SYMPOSIUM

A CASE OF CONFLICT OF CULTURES: END-OF-LIFE DECISION MAKING AMONG ASIAN AMERICANS

Pat K. Chew*

I. INTRODUCTION

Our culture is the “lens” through which we see the world. It provides an explanatory model for the way we think and the way we behave. It indicates our values and norms, even when we are not deliberately thinking about them. It shapes the logic we have for explaining life experiences and influences our decision making. Culture is especially relevant during key life events, such as births, marriages and deaths. Culture is clearly salient during end-of-life decision making.

This essay presents a case example of a conflict between two cultures. One culture is the U.S. mainstream culture, as illustrated in a federal statute, the Patient Self-Determination Act. This statute provides legal guidelines for health care providers dealing with individuals’ end-of-life decision making. Lawyers and health care providers refer to these guidelines in their counseling and treatments, apparently assuming that these guidelines are in the best interest of those they serve. The other culture is Asian American culture and its approach to end-of-life decision making. As this es-

* Judge J. Quint Salmon and Anne Salmon Chair and Professor of Law, Distinguished Faculty Scholar, University of Pittsburgh School of Law.


3 The Patient Self-Determination Act is found in the Omnibus Budget Reconciliation Act of 1990, §§ 4206, 4751. It has been codified at 42 U.S.C. §§ 1395cc(a)(1)(Q), 1395mm(c)(8), 1395cc(f), 1396a(a)(57), (58), 1396a(w) (2011).
say will discuss, Asian Americans have strong and long-established beliefs, values, and priorities that are relevant to end-of-life decision making. Some of these cultural norms may be contrary to U.S. mainstream culture, thus creating a conflict between two cultures.

Understanding the role of culture in the United States is especially timely today and will become increasingly so. The country is becoming more racially and ethnically diverse, and hence more culturally diverse. This demographic shift toward diversity has taken place predominantly in metropolitan areas and is fueled largely by the growth of the Hispanic and Asian populations. Together these groups account for approximately 60% of the population growth in the last decade. For example, 29 of the 100 largest metro areas doubled their Hispanic populations, with Mexican-Americans being a major contributor to this trend. A full one-third of all Asian Americans live in three cities: New York, San Francisco, and Los Angeles.

Furthermore, there are dramatic differences in the racial composition of older versus younger Americans. While there is less racial diversity among older Americans, younger Americans are more racially heterogeneous. Consider that 49.8% of children under one year are of a racial or ethnic minority. This suggests that in the not-too-distant future, racial minorities will emerge as the majority population.

II. Asian American Culture

This essay focuses on Asian American culture in end-of-life decision making. However, determining what constitutes Asian American culture is challenging. There are numerous subgroups based on ancestry within the Asian American population, each with its own distinctive characteristics. As shown below, the larg-

---


5 Dougherty, supra note 4.

6 Id.

7 Id.

8 Id.

9 Id.
A CASE OF CONFLICT OF CULTURES

est is Americans of Chinese descent, representing almost a quarter of all Asian Americans. There is also substantial representation from those of Asian-Indian, Filipino, Vietnamese, and Korean backgrounds. Chinese Americans are concentrated in certain large metropolitan cities, while Asian-Indian Americans are more widely dispersed.

<table>
<thead>
<tr>
<th>Asian American Groups By Ancestry</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chinese</td>
</tr>
<tr>
<td>Asian-Indian</td>
</tr>
<tr>
<td>Filipino</td>
</tr>
<tr>
<td>Vietnamese</td>
</tr>
<tr>
<td>Korean</td>
</tr>
<tr>
<td>Japanese</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

There are also variations within each Asian American subgroup. For instance, Chinese Americans have different attributes. They may be of different generations, level of acculturation, gender, sexual orientation, educational level, religion, and geographical location, all which may affect their cultural values. At the same time, individuals may identify with multiple cultures or emphasize certain cultural practices in some situations but not in others.

