# Acculturation and End-of-life Decision Making: Comparison of Japanese and Japanese-American Focus Groups

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## Abstract

Variation in decision-making about end-of-life care among ethnic groups creates clinical conflicts. In order to understand changes in preferences for end-of-life care among Japanese who immigrate to the United States, we conducted 18 focus groups with 122 participants: 65 English-speaking Japanese Americans, 29 Japanese-speaking Japanese Americans and 28 Japanese living in Japan.

Negative feelings toward living in adverse health states and receiving life-sustaining treatment in such states permeated all three groups. They tended to show their preferences on the basis of the concerns of their own value by family members. Fear of being *meiwaku*, a physical, psychological or financial caregiving burden on loved ones, was a prominent concern. Then they preferred to die *pokkuri* (popping off) before they become end-of-life stage or physically frail. All groups preferred group-oriented decision-making with family. Although advance directives were generally accepted, Japanese participants saw written directives as intrusive whereas Japanese Americans viewed them mainly as tools to reduce conflict created by dying person's wishes and a family's *kazoku no jo* -- responsibility to sustain the dying patient. These findings suggest that in the United States Japanese cultural values concerning end-of-life care and decision-making process are largely preserved.

## INTRODUCTION

Decision making at the end of life in a cross-cultural context can be particularly difficult because these emotion-laden decisions are embedded within a matrix of cultural beliefs and values. Variations in end-of-life care exist even in mainstream decision making models in the United States, but the fundamental value respect for a patient's autonomy.[1, 2] Following this principle, and because many patients have lost decision making ability before end-of-life decisions are made, advance directives have risen to prominence in the U.S. in order to preserve autonomy in end-of-life decisions.[3] However, some ethnic groups, such as Asian Americans and Mexican Americans, classically hold different models for the process of decision making at the end of life.[4, 5, 6, 7] For instance, disclosure of a terminal diagnosis and talking with patients about dying may be considered inappropriate behaviors.[8,9]

Competent end-of-life care requires attention to and proficiency with the beliefs and practices of diverse cultural groups.[10, 11, 12] We address an added dimension to the current cross-cultural literature on end-of-life decision making by focusing on the effect of acculturation within a single ethnic population.

The population of Americans of Asian and Pacific Islander (API) heritage is one of the ethnic groups for which classic end-of-life decision making differs from that in the U.S..[13, 14] As the number of API elderly increases, U.S. physicians are more likely to encounter difficulties in end-of-life decision making related to differences between usual behavior and API expectations concerning disclosure and hierarchical physician-patient relationships.[12, 15, 16] Japanese Americans are the sixth largest API group in the U.S., with a complex immigration pattern resulting in a heterogeneous Japanese American society. At present, about two-thirds of Japanese Americans were born in the U.S. Many speak English as their primary language, receive education in the U.S. and marry individuals of non-Japanese descent.[17] Such heterogeneity complicates the understanding of cultural norms, and no qualitative studies have focused on decision-making preferences at the end of life in the Japanese-American population[18].

In Japan, however, decision making about end-of-life care has been extensively described.[18, 19, 20, 21] As in the U.S., the notion that a patient's preference for care should guide decision-making is generally accepted in Japan. The practical ramifications of this belief, however, differ between the U.S. and Japan due to variation in cultural background, social structure, and the patient-physician relationship. For example, Japanese physicians often do not provide their patients with information sufficient to make decisions, and physicians and family members in Japan often overrule patient's preferences for medical care.[20, 22, 23] For Japanese Americans, neither cultural norms nor the effects of acculturation has been described. While acculturation has been demonstrated in studies of behavioral risk factors for disease,[24] little is known about the effect of acculturation on the end-of-life decision-making models of Japanese Americans. Variation in acculturation to U.S. values may affect patient and family satisfaction with the process and outcome of such decisions.

This study aimed to understand and compare the end-of-life decision-making models of Japanese living in Japan and Japanese Americans. We explored attitudes toward disclosure, preferences for decision-making at the end-of-life, and advance directives. We were particularly interested in whether attitudes more prevalent in Japanese culture in Japan were retained or whether and how these views were altered by acculturation to U.S. society.

