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Top Ten Tips Palliative Care Clinicians Should Know About Caring for Chinese American Patients

Cynthia X. Pan, MD,[1] Esther J. Luo, MD,[2] Eric Wang, BS,[3] Deborah A. Szeto, MSN, RN,[4] Hillary Lum, MD, PhD,[5] Jessica Ma, MD,[6,7] Sandy Chen Stokes, RN, MSN,[8] Sandy Chan, LCSW, APHSW-C,[9] Christian Wong, DO,[10] Jing Guo, MD,[11] Lifeng Wang, BCC,[12] Victor Chang, MD,[13,14] and Robert S. Crupi, MD[1]

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Abstract

The Chinese American population is one of the fastest-growing communities in the United States, composed of ~5.4 million people, and represents ~5.5% of overseas Chinese populations. With an expected exponential population rise, Chinese American patients who experience serious illness or approach end-of-life (EOL) may find their cultural values influencing the medical care they receive. Palliative care clinicians must recognize diverse cultural beliefs and preferences of Chinese American patients and their families. In this study, we provide 10 cultural pearls to guide the provision of palliative and EOL care for Chinese American patients, including discussions of Chinese traditions, communication strategies for Chinese patients and families, advance care planning, and EOL care beliefs.

Keywords: advance care planning; Chinese American; communication; end-of-life; filial piety; goals of care; palliative care

Introduction

Chinese persons comprise the largest population in the world, with China's population at 1.4 billion as of 2020. The ''Chinese Diaspora'' includes people born in China but who are living outside of China as well as those who identify as Chinese based on language or ancestry. The Chinese American population is one of the fastest growing communities in the United States, composed of ~5.4 million people, representing about 5.5% of overseas Chinese population. About 62% of Chinese living in the United States are foreign born, with varying degrees of acculturation. Chinese

[1]Division of Geriatrics and Palliative Care Medicine, Department of Medicine, NewYork-Presbyterian Queens, Weill Cornell Medicine, Flushing, New York, USA.
[2]Outpatient Palliative Care, Supportive Care Services, Kaiser Permanente, Santa Clara, California, USA.
[3]Division of Geriatrics and Palliative Care Medicine, Department of Medicine, NewYork-Presbyterian Queens, Flushing, New York, USA.
[4]Inpatient Palliative Care, Supportive Care Services, Kaiser Permanente, Santa Clara, California, USA.
[5]Division of Geriatric Medicine, Department of Medicine, University of Colorado School of Medicine, Aurora, Colorado, USA.
[6]Geriatric Research, Education, and Clinical Center, Durham VA Health System, Durham, North Carolina, USA.
[7]Division of Internal Medicine, Department of Medicine, Duke University School of Medicine, Durham, North Carolina, USA.
[8]Chinese American Coalition for Compassionate Care (CACCC), Shingle Springs, California, USA.
[9]Department of Palliative Medicine and Geriatrics, Stanford Health Care. Palo Alto, California, USA.
[10]Department of Medicine, Albany Medical Center, Albany, New York, USA.
[11]Division of Hospital Medicine, Department of Medicine, NewYork-Presbyterian Queens, Weill Cornell Medicine, Flushing, New York, USA.
[12]Department of Pastoral Care and Education, NewYork-Presbyterian Queens, Flushing, New York, USA.
[13]Section Hematology/Oncology, Medical Service, VA New Jersey Health Care System, East Orange, New Jersey, USA.
[14]Division of Hematology Oncology, Department of Medicine, Rutgers New Jersey Medical School, Newark New Jersey, USA.
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Americans are a heterogeneous group with different geographical, cultural, educational, socioeconomic, and dialect backgrounds. Chinese Americans may come from mainland China, Taiwan, Hong Kong, or other countries such as Singapore and Malaysia. Other than place of origin, Chinese Americans may also hold different religious or philosophical beliefs, including Taoism, Confucianism, Buddhism, Islam, and Christianity.[1,2]

Accompanying the rapid growth of the Chinese population is the number of people facing serious illness. The three leading causes of death for Chinese Americans are cancer, heart disease, and stroke.[3] To meet the diverse needs of Chinese Americans living with serious illness, and their families, palliative care (PC) clinicians must embrace cultural humility. Understanding cultural beliefs within the Chinese patient-family structure is an important step before engaging in medical discussions related to PC. Serving as a cultural navigator, this article introduces 10 cultural tips and pearls to be mindful of when caring for and having conversations with Chinese American patients and their families living with serious illness about advance care planning (ACP), goals of care (GOC), and end-of-life (EOL) care (Table 1).