Further, there is ambiguity over how to determine these attributes. The degree of acculturation, for example, is difficult to measure. One proxy for acculturation to U.S. norms is language acquisition. Thus, one can distinguish between Japanese-Americans who speak primarily English, Japanese-Americans who speak primarily Japanese, and Japanese in Japan—with the assumption that the first group is the most acculturated. Another approach is identifying when an Asian American immigrated to the United States—with the assumption that those who immigrated long ago are more acculturated than those recently immigrated. Thus, one can distinguish between someone who was born in Japan but immigrated to the United States (first-generation Japanese American

10 Id.
“Issei”), someone who is born in the U.S. (second-generation Japanese American “Nisei”), and someone who is born in the U.S. to second-generation parents (third-generation Japanese American “Sansei”). Some researchers make even further distinctions, such as someone who was born in Japan but immigrated to the U.S. at a very young age (“1.5 Japanese-American”).

III. Standard U.S. Professional Advice

Lawyers’ and health care providers’ standard professional advice regarding end-of-life planning and decision making is captured in the Patient Self-Determination Act. This federal statute requires certain health-care facilities receiving Medicare or Medicaid funds to advise all patients of their rights under state law to execute advance directives. Advance directives are written instructions for end-of-life care when an individual is incapacitated. Advance directives are usually captured in legal documents such as a living will or durable power of attorney for health care. The Act also provides for a national campaign to “inform the public of the option to execute advance directives and of a patient’s right to participate and direct health care decisions.”

A close reading of the statute and other commentary on the statute indicates that the law is based on interrelated values and principles:

- **Advance planning**, including advance care directives, is encouraged. Advanced directives empower people to be better informed and more active in their end-of-life decision making. Giving notice of one’s wishes ensures that health-care providers will respect the patient’s wishes. Wide-spread advance planning by patients may also result in less drastic medical treatments, yielding overall cost benefits in the health care system.

14 42 U.S.C. §§ 1395cc(a) (2011), see also supra text accompanying note 3.
15 Id. at § 4206(a)(3).
16 Id. at § 4751(d)(1).
Patients should be well-informed so they can exercise their decision making rights. Patients who are well-informed about advance directives would also be more likely to execute advance directives, thus exercising their personal autonomy.

Patient autonomy is an important right. Individuals should make their own end-of-life decisions.

Communications dealing with end-of-life decision making between the clients and their lawyers and health-care providers should be as clear as possible. In the U.S., clear communication is presumed to occur through literal and transparent communications, as captured by the adage “Say what you mean, and mean what you say.” Effective communication helps clients be well informed, so they can exercise personal autonomy in their advance directives and end-of-life decision making.

IV. CONTRASTS BETWEEN STANDARD ADVICE AND ASIAN AMERICAN CULTURE

What if standard U.S. advice, as exemplified in the Patient Self-Determination Act and its underlying principles and values, and Asian American cultural values and practices on end-of-life decision making differ? Medical anthropologists and other scientists have studied Asian Americans cultural attitudes and norms in end-of-life decision making.18 In some studies, the population sample is Asian Americans of a particular ancestry, most typically East-Asian Americans of Chinese, Japanese, or Korean ancestry. In fewer studies, the population is a cross-section of different Asian American subgroups. Thus, while this article, out of convenience, uses the term “Asian American,” the author recognizes the limitations and cautions in generalizing from studies of some Asian American subgroups to Asian Americans more generally. When-

ever possible, the particular ancestry of the study population is identified.

As the following discussion substantiates, there are numerous examples of Asian American cultural practices and values conflicting with standard U.S. advice on end-of-life decision making:

A. Standard U.S. advice is to encourage an individual’s advance planning and advance care directives, but what if Asian American culture is contrary to this advice?

Advance planning and executing advance care directives require that lawyers and health-care providers help their clients and patients become fully aware of, and informed about, advance care options and carefully plan and execute the necessary arrangements and documents. These activities are not effectively achieved if clients and patients do not want to meaningfully discuss with their lawyers and health-care providers the relevant issues and options.