## METHODS

In order to perform a qualitative cross-cultural analysis regarding the relationship between acculturation and end-of-life decision making among Japanese Americans and Japanese in Japan, we conducted 18 focus groups with 122 participants in three groups of Japanese participants defined according to their country of residence and language: 1) Japanese living in Japan (5 groups), Japanese-speaking Japanese Americans (4 groups), and English-speaking Japanese Americans (9 groups).Language was used as the distinguishing characteristic of the two Japanese American groups because it is recognized as a key component of acculturation [25] and because classification based on other measures was beyond the capacity of this study. The focus groups were conducted in 1996 and 1997. We aimed to include people over the age of 65 because they are more likely to face end-of-life decisions in the near future. Four of the five focus groups in Japan were convened as gender-specific groups while all Japanese American focus groups were gender-mixed.

One moderator and at least one co-moderator conducted each focus group discussion. A Japanese moderator led the Japanese-speaking Japanese American focus groups and the same moderators conducted the Japanese focus groups held in Japan. At least one Japanese co-moderator participated in the English-speaking Japanese American focus groups. Focus group discussions averaged two hours in length and each focus group session included five to nine participants, all of whom provided written informed consent. Given the cultural disparity between the Western and Japanese models of end-of-life decision-making, a grounded qualitative approach was employed [26] within a framework derived from the Japanese thinking-and-behavior style that is based on group orientation.[27] The study protocol was approved by the UCLA IRB.

The focus group protocol was developed by a health psychologist, a medical anthropologist, and a physician, in concert with Japanese American and Japanese physicians. Except for language, the protocol was identical for all focus groups and was designed to generate an open-ended discussion of four topics: (1) experiences with end-of-life care and decisions for relatives and friends, (2) attitudes toward end-of-life care, (3) preferred decision-making models for end-of-life care, and (4) attitudes about advance directives.

Toward the conclusion of each focus group, the moderators presented to each group's participants a summary of their perceptions of the views expressed during the session. They also presented possible divergent views to participants at the end of each Japanese and Japanese-speaking Japanese American session to prompt additional discussion, to test social desirability of the prior discussion, and to challenge a potentially culturally framed mode of response.

All sessions were audiotaped and then transcribed verbatim in the language of the group. Initially, the full transcripts were read without coding so that the overall themes could be understood, and homogeneity and discrepancy within groups and among sets of focus groups could be noted. Two bilingual reviewers read all transcripts and then independently developed open codes that were applied to the entire text. We firstdeveloped preliminary codes during initial transcript review. Reviewers then re-read all transcripts and sentences and phrases were coded. The "Participants' past experiences" section of each focus group required repetitive re-coding because this section yielded many diverse themes. When new codes were detected, prior text was re-reviewed. After the full text was labeled with open codes, the two coders' transcripts were compared. Discrepancies required a return to the textual elements to achieve agreement.[28] As a second step, open codes were categorized and axial codes were added. Coded passages were sorted using the "cutting and pasting" technique.[29] Codes were collected within topics, and a framework developed to identify major themes in each topic category. Lastly, one reviewer evaluated the themes within focus group sets and then compared themes across the three sets of focus groups. A second reviewer checked the analyses for coherence. We present the themes developed from each area of inquiry and compare findings across the three sets of focus groups.

## RESULTS

Most participants were over age 65, with Japanese-speaking Japanese Americans more likely than other participants to be 65 years and over, with the remainder over age 40. Half of the sample from Japan was male with a male predominance in the Japanese American groups. (Table 1)

All three groups, Japanese living in Japan, Japanese-speaking Japanese Americans and English-speaking Japanese American, described extensive experience with end-of-life decisions. Focus group participants were not reticent to discuss death, their experiences, or what these events meant to them. Table 2 summarizes the findings in the areas of interest.

