.S. victory over Spain in 1892, at which time the Philippines was ceded to the U.S. As a U.S. territory, Filipinos were considered U.S. nationals and, therefore, immigration was unrestricted. Almost 120,000 Filipinos came to work on Hawaii sugar plantations between 1906 and 1934. Immigration was severely curtailed in 1935, when the Philippines was granted commonwealth status. But with the Immigration Act of

1965, Filipino immigration accelerated and, in 1990, Filipinos comprised about 15% of the state’s population.^{14, 19-20}

The Vietnamese are among our most recent immigrant groups, first arriving in the U.S. after the fall of Saigon to the Vietnamese Communists in 1975. A second group, called “boat people,” are those who fled Communist rule on foot or boat, often spending time in refugee camps before relocation. Established in the early 1980s, Vietnam’s Orderly Departure Program allowed controlled immigration directly from Vietnam for political prisoners, Amer-Asians, and those whose family members were already U.S. citizens. The 1990 Census estimated the Vietnamese population in the U.S. at 614,547, a 134% increase over 1980. Vietnamese comprise less than 1% of the Hawaii’s population.^{14, 21}

Traditional Beliefs about Death

Native Hawaiian beliefs about death and dying are influenced by both Native Hawaiian traditions and Christianity. A focus group member explained that death is accepted as a part of life by most Native Hawaiians, who see an “openness” between this life and the next. For example, a participant explained that when we complete our tasks on earth, it is time to die and “move on to the next realm.” Others believed that, upon death, people are reunited with loved ones who have died before. We heard several stories about communication between realms, e.g., either dreaming about or seeing signs about the deceased. We also heard that touching a dead body may make you sick, as the dead body is “empty and can take the living person’s *mana*.”

Chinese participants reported that their traditions are influenced by three religions—Confucianism, Taoism, and Buddhism. In Confucianism, it is believed that the body should be preserved in order to respect one’s parents, and that ancestor worship is very important. In Taoism, longevity is emphasized and stimulates discussions about the right foods to eat in order to maintain health and obtain long life. The Buddhist religion teaches that one must be good in the present life in order to be reincarnated on a higher level in the next life. A premature death is considered bad luck, as this is thought to mean that someone has done something bad and is being punished. To prevent this, one should avoid offending anyone, treat parents with respect (filial piety), and take care of the older generation in this life.

Vietnamese Buddhist beliefs are similar to traditional Chinese beliefs, as China dominated Vietnam for many centuries. The concept of karma is important. While death is the final destruction of the body, the soul remains and is reborn; but how a person is reborn depends on his/her actions. If a person dies a terrible death (through accident or illness), it is because he/she is being punished for bad behavior in this life or a past life. A child may die because he/she is paying for a misdeed in a past life or for a misdeed of someone else in the family. If a child commits a crime, a parent may have to pay for it in his next life. Many children are very good so that their parents will have a good next life. The goal is to be reborn as a person without karmic debts and then to continue achieving a higher level of rebirth. You can tell when someone has been reborn at a higher level because they are “good-looking and live a comfortable life.” While Buddhism is the dominant religion, a number of Vietnamese in the U.S. are Catholic, a remnant of an 80-year occupation by the French.

Japanese Buddhist participants said that death is a part of the natural process of life and is not a finality. In fact, the present world is painful and unsatisfactory because of the worldly attachments people have to it. The next world is a better place because people are relieved of those attachments and there is peace. It is felt that when

a person who has faithfully listened to the teachings of the Buddha dies, his/her soul can be reborn into this better place, sometimes called the Pure Land. There is a belief in Buddhism that the last thoughts of a person before his or her death determines the rebirth. If one is confused or angry at the time of death, one's soul would likely be reborn in a different (worse) state than if this person had died peacefully. Despite the belief that karma affects life events, study participants said that personal karma is not openly discussed and that it is not appropriate to say, "you must accept it because it is your karma." Along with personal karma, there is also a collective karma over which there is no control (hurricanes, typhoons, war, etc.). We also heard that many Japanese in Hawaii left Buddhism following Japan's bombing of Pearl Harbor in World War II, as Japanese Buddhist ministers (and others in leadership positions) were sent to internment camps. Some Japanese Americans became Christians at this time and others stopped participating in organized religion altogether.