Effective communication on these topics is challenging and realistically infeasible for some Asian Americans, notably those who adhere to traditional Chinese beliefs. While discussion of death may be uncomfortable in many cultures, traditional Chinese beliefs take this attitude to more of an extreme, viewing death and ill health as taboo topics.\textsuperscript{19} Death is considered mysterious and frightening. It is considered impolite and bad luck to discuss. One example of this ongoing custom in Asian culture is illustrated in the research that life insurance companies who want to successfully enter the China market conduct.\textsuperscript{20} They have found that this taboo on discussing death and ill health makes it very difficult to raise the topic of buying life insurance with prospective Chinese customers.

The Chinese also distinguish between a “good death” and a “bad death.”\textsuperscript{21} A good death is one in which an individual lives a long time after having lived a full and dignified life, ideally filled

\begin{itemize}
  \item[20] \textit{Chan, supra} note 19 (detailing social and economic barriers to Chinese life insurance market, given ingrained Chinese cultural taboo on topic of death).
  \item[21] \textit{Id.}
\end{itemize}
with many descendants and prosperity. A bad death is one that occurs unexpectedly and prematurely, precipitated, for instance, by an accident, disease, or sudden illness. The most superstitious fear is that these individuals were cheated out of long and healthy lives and therefore turn into “hungry ghosts” menacingly lurking around. Even if one does not believe in these superstitions, this engrained belief of death as a taboo subject shapes Chinese-American behavior. It renders discussion of possible death and particularly premature death as contrary to cultural customs and thus socially offensive.

Other Asian American groups have varied attitudes toward advance planning. One study of four groups of Asian Americans’ attitudes toward advanced directives found contrasts. Filipino Americans were not comfortable with “planning for death,” although those who had lived in Hawaii were familiar with advance directives. Vietnamese Americans were familiar with the concept of advanced directives. As Chinese Americans became more acculturated, they were also more accepting of advance planning. Finally, Japanese Americans were comfortable in discussing advanced planning, perhaps because Buddhist ideology encourages discussions of death. Other studies of Japanese-Americans indicated more comfort with discussing advance planning, particularly if they thought it would relieve their family’s burden and as they became more acculturated.

B. Standard U.S. advice is to have a well-informed patient, but what if Asian American culture is contrary to this advice?

Standard U.S. advice is to fully inform patients about their condition and possible treatments so that they have maximum information for deciding how to proceed. However, Asian American cultures have different priorities. They strive to protect patients by not “telling the truth.” The belief is that telling patients an especially dismal prognosis, for instance, only creates unnecessary suf-
ferring and pain for patients.\textsuperscript{28} It may even be that telling them the truth about a dismal diagnosis may hasten their death because of the discomfort and angst that news creates. Thus, not telling patients the truth may be a way to prolong their lives. As described by a Korean-American’s decision to not disclose his wife’s cancer diagnosis: “We kept it a tight secret . . . If she knew, she would not be able to live longer because of the fear.”\textsuperscript{29}

Studies of Japanese-Americans indicate variations on presenting patients with “bad news,” depending on the level of acculturation.\textsuperscript{30} Matsumura and his colleagues, for instance, found that more acculturated patients had a stronger desire for disclosure of bad news.\textsuperscript{31} They also found, however, wide variability within groups of the same acculturation level.

C. \textit{Standard U.S. advice is to maximize the patient’s autonomy in decision making, but what if Asian American culture is contrary?}

In standard U.S. practice, patient autonomy is a priority in end-of-life decision making. In Asian American culture, however, the family and not the individual is the primary decision maker.\textsuperscript{32} This is a persistent cultural preference among Chinese Americans, Korean Americans, and Japanese Americans. The belief is that family members should collectively share the difficult decision making prompted by end-of-life issues, and that the family should intentionally not burden the patient. Thus, the family, not the individual, should receive the pertinent information and decide what is best for the collective interest.