### *Presenting Bad News*

Participants in all three groups indicated that talking about death and dying was not taboo in their daily conversations. Discussions were common among family members or with healthcare personnel when their lives were not threatened. Such discussions, however, did not occur with patients who were close to death. A common theme among the groups was the desire that "bad news" should be given to the patient's family before the patient. One Japanese-speaking Japanese American woman described her experience as follows:

> *When my husband... went to the doctor, he was told that he had cancer. Then he had an operation. He thought that only one region was involved. It was removed then, but in the meantime, it turned out to recur and spread, to be worse. His mother and sister also had cancer and had operations, but theirs did not spread. My husband still believed that only one region was involved. I already knew the truth, but I was not able to tell it to him.*

In contrast, direct disclosure to the patient was more common and was a more acceptable behavior for English-speaking Japanese Americans. However, even they related their dissatisfaction with physicians who informed patients directly. They felt that the family should be informed first and then family members would share the appropriate information with the patient. One English-speaking Japanese American woman related the following:

> *I rather that the doctor talk to my husband, and my husband could talk with other members of the family. I think that my husband would evaluate whether it is the right thing to tell me or not.*

Another English-speaking Japanese American stated:

> *In general, people are expected to be told. But in my feeling, and Japanese culture, a lot of families don't want to tell this person such bad news."*

Compartmentalizing information was important not only to protect patients from bad news, but also because information was needed by the family in order to make decisions. An important role of familial decision-making was to decide how much information a patient should receive. One participant in Japan related his experience:

*[When my wife had cancer,] her physician disclosed the diagnosis to my son and me first. He asked us whether he should tell her that she had cancer. We discussed together and answered not to tell her the truth. Because we knew she was a sensitive person, she would be so surprised if she knew the truth. Our physician accepted our preference and did not tell anything to her.*

### ***Attitudes Toward End-of-life Care***

Participants in all three groups idealized their end-of-life process as *pokkuri* which means in Japanese "popping off" or "dying suddenly without prolonged suffering." Dying should occur without a troublesome end-of-life process. Thus, nearly all participants expressed negative feelings toward living in adverse health states. Nonetheless, they focused minimally on personal suffering. Instead, participants in all three groups were concerned about becoming a burden on their family, using the term *meiwaku*. Both Japanese and Japanese-American participants focused on the level of caregiving burden that would be borne by their families, and all groups expressed a strong unwillingness to burden others. One Japanese participant stated this attitude as follows:

> *If the patient remains unconscious like an only-breathing dead body, family members have to stay with him at the expense of their huge sacrifice during that time. It is a lot of burden, every morning, evening, midnight. I think the recent progress of medicine has created tragic cases in some ways.*

Another Japanese participant stated:

> *[When I have a terminal illness] I strongly do not want to put a severe strain on my family. I do not want to give them hard pain. Therefore, I want to reject life-sustaining treatment....*

While the Japanese group expressed such burdens in terms of the family's physical and mental caregiving responsibility, Japanese American groups often expressed family burdens in financial terms. One English-speaking Japanese American participant said:

> *One of [the values] is not bothering [other] people.... When you are living there, if you know every day you're there it is very expensive. Somebody has got to pay for it. If your children are having to, it's coming out of their inheritance or they are having to pay for it...*

### *Preferred Decision-making Model*

Concerning the preferred decision-making model for end-of-life care, all groups we studied preferred a group-oriented (particularly a family-oriented) model. This model resulted in decision-making by a consensus among the physician and the family, and at times, the patient. All groups rejected a decision-making model focusing purely on an autonomous individual. One Japanese-speaking Japanese American stated,

> *[The decision maker] should not be one person. If you have four or five family members, they should equally discuss and decide.*

An English-speaking Japanese American remarked similarly,

> *[One group] really can't make the decision because they don't have the decision endorsed by everyone in the family.*

In making a group decision, all sets of focus group participants desired some degree of familial control of information flow to the patient, particularly when the news was very bad, such as revealing a fatal prognosis. Although decision-making was centralized in family consensus across all groups, there were some differences concerning who should be the principal decision-maker and how much information should be disclosed.