Our Filipino informants said that the Catholic religion had an important influence on death and dying in Filipino culture. This is not surprising given that the vast majority of Filipinos are Catholic as a result of 330 years of Spanish rule. In Catholicism, there is no need to fear death "because the Lord has created us and will be the one to take our lives back. If a person is worthy, and has followed the doctrines of the Lord, he/she will go to heaven after death. Sinners will go to hell or purgatory."

Advance Directives

Native Hawaiian participants agreed that few Native Hawaiians talk about wills or living wills. A reason was that the property automatically goes to the spouse and then to the children, so there was not need for a will. We heard that some members of the older generation may believe that talking about death will bring on death. Participants in research, however, said that they knew many Native Hawaiians who do make their wishes concerning death known to their loved ones. For example, a participant had already told her family about the kind of funeral she wants when she dies, including the foods to be served.

Chinese participants noted that Chinese people have traditionally thought it was bad luck to talk about death. Recent immigrants noted that living wills are not promoted in Hong Kong or in mainland China. The younger generation of Chinese in Asia and the U.S., along with the long-time U.S. residents, are more Westernized and more open to advanced planning. In addition, we heard that Chinese become very interested in living wills once they have witnessed our ability to prolong life. For example, a participant stated that, as a result of her grandfather lingering in a coma for 4 years, both of her parents decided to get living wills. Although participants were generally in favor of living wills, and believed that the best time to complete them was when a person was young and healthy, few had them.

Among Japanese Buddhist participants, there was a general consensus that planning for death was a good idea. For Buddhists, we heard, "if you don't think about death, you cannot live." On the practical side, participants thought that most Japanese Americans saw the usefulness of advanced directives and many had already executed such documents, although the Buddhist temple does not yet have a specific stand on advanced directives.

Among the Filipino participants, the most educated (including a Catholic nun) had thought about and/or executed living wills and funeral plans. Others, who were linked with social service agencies, remembered a lecture by an attorney who helped many of them complete living wills. However, the newer immigrants and those with the least education were quiet on the subject, finally saying that

"Filipinos don't like to talk about death or funerals; at the most, they may have picked a cemetery plot." The youngest focus group member said that she had discussed life support with her father, who told her he would not want to be sustained by machines. However, she has been unable to get him to put these wishes in the form of a living will.

Very few of the Vietnamese participants were familiar with living wills or with giving power of attorney. In response to this question, we heard that "in planning for death, people pray a lot" and that people should put aside money to cover funeral expenses. Another participant thought it was a good idea to prepare a will dispensing property.

Organ Donation

Native Hawaiian participants had varying feelings about organ donation. One was in favor of it and had designated so on her driver's license. Another said she would not donate her organs, nor would any of her family, because she believed that God made her body and she should leave this world with her body as it is. The others said they were unsure about donating organs, although they recognized the merit in it.

Chinese participants said that resistance to organ donation stems from the desire to die intact and from the Confucian belief that one's organs are gifts from one's parents and that it would be disrespectful to destroy them or give them away. There was also some concern that people who receive donated organs may be reborn with the donor's face. Of the participants, one reported carrying a donor card and two others were supportive of organ donation but had not taken any action to indicate so. Another said that it "gives me a creepy feeling to think that someone would cut me up" so he was against it. One doubted whether doctors who needed kidneys for another patient would treat the donor's disease or injury aggressively. The remaining Chinese participants were unsure.

Few Vietnamese informants were in favor of organ donation as they did not want to be born into the next life missing an organ. One said it was unsanitary and another thought that it was scary. According to the Buddhist reverend we interviewed, Buddhism makes no direct reference to organ donation so it is not known if organ donation is an acceptable practice. Theoretically, it would be a good idea since in death, the body means nothing (only the soul is reborn) and organ donation may help another. Although the reverend thought that donating organs to help others was a "wonderful idea," he thought that few in his congregation would consider it.

Among the Japanese Buddhists, resistance to organ donation stems from the hesitance to deface one's body, which is a sacred gift from the ancestors. It was also believed that you "have to go whole." Again it was noted that Buddhist thinking would support organ donation, as only the soul is reborn and it would be good to help others by donating organs. Participants, however, said that the topic was not openly discussed. They were willing to discuss it with us and one participant changed her mind in favor of organ donation when she learned that no one would be able to see any difference in her body at the mortuary after the organ was removed (i.e., the body would look intact).