Tip 1: Because Relationship, Harmony, and Reliance Within the Family May Supersede Autonomy, Advance Care Planning Needs to Identify the Family Hierarchy and Elicit the Patient's Desire to Participate in Decision Making

Many Chinese American families prioritize input from key family members over decisions of the patient. As a result, ACP needs to identify the hierarchy of decision making in the family. The hierarchy may prefer the parents, oldest son, or may prioritize a health care provider who is part of the family, even if they are younger or more distant. Relationships, harmony, and mutual reliance within the family are important cultural considerations.[4] At the same time, providers must always assess the patient's understanding of his/her medical condition and interest in participating in medical decision making, encouraging all voices to be heard.

Some family members may be reluctant to discuss taboo subjects to avoid disrupting family harmony.[4] Therefore, a facilitated, indirect approach to early ACP may be beneficial (see Tip 2). A useful platform may be the Heart to Heart (HTH) Cards and HTH Cafes in Chinese community settings.[5,6] Both provide safe tools for starting conversations about EOL planning and preferences related to spiritual, physical, financial/legal, and social needs.

Family meetings, where the health care team can build trusting relationships with the family, can also facilitate discussion of sensitive ACP issues. Bringing in team members who may know the patient and family better than the health care provider can be especially helpful. There will often be a sense of relief from direct conversations that happen in family meetings. Providers can help relieve the burden of GOC conversations by serving as facilitators, remembering that conversation is the key to understanding and clarifying one's EOL needs and preferences.

Tip 2: Acknowledging That Traditional Filial Piety Can Influence Families to Pursue Intensive EOL Treatments That Conflict with the Patient's Desire for Comfort-Focused Care Can Build Respect and Decrease the Medical Team's Moral Distress

Filial piety, Xiàoshùn (孝顺), is one of the most important Chinese virtues. To be filial is to respect one's parents, elders, and ancestors, and to do ''everything'' for them. Its reciprocity speaks specifically to the parent-child relationship. Parents provide for their children with food, money, shelter, and education. In return, children are expected to care for their parents when they become old and/or ill.[7] When Chinese patients experience serious illness, family/surrogates may perceive continuing life support as fulfilling one's filial responsibilities and be praised by societal norms.[8]

Table 1. Top Ten Tips for Palliative Care Clinicians Who Care for Chinese American Patients

Tip 1	Because relationship, harmony, and reliance within the family may supersede autonomy, advance care planning needs to identify the family hierarchy and elicit the patient's desire to participate in decision making.
Tip 2	Acknowledging that traditional filial piety can influence families to pursue intensive EOL treatments that conflict with the patient's desire for comfort-focused care can build respect and decrease the medical team's moral distress.
Tip 3	In contrast to a more direct American/Western approach, discuss advance care planning with Chinese patients using indirect approaches to avoid offending the patient and family.
Tip 4	Use interpreters to discuss sensitive topics such as EOL care and to accurately describe palliative care and hospice care.
Tip 5	Chinese American patients may hold cultural values or preferences that can affect medical care, including beliefs about the taboo of talking about death.
Tip 6	As individuals, Chinese American patients hold a range of preferences and goals of care regarding EOL interventions.
Tip 7	Providing food at EOL represents filial responsibility, hope, and expression of affection.
Tip 8	Many Chinese American patients are open to hospice care if explained in a practical way.
Tip 9	Engage chaplaincy to help support patients through using plain language and a practical approach when introducing the service.
Tip 10	Chinese culture inherently respects physicians, so it is important for clinicians to build a trusting relationship, provide a safe space to discuss difficult topics or mediate conflicts, and feel comfortable making medical recommendations.

EOL, end-of-life.

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Traditional filial piety is rooted in Confucian philosophy, as is maintaining harmony and respect. Family constitutes the foundation of most Chinese Americans' value. In contrast to the American culture, major medical decisions are made by the family unit rather than by the individual.[4] This can result in decisions that seem to override the individual patient's preferences, with the acceptance of the patient.