Generally speaking, the Japanese focus group participants wanted end-of-life decisions to be made by the physician with the family's input. They permitted the physician to make the final decision, but they expected the decision to incorporate the family's perspective. However, there were repeated expressions of concern that physicians overrule family decisions. One Japanese focus group participant said,

> *I believe that my family will convey my wishes on my behalf even if I can't speak anymore. But eventually, when my family's wishes and the doctor's opinion conflict, we may have to obey the doctor's opinion...*

Dissatisfaction with aggressive life-sustaining treatment and excessive physician paternalism punctuated many of the Japanese focus group discussions. Another Japanese participant stated:

> *Once we are hospitalized, we hesitate to talk about our own preferences.... There is an atmosphere that we have to obey the physician's opinion. So when a doctor gives his or her suggestions, we have to say 'Yes, please.'*

Another Japanese participant expressed his frustration with his physician:

*My mother had bile duct cancer, and in the end she was inserted with tubes. And even if she insisted that she did not want to [have any more tests], she was forced to have laboratory tests. I have never forgotten the scene. I will never be able to forgive those doctors. It's more than ten years since then, but I hate to recall that, even now.*

On the other hand, the two sets of Japanese American groups described more of a partnership role for the physician in end-of-life decisions and never raised the issue of paternalistic behavior. One Japanese-speaking Japanese American woman described her experience in this way:

> *[My husband] existed like a vegetable. He was on many life-prolonging machines. The doctor called us, and we -- I and my son and relatives -- discussed together. Finally the doctor and our family reached the same opinion. We were sure that our Dad did not want to live with such machines.*

English-speaking Japanese Americans retained a family-oriented decision-making model, but focused more on the patient's role, particularly if the patient was young or long-term care was required. They more often accepted the patient's participation in the discussion, and at times even welcomed the patient as a main decision-maker.

In increasing the patient's role in decision-making, both sets of Japanese American groups advocated more information disclosure to the patient compared to the Japanese focus groups. In this way, the patient could be more involved in the decision-making process. However, even the English-speaking Japanese American groups often felt that the family should decide whether the patient should play a role in decision making. An English-speaking Japanese American said:

> *I think [the decision is made] usually in the family. In the discussion with them, maybe they will decide on whether the patient enters into the discussion....*

*Attitudes About Advance Directives*

Participants in all three groups accepted the concept of advance care planning for terminal illness. However, there was universal concern that advance directives might conflict with the expected role of family members in end-of-life decision-making. This contradiction was expressed poignantly in the dissonance between what participants would want for themselves and what they would want for loved ones. Nearly all participants rejected aggressive treatment for themselves in the setting of future terminal illness. Nevertheless, they desired that a loved one should be kept alive, even if they knew that this individual's explicit wish was to forgo aggressive care. While most participants accepted that the family would override the patient's preference under these circumstances, there was profound ambivalence. Focus group participants were concerned about the conflicts caused by these feelings. Many Japanese participants described this feeling in terms of *kazoku no jo*, which denotes the family's requirement to act in a benevolent fashion toward the patient:

> *Even if the patient's will is clear, it is hard for the family to withdraw treatment - this is kazoku no jo [benevolence of family].* (Japanese participant)
>
> *As family members' jo, we'd like to do our best to give any treatment that we can for our loved one.* (Japanese-speaking Japanese American)
>
> *You don't want your mom to die. Even if she is just a vegetable, she is still something [to family members], no matter what you say.* (English-speaking Japanese American)

Notably, these similar attitudes translated into vastly different behaviors concerning advance directives between the Japanese groups and the Japanese American groups. The Japanese groups were reluctant to give power to advance directives and they disliked the concept of written documents. In addition, they voiced reluctance to involve lawyers and hospitals in end-of-life decisions. A Japanese participant related the following reasoning:

> *I do not want too much [life-sustaining treatment]... I want to be allowed to die as naturally as possible. But, things like this, can we request the doctor [to let us die naturally] after we lose consciousness? No, we can't.... So what shall I do? You may say if I write a living will, it will be only my idea. We do not follow individualism. I have my*

*family and my doctor. I don't want them to regret only because I write my will. That is what worries me most.*

In contrast, the Japanese American groups readily accepted advance directives. However, these documents were viewed not as a way to promulgate their autonomy in end-of-life care, but as a way to relieve familial burdens. Some participants said that they already had signed an advance directive.