The Filipino participants also gave a variety of responses. Theoretically, helping others by donating an organ would be good and, if only the soul goes to heaven, why not give body parts to the living who are in need. In reality, few of the first generation Filipino Americans had considered the idea or were open to it. The more educated participants and the second generation participants had thought about organ donation and were willing to consider the idea, although none were official organ donors.

Suicide

Among the Filipino participants, there was consensus among participants that suicide is not acceptable as it goes against the Fifth Commandment: Thou shall not kill. If a person commits suicide, the priest may refuse to perform a funeral service and may not allow the body to be buried in the Catholic cemetery. Focus group participants made these comments: "You don't go to heaven if you commit suicide," "you are not forgiven," and "you are a sinner." The single Protestant Filipino participant reported that her church would allow a service to be performed for someone who committed suicide, as they believe that Jesus forgives this person.

The Native Hawaiian participants said that if someone commits suicide, it's often the fault of someone else who has rejected them or hurt them in some way. Most felt that those who commit suicide should be given a church burial and felt it was harsh of the Catholic Church to not allow those who commit suicide a Catholic funeral or interment.

Chinese participants reported that suicide is considered wrong among Chinese. In traditional Chinese culture, however, suicide may have been acceptable for females who were raped or wanted to avoid being raped and people captured by enemies during war. In fact, a woman who commits suicide because of being raped may return as a hungry ghost to haunt the person who raped her. While the burial service would be the same, the family of a person who has committed suicide would attempt to cover up the suicide because of shame, and they would likely mourn privately.

Vietnamese participants told us that Buddhist teaching equates suicide with killing. Most Vietnamese think that suicide is wrong and teach this to their children at a very young age. The only exception is in war; a military man who commit suicide instead of surrendering to the enemy will go to "a higher place in the after life." However, most go to Suicide Land and are very unhappy since they have not paid back their karma and it will follow them. For example, the soul of a person who commits suicide at age 30, but was supposed to live until age 80, will live in Suicide Land for the next 50 years to make up the difference. The unhappy ghost of the person who commits suicide may also return to bother the living. The funeral is the same for a person who commits suicide, but mourners feel more sorrow for the surviving family members.

Japanese informants concluded that there are two ways to look at suicide. One is that a person was bestowed life by parents and ancestors, and should take care of it so as not to hurt the ancestors. In addition, the taking of any life is wrong, even one's own. But, although suicide "is not good," sometimes it is the only way out of a bad situation. In the Buddhist belief, it doesn't matter how a person dies because the Buddha is compassionate and embraces all beings without discrimination and the funeral service is the same, regardless. Thus, participants felt it was best to take a compassionate and non-judgmental view of suicide.

Euthanasia

Few of the recent Filipino immigrants had any experience with passive or active euthanasia and were not even that familiar with the terms. When terms were defined, participants felt that hastening death would be wrong because it resulted in killing, which is against the Fifth Commandment. Again, those who were more educated and those who had worked with aged and terminally ill patients, agreed that "allowing death to come" by withholding life support or increasing pain medication was acceptable. They were not in favor of more active measures or assisted suicide, however.

The Vietnamese participants told us that euthanasia is not acceptable because killing is immoral and because people have their own karma to fulfill. Therefore, families would probably not allow the

life of a family member to be shortened, even if the suffering was great. The exception seemed to be if the dying person was in an institution that the family couldn't afford. In this case, the hastening of death may be allowed, but this was not something the family could openly discuss. A participant explained that, in this case, if life support was removed and the person died, then it would signify that it was time for that person to go. Several stated that they themselves would not want to be kept alive on life support.

Among the Chinese participants, there was a general consensus that disconnecting tubes or providing an overdose of pain medicine to end suffering of a loved one was acceptable to most Chinese Americans. Participants would expect careful control and extensive discussion before supporting any activity that may cause death. They would also want some assurance that this was within the person's wishes and would hope to see such a wish in writing. A focus group member noted that, given the importance of filial piety, it would be difficult for children to remove life support from the parents as relatives may say, "oh, how come you can do this to your parents?"