In the context of EOL care, it is common to have families override the wishes of the patient. For example, the patient may prefer to stop artificial nutrition and die at home but the family may want to do everything to prolong the patient's life, including continuing artificial nutrition, as part of fulfilling their filial duties. Initiating ACP discussions and forgoing aggressive treatments may be viewed as being unfilial and may result in disapproval from their community. However, it is important to remind family members that reducing suffering is also a filial act.

Clinicians should acknowledge the respect and filial piety demonstrated by the family, and frame serious illness discussions as ways to fulfill some of their filial responsibilities. For example, if the patient prefers to stop artificial nutrition and die at home, clinicians can reframe that being filial means to honor the patient's wishes, encourage comfort or pleasure feeding with their favorite foods (rather than artificial nutrition), respect the patient's wish to be at home, and offer home hospice care as an extra layer of support.

Tip 3: In Contrast to a More Direct American/Western Approach, Discuss Advance Care Planning with Chinese Patients Using Indirect Approaches to Avoid Offending the Patient and Family

Many Chinese American patients have favorable attitudes toward ACP, but may also have cultural concerns about filial piety and disrupting family harmony by discussing death and dying. Consequently, many Chinese American patients prefer having providers initiate ACP conversations rather than having to bring the topic up themselves.[9,10] To promote engagement, it is helpful to frame ACP with less focus on autonomy and more emphasis on a way to reduce family disharmony or burden/suffering while promoting filial piety.[11–13] Acknowledging taboos and asking permission to initiate such discussions is recommended.[14] Providers can assess patients' readiness to engage by noting attitudes, verbal and nonverbal communication cues, and using clinical judgment.[14]

Communication strategies for Chinese populations promote indirect approaches.[10] This aligns with a well-known Chinese proverb ''Yīqiè-jǐn-zài-bù-yán-zhōng'' (一切尽在不言中), which means ''Everything is in the unspoken.'' Some strategies include the following: (1) asking patients to discuss their perspectives on another person's EOL experiences; (2) when using hypothetical scenarios, ask for patients' opinions rather than directly asking about their preferences; (3) using the provider's personal experiences to start ACP conversations; and (4) normalizing discussions by stating they are required by hospital policy or state law.[15]

Because of sensitivity around EOL within Chinese culture, utilize an indirect approach when engaging Chinese American patients and families in ACP discussions. Additional strategies include the following: (1) referencing traditional proverbs to help patients make sense of their illness; a well-known proverb is ''shēng-lǎo-bìng-sǐ'' (生老病死), which means ''the life cycle of birth-aging-sickness-dying''; (2) using nonverbal cues, such as silence/pausing, and gesturing with head nods/shakes, rather than giving detailed explanations, to illustrate the gravity of the situation; and (3) inviting family members to step outside the room to convey a sense of seriousness.

Tip 4: Use Interpreters to Discuss Sensitive Topics Such as EOL Care and to Accurately Describe Palliative Care and Hospice Care

Only 1.8% of Medicare hospice patients in the United States were Asian in 2018.[16] Many Asian patients lack English language proficiency, making them vulnerable to health disparities. The use of professional interpreters can help diminish those disparities by increasing patient satisfaction, improving adherence and outcomes, reducing adverse events, and limiting malpractice risk.[17,18]

Many Chinese American patients speak different Chinese dialects. For example, clinicians who speak Mandarin may not be able to effectively communicate with Cantonese-speaking patients. While the dialects display verbal/sound/tonal and colloquial differences, most of the written characters remain similar and provide the basis for an alternative option for communication.

In the PC setting, using trained interpreters can reduce the potential for misunderstanding when conveying serious illness information, and may obviate the family member from the distressing role of breaking bad news. Because of the sensitive nature of EOL conversations, it is not recommended for family members to serve as interpreters. Federal, state, and institutional policies require offering interpreter services. Interpreters serve as cultural brokers who can help highlight cultural dynamics that may be lost during interpretations. Interpreters have reported little preparation time before translating a consultation and finding encounters with death and dying emotionally challenging.[19] PC team members can support interpreters by facilitating brief emotional and medical preparation before discussing EOL information with patients and families.