For example, one Japanese-speaking Japanese American remarked that his reason for completing an advance directive was to reduce his family's emotional conflict over not beginning life-sustaining treatment:

> *Personally, I need to write it [advance directive] because all my family is living in Japan and I am alone in the U.S. So, in order to avoid [being] a burden on others, I would like to deal with everything related to myself. Yes, I want to leave one [advance directive].*

For some English-speaking Japanese Americans, advance directives were seen as a tool to solve the conundrum of accepting the notion that a patient's preferences should be followed while also permitting the family to act with benevolence. These participants expressed concern that family members who let a patient die without life-sustaining treatment would regret their decision even if it followed a patient's wishes.

## DISCUSSION

The findings from these 18 focus groups reveal openness toward end-of-life topics among both Japanese and Japanese-Americans. Personal experiences differed among the three sets of groups principally because of differences in disclosure of information and decision making styles. Participants in all three groups expressed traditional Japanese cultural themes concerning attitudes toward end-of-life care, but the manifestation of these attitudes in terms of decision making and advance care planning differed. Taken together, these findings suggest that Japanese values concerning end-of-life care are preserved among first and second generation Japanese Americans, but acculturation affects how these values are manifest within U.S. society.

### *Preserved Values*

Japanese cultural values appear to be preserved in the Japanese-speaking and English-speaking Japanese American groups. Such values, deeply held by the focus group participants in Japan, are largely distinct from Western views.[4, 12]

Family control of information disclosure to the patient was emphasized among all three sets of focus group participants. Most participants insisted on the provision of information to family members before informing the patient if the news was very bad. It should be noted that, even in Japan, not all bad news was withheld from patients; much information about adverse (but not terminal) diagnoses would be revealed directly by a physician to a patient.[20] For worse news, physicians and family members together decide on the appropriate level and timing of disclosure. In Japan, this remains the dominant mode of information disclosure toward the end of life.[30, 31] The demise in 1989 of the prior emperor Hirohito, who had terminal pancreatic cancer, was a typical example. The diagnosis was not disclosed to him or to the public until his death. Newspapers that prematurely reported his diagnosis were severely criticized.[32] From the perspective of a Western, autonomy-based model, such secrecy might be considered unacceptable, but Japanese and Japanese-descent Americans found this mode of privacy of information to be acceptable concerning disclosure to others. Surveys conducted in Japan show that nearly three-quarters of Japanese people would not want to disclose the diagnosis to a family member who has terminal cancer. Yet a majority of them want to be told when they have a terminal illness.[33, 34] Older Koreans in the U.S reported similar attitudes toward end-of-life decisions in a prior study. Those individuals wanted to know critical clinical information about themselves, but did not want family members to be told.[4, 35, 36]

Participants repeatedly underscored the discordance between what they would want done for themselves at the end of life and what they feel compelled to do for family members. They eschew prolonged survival in adverse health states yet they focused on the physical, psychological and financial burdens on family caregivers rather than on personal suffering. Many participants explained this feeling as "I do not want to be a *meiwaku* (annoyance) for my loved ones." Japanese Americans and Japanese alike expressed a powerful unwillingness to be a burden on their family.

The conflict between the family's preferences and the patient's will permeated all three sets of focus groups. Patients desired to reduce caregivers' burdens, whereas caregivers' responsibility according to *kazoku nojo* does not permit them to give up on a loved one, even if she or he were in poor clinical condition.[37] The participants were cognizant of this emotional conflict.

This shared value of meiwaku and the discordance with kazoku nojo leads to the most notable difference between Japanese and Japanese Americans: their acceptance of advance directives. Some Japanese Americans had completed or desired advance directives to relieve family members of responsibilities, however, the intent of the Japanese Americans differs from the autonomy model (Akabayashi 2003 >> 文献A).[38] The advance directive would function as a "proxy for the proxy," supporting and redirecting the actions of family members whose jo would prevent the withdrawal of life-sustaining treatment. This reveals that apparent acceptance of advance directives must be understood in a cultural context. For Japanese Americans, advance directives are not meant to be expressions of autonomy as much as a means to alleviate the emotional burden of family members for accepting withdrawal of the life-sustaining treatments of their loved one. Japanese participants perceived the same need, but rejected formal signed advance directives.