In one study of Japanese-Americans by Bito and colleagues, the researchers grouped the study participants by level of acculturation, thus distinguishing between Japanese who were born in Japan and living in Japan, Japanese-Americans who spoke primarily

\begin{itemize}
    \item \textsuperscript{28} \textit{Id}, at 2997 (describing various studies indicating families’ opposing full disclosure of medical information).
    \item \textsuperscript{29} Leslie J. Backhall, et al., \textit{Bioethics in a Different Tongue: The Case of Truth-telling}, 78 J.\textit{ Urban Health} 59 (2001).
    \item \textsuperscript{30} Matsumura, \textit{supra} note 18, at 533-35; Bito, \textit{supra} note 12, at 254-55.
    \item \textsuperscript{31} Matsumura, \textit{supra} note 18, at 533-35.
    \item \textsuperscript{32} Kagawa-Singer & Blackhall, \textit{supra} note 18, at 2994, 2998; Bito, \textit{supra} note 12. \textit{See also} Kwak & Haley, \textit{supra} note 18 (finding that Asians and Hispanics were more likely to prefer family-centered decision making).
\end{itemize}
Japanese, and Japanese-Americans who spoke primarily English.33 There were some cultural variations across these three groups, but there were also some persistent similarities. Both Japanese-American groups preferred the family to be the primary decision maker. The groups varied on the role of the patient and the physician. The Japanese-speaking Japanese Americans were more deferential to the physician; the English-speaking Japanese Americans thought the patient could participate in the decision making.

D. Standard U.S. advice is that lawyers and health-care providers should have literal and transparent communications with their clients and patients, but what if Asian American culture is contrary to this advice?

The common assumption is that it is best for all concerned to fully discuss in appropriate detail the medical diagnosis and the range of alternatives around end-of-life decisions. Literal and transparent communications between lawyers and their clients and health-care providers and their patients is presumed optimal, so that patients will have a clear understanding of all the relevant information.

Asian Americans, however, are less likely to be literal and transparent communicators. Instead, they are more likely to use high-context communications.34 This means that what they say has to be understood within the context in which they say it. Asian American cultures tend to have implicitly understood values, expectations of appropriate behavior, and important nonverbal cues. In these ways, Asian Americans are less verbally expressive, although the communication between individuals in this culture is well understood. To illustrate, the Chinese term “Zhih Yi” denotes nonverbal communication, “just knowing what the other thinks and feels;” the Japanese term “inshin denshin” denotes a similar concept of knowing without being told; and the Korean word “nunchi” denotes understanding through social, nonverbal cues.”35
What if Asian American patients want to know more about their medical condition? Given the cultural sensitivities about “truth-telling” discussed earlier, it is important to consider how patients learn about their situation. In Asian American cultures, learning “the truth” more indirectly, euphemistically, delicately, or nonverbally may be preferred over direct literal communication.\textsuperscript{36} Indirect communication may also help the family and the patient minimize embarrassment and honor, thus “saving face.”\textsuperscript{37} Matsumura and his colleagues explain that Japanese culture particularly emphasizes in end-of-life care a “tacit agreement based on implicit communication ("ishin-denshin") with extensive use of nonverbal cues, such as silence, pauses between words, eye-contact, affective posture, and nuance and tone in communication about unrelated topics.”\textsuperscript{38}

Given these communication practices, non-Asian American professionals’ literal and transparent communication styles may be misunderstood and offensive to their Asian American clients. At the same time, the Asian Americans’ more indirect high-context communication style may incorrectly signal to their lawyers or health-care providers that they have no questions or unresolved issues, when in fact they do.

Research also indicates Asian Americans’ general foci in their communications. When end-of-life is threatened or imminent, Asian Americans are more other-focused.\textsuperscript{39} Euro-Americans tend to be more internally focused, dwelling on whether or not they lived a good life, the meaning of their life, and what their legacy will be. In contrast, Asian Americans tend to be more concerned about whether or not their family and significant others will be overly burdened, happy, or taken care of during the crisis period that precedes their death and the transition period after death. As in their lives more generally, Asian Americans sense of self is tied to those of other people, particularly those in their families and in-group.\textsuperscript{40} Social science research also indicates that Asian Ameri-
cans have a distinct ideal affect. Ideal affect is an individual’s preferred emotional state. Social science research indicates that Asian Americans are more likely to prefer a harmonious and calm emotional state. In contrast, Euro-Americans prefer a state of more variety and excitement. Thus, Asian Americans’ verbal and non-verbal communications should be put in the context of them being more other-focused and desiring a calm state.