From Japanese participants, we heard that there was no Buddhist stand on euthanasia but that the Buddhist temple would support the family's decision in relation to the withholding or withdrawal of life support. We heard the Japanese word *akirameru* which means "to leave things as they are." That is, instead of using technological means to sustain life, people could allow loved ones to die naturally.

All of the Native Hawaiian participants were in favor of passive euthanasia. One stated that, "for me personally, I tell my family to make sure they do all they can to save me, but then let me go and I won't come back and bother you guys." Another said that, in her family, they have all decided they will allow the person to "leave" and not keep them on artificial support. They felt that machines just extend death and, as a result, the spirit is stuck half-way in between this realm and the next. At this point, it was "better to allow them to go."

Discussion

Findings from this cross-cultural study of responses to death and dying revealed similarities and differences among the five ethnic groups. An important similarity was the participants' willingness to discuss their experiences with death, despite our expectations of reluctance. Given this, physicians and other health care professionals should be less hesitant to broach the subject with their patients.

The differences among groups, however, were also apparent. Although the Japanese, Chinese, and Vietnamese groups share a Buddhist history, they varied in their views of karma and suicide. For example, in Japanese Buddhist culture, personal karma is not openly discussed, nor are misfortunes attributed to a person's past karma. In Vietnamese and Chinese cultures, accidents, illnesses, and premature death are often considered a result of a person's misdeeds in a past life. Suicide was considered unacceptable by Vietnamese and Chinese groups and a mortal sin by Catholics, whereas the Japanese Buddhist group thought suicide should be viewed in a compassionate, non-judgmental manner.

Within-group differences were also observed, based on length of time in the U.S. and level of education. For example, beliefs among our Chinese American informants differed depending on if they were third and fourth generation Chinese Americans who grew up Christian, new immigrants who were young and Christian, and new immigrants who were older and Buddhist/Confucian. Among the Vietnamese and Filipinos, differences were seen between the more educated key informants and the less educated focus group members. In general, although the traditions of the native culture are known and respected, those who were more educated and accultur-

ated were more likely to have thought about living wills, organ donation, and euthanasia.

Of interest as well is the concept of using the values inherent in the different cultures as a base for education about death-related issues. For example, Buddhism and Catholicism both emphasize the importance of "giving" and "helping others." They also believe that it is the soul, not the body, that "is reborn" or "goes to heaven." Can these concepts be incorporated into educational strategies that will increase their willingness to become organ donors? Similarly, the Buddhist concept of *akirameru* could be incorporated into discussions about euthanasia. On the other hand, proponents of physician-assisted suicide may want to change their terminology (perhaps to "assisted dying") as suicide had such negative connotations for our Chinese, Filipino, and Vietnamese respondents. Findings along this line point out the sensibility of centering discussions about such controversial issues as physician-assisted suicide within churches, as they play an important role in explaining and celebrating life (and death) events.

Financial concerns also emerged as a trigger for changing attitudes toward euthanasia. Several informants in the Vietnamese and Chinese groups mentioned that "pulling the plug on a family member who had no hope of recovery" may be justified if the family could not afford to pay for prolonged life support. The economic argument is powerful and will become more impressive as federal insurance benefits are reduced and individual out-of-pocket expenses increase.

Methodologically, the study was constrained by a small sample, limited to a few key informants and a handful of focus group participants for each ethnic group. Thus, findings from this work cannot be generalized to the larger population. Future studies are indicated and interviews should include larger and more representative samples from each group. It would also be important to ask more detailed questions about physician-assisted suicide.

Given the shortage of existing literature on cultural differences in death and dying practices, this study provides a modest amount of information on the thoughts of five different ethnic groups on the more controversial aspects of death and dying—advanced directives, organ donation, suicide, and euthanasia. The findings also suggest that customs are affected by a number of factors—years in the U.S., educational attainment, economics, religion—and are changing rapidly. Thus, the importance of the study lies less in the cultural details provided by the participants and more in the fact that differences exist and need to be assessed and respected. The study also provides insight into cultural traditions that could be incorporated into educational efforts about end-of-life decision making and the anticipated legalization of physician-assisted suicide.

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