The notion that end-of-life decisions should be settled by group consensus of family members is another value that appears to be preserved across the three groups. Many prior studies have demonstrated that some ethnic groups in the U.S., such as Native Americans, African-Americans, Mexican Americans and Korean Americans, prefer the family unit to participate in end-of-life decisions .[4, 8, 16, 39] Most participants in this study also desired that their family members be involved in significant medical decisions. In Japanese culture, important decisions must account for how one's behavior influences others (Brannigan 1999, Morita 2004[41] >> 文献B).[40, 41] This notion derives from the Japanese respect for harmony and interdependence, rather than individual autonomy,[42] as in the Japanese proverb "[we should] make everything right with harmony".[43] This model subjugates autonomy to the more compelling value of collective well-being.

In Ruth Benedict's classical analysis, she concluded that Japanese culture is a "culture of shame".[44] "Shame" in this context meant that Japanese people tended to avoid confrontation with others. Japanese would choose preferences reflecting "our" wishes (including loved ones) rather than "my" wishes. This feeling is rooted in *enryo* (reservation) behavior, a core feature of Japanese culture.[45, 46, 47, 48] In Japanese culture, stating one's personal preferences or opinions is often regarded as ill-mannered or selfish. Priority is given to "collective welfare" rather than "individual welfare." The focus group findings suggest that these values continue to be compelling for Japanese Americans. For Japanese and many Japanese Americans, "autonomy" rests at the family level.

### *Influences of Acculturation*

Despite the preservation of cultural values and shared overall decision-making model, some attitudes toward end-of-life decision-making behavior appear to change with acculturation to mainstream U.S. culture and attitudes toward health care and autonomy (see Table 2).

First, disclosure of a terminal diagnosis became more acceptable with acculturation.

Such information, however, is still disclosed to the family, who then deliberate and may choose to give the information to the patient in due time and in the proper format. Healthcare providers need to be aware that in disclosing bad news to an acculturated Japanese American, one would not be able to predict the acceptability of disclosure without inquiring. This inquiry can usually be asked of the patient in a tactful fashion.[12, 14] Based on these focus group findings, in most cases disclosure would be directed first toward the family.

A second area of difference by acculturation is found in the decision-making model. The dominance of the physician in decision making is diminished in the U.S. where there is a less hierarchical physician-patient relationship.[30, 49, 50] While the structure of decision making retained a group-orientation, the role of the patient was more prominent among English-speaking Japanese Americans, for whom the patient played a prominent role in decision-making within the family.

Third, while all three groups accepted the concept of advance care planning, Japanese participants rejected formal advance directives. People in Japan do not wish to introduce legal mechanisms into intimate healthcare decisions that they see as the purview of the family and physician. This is consistent with the less frequent personal use of lawyers in Japan compared to the U.S..[51] Furthermore, legal documents tend to be confrontational, a posture to be avoided in Japan, and may interfere with decision making at the level of the family unit.[52]

Last, the perception of the family's caregiving obligation seems to shift to some degree with greater English-speaking comfort. Japanese-speaking Japanese Americans reported less familial caretaking expectation than the Japanese in Japan, and English-speaking Japanese Americans reported that the healthcare system would attend to long-term care. Noteworthy, however, the children of the English speaking Japanese were not included in the focus groups and therefore we do not know how much obligation the adult children of these participants may feel. Similarly, adult children in Japan were not included; changing economic conditions and urbanization in Japan may affect the propensity and ability of children to be intimately involved in the daily care of their parents at the end of life due to geographic distance and obligation to their own children. In Japan, participants still strongly held the expectation that family members would look after disabled or dying loved ones,[53] although it is not always actuated.[54] Usually, the eldest son and his wife are obligated to live with their parents and care for them. On the other hand, many Japanese American elderly remarked that they did not resist living in a nursing home or living apart from their children.[55] Often, however, this is due to reluctance on the part of the elderly to impose upon the Americanized lifestyles of their children, not because they themselves would not like to have this familial care.