V. CONCLUSIONS AND IMPLICATIONS

This case analysis of Asian American culture in end-of-life decision making illustrates a more general point. Given the increasing racial and ethnic diversity in the United States, professionals should be sensitive to the possibility of conflict between mainstream U.S. norms and the values and practices of Americans of minority backgrounds. While this essay explores Asian Americans in end-of-life decision making, similar inquiries about cultural values should be asked of other groups, including African Americans, Hispanic Americans, and Native Americans.42

By studying distinctive practices and values of some Asian American groups, this essay has identified the following cultural practices. These practices appear to conflict with mainstream U.S. culture, as suggested in the federal law, the Patient Self-Determination Act:

- Advance planning activities, such as the use of advance care directives, may be sensitive and even taboo. Conversations about death may be viewed as impolite or bad luck.
- Professionals’ full disclosure to the patient of her or his medical prognosis may be considered harmful. Out of love, protection, and respect for the patient, families and others not “telling the truth” may be preferred.
- The family, not the patient, should be well-informed about the medical diagnosis and alternative medical treatments. The family, not the individual, is guiding the decision making at end-of-life.

---

41 Jeanne L. Tsai, Ideal Affect: Cultural Causes and Behavioral Consequences, 2 PERSPECTIVES PSYCHOL. SCI. 242 (2007); Jeanne L. Tsai, et al., Influence and Adjustment Goals: Sources of Cultural Differences in Ideal Affect, 92 J. PERSONALITY 1102 (2007).
42 See Kwak & Haley, supra note 18 (describing research on a range of racial groups including African Americans, Hispanics, Native Americans, Asian Americans, and Whites).
There are distinctive communication patterns in Asian American cultures that are neither transparent nor literal, at least as compared to mainstream American communication patterns. Asian Americans tend to be more contextual, indirect, and focused on others. These communication styles may well occur in end-of-life care decision making.

While lawyers and health-care professionals should be sensitive to distinctive cultural practices and values of Asian Americans and other minority groups, they should also be cautious about generalizing from a group’s characteristics to the individual client or patient. As described by Kagawa-Singer and Blackhall, professionals being “culturally skilled” takes care: “Assuming a Chinese woman would not want to be told of her diagnosis because she is Chinese is stereotyping. Insisting that she must be told, even at the risk of violating her rights, is a form of cultural imperialism. The challenge is to navigate between these poles.”

Kagawa-Singer and Blackhall offer specific questions and strategies for gathering the relevant information for ascertaining a particular individual’s culture in end-of-life decision making. They organize these questions around five dimensions of the patient and her or his family: (1) their attitudes about death, dying, and truth-telling; (2) their spiritual beliefs about death, the afterlife, and miracles; (3) the historical and political context of the patient’s life, including their immigration and acculturation experiences; (4) their preferred decision making in general and particularly involving the patient and family; and (5) the available resources, such as translators or community and family members, to interpret the cultural dimensions of this case.

Finally, explorations of cultural conflicts are not just abstract discussions: ideally, they help lawyers and health care professionals provide higher-quality services and more humane care. As the Kagawa-Singer and Blackhall framework above suggests, there are practical strategies for being culturally skilled about clients and patients. With this knowledge, professionals can help their clients
navigate legal and institutional requirements in ways that are more in sync with their cultural preferences. They can also help them exercise all their degrees of freedom in end-of-care decision making so that any cultural conflicts are resolved in ways that best attend to the clients’ needs.

decisions. When there is important medical information and decisions to be made, should I first come to speak with you alone, or to only your family, or everyone together?” This approach helps the physician respectfully gather the necessary information on preferred cultural preferences for end-of-life care. Matsumura, supra, note 18.