## LIMITATIONS

Our qualitative study has several methodological limitations. First, the study samples were derived from limited geographic areas in Japan and the United States. Because the participants were sampled in Tokyo and Los Angeles, they represent only urban residents. In Japan the population in rural areas tends to have more conservative views than the urban population.[56] Similarly, Japanese Americans in Los Angeles are likely to be different from those elsewhere in the U.S. Japanese-Americans in Los Angeles have easy access to Japanese newspapers, Japanese associations and Japanese temples. In addition, the Los Angeles samples were recruited from Japanese agencies and organizations, thus selecting individuals with strong ties to the Japanese American community. These constraints limit the generalizability of our findings.

Second, a formal analysis of acculturation was not performed in this study and we identify acculturation to U.S. society only by primary language. Although language preference is a key component of acculturation, other factors also affect acculturation.[25, 57] Since language was the only indicator used for acculturation, the more multi-dimensional aspects of this construct were not discernable.

Third, this study was conducted among predominantly older subjects. The U.S. focus groups included few third generation (Sansei) participants. In fact, many participants pointed out that their children or grandchildren have different attitudes toward end-of-life decision making, indicating that changes will continue to occur over time.

## CONCLUSIONS AND RECOMMENDATIONS

Recognizing these limitations, we believe that we have conducted one of the first studies of the acculturation of attitudes and decision-making model concerns end-of-life care. We draw several conclusions from these data that have implications for the end-of-life treatment of Japanese and Japanese-Americans.

Universal application of an autonomy-based end-of-life decision-making model to all Japanese Americans would not conform with the cultural norms of many of these individuals.

A monolithic autonomy model would likely produce conflict among more traditional patients, families and providers, resulting in ill feelings among family and friends and perhaps suboptimal clinical outcomes. The repercussion of such experiences may subsequently deter future discussions about care at the end of life, with the family as well as other community members.

Culturally sensitive and skilled end-of-life care requires recognition that attitudes toward end-of-life care and models of end-of-life decision making are modified by acculturation. The clinician who recognizes that a patient might adhere to a non-Western model of end-of-life care can carefully explore the patient's and family's expectations and negotiate more appropriate channels for information disclosure and facilitate decision making, and when appropriate, advance care planning.[12]

Japanese health care providers should note the dissatisfaction expressed by the Japanese focus group participants toward physicians' paternalistic attitude in end-of-life decisions. Further research should explore the effect of the strongly hierarchical Japanese physician-patient relationship on the dying process for both patients and families. Other cross-cultural studies indicate similar variations among countries exist, but little study has been conducted in this area internationally.[58]

Finally, this exploratory study demonstrates the need for additional qualitative and quantitative evaluation of end-of-life attitudes and models within and between cultural groups. Understanding cultural differences and the effect of acculturation may reduce cultural conflicts and misunderstandings and lead to improved care for patients and families at the end of life.

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**Table 1**

**Description of the Three Focus Group Samples**

| | Japanese in Japan | Japanese-speaking Japanese Americans | English-speaking Japanese Americans |
|---|---|---|---|
| **Number of focus groups** | 5 | 4 | 9 |
| **Number of participants** | 28 | 29 | 65 |
| **Source of participants** | Community and clinic sites, Tokyo | Japanese housing complex and nursing home, Los Angeles | Japanese community centers and nursing home, Los Angeles |
| **Dates of focus groups** | October 1996 to January 1997 | September to December 1996 | January to March 1996 |
| **65 years or older (%)** | 71% | 84% | 52% |
| **Male (%)** | 50% | 79% | 60% |
| **Generation*** | Not applicable | | |
| ***Issei*** | | 1 | 7 |
| ***Shin-Issei*** | | 17 | 0 |
| ***Kibei*** | | 4 | 0 |
| ***Nisei*** | | 7 | 38 |
| ***Sansei*** | | 0 | 20 |

* We did not identify mixed generation participants. The participants were asked to select one of the five categories below.

*Issei* = first generation immigrants
*Shin-Issei* = emigrated after World War II
*Kibei* = born in the US, raised and educated in Japan, and then later returned to the US
*Nisei* = second generation
*Sansei* = third generation