Another reason for interpreters is that some translations of terms for hospice and PC in Chinese do not accurately reflect the meaning, and may alarm or mislead vulnerable patients and families. For example, the Google translation of PC is ''姑息治疗 (Gū-xí-zhì-liáo).'' Back translated, the meaning is essentially ''Do-nothing care.'' Similarly, the current Google translation of Hospice is ''临终关怀'' (Lín-zhōng-guān-huái), literally meaning ''Last-minute care.''[20] We recommend reviewing key terms with the interpreter before initiating the encounter to minimize differences between interpreter and clinician statements, therefore improving patient understanding. We recommend using updated Chinese terms for PC and hospice.[20,21] See Table 2 for ''Translations for Key Terms in Palliative Care, Hospice, and End-of-Life Care.''

Tip 5: Chinese American Patients May Hold Cultural Values or Beliefs That Can Affect Preferences in Medical Care, Including Beliefs About the Taboo of Talking About Death

Chinese Americans may hold certain cultural values/preferences and beliefs that affect EOL treatment decisions and preferences. Superstition was found to be a predictor of death anxiety in a study of Chinese undergraduate students in

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Table 2. Translations for Key Terms in Palliative Care, Hospice, and End-of-Life Care

Category	*English*	*Pinyin*	*Chinese*	*Approximate English meaning*
General	Advance care planning	Shìqián-liáohù-jìhuà	事前療護計劃	Before-events-happen planning
	Hospice	Ān-níng-liáo-hù	安寧療護	Comfort- and peace-oriented care
	Palliative care	Huǎn-hé-liáo-hù	緩和療護	Gentler and kinder approach to care
	Quality of life	Shēngmìng-pǐnzhí	生命品質	Life quality
EOL	Cardiac arrest	Xīnzàng-tíngzhǐ-tiàodòng	心臟停止跳動	Heart stops functioning
	Cardiopulmonary resuscitation (CPR)	Xīnfèi-fùsū-shù	心肺復甦術	Heart-lung restart treatment
	DNR/DNI	Bùzuò-xīnzàng-fùsū	不做心脏复苏	Do not attempt heart restart
	Respiratory arrest	Hūxī-tíngzhǐ	呼吸停止	Breathing stops

These and additional terms are available in the CACCC glossary: https://caccc-usa.org/en/resource/glossary.html
DNI, do not intubate; DNR, do-not-resuscitate order.

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Hong Kong.[22] Some examples of cultural values and beliefs are included in Table 3.[23] It is important for clinicians to elicit and acknowledge the importance of Chinese American patients' cultural beliefs. Active listening and meeting patients where they are will show respect and build rapport for further decision making.

Tip 6: As Individuals, Chinese American Patients Hold a Range of Preferences and Goals of Care Regarding EOL Interventions

Chinese American patient values and preferences vary widely in EOL care. It is crucial to understand preferences for EOL care treatments at the individual patient and family level. Chinese American patient preferences in EOL decisions are influenced by multiple factors: (1) social determinants of health[25] (education, socioeconomic, neighborhood, and so on); (2) cultural background; (3) acculturation; (4) spirituality; (5) perception of harmony or desire to avoid tension among self and family; (6) knowledge of or experience with PC and hospice; (7) beliefs and expectations around EOL care; (8) perspectives and influence of family; and (9) perspectives and influence of health care providers and community stakeholders.[11,26]

Clinicians should ask Chinese American patients about these factors to individualize EOL care for this heterogenous population. EOL priorities need to be elicited, as priority values among Chinese Americans range from ''being free

Table 3. Examples of Chinese American Cultural Beliefs/Values That May Affect End-of-Life Care

The ''Yin (阴)'' *and* ''Yang (阳)''	Chinese Americans may find health and harmony between complementary energies such as cold and hot, dark and light. These forces, called yin and yang, may affect medication and food consumption during illness.	
Colors	Red	In Chinese tradition, red is a Yang color, which can ward off darkness and evil spirits. During CNY, Chinese Americans commonly give red envelopes to children, and hospitalized Chinese patients may give red envelopes to health care providers for good luck. When conducting PC meetings, clinicians may wish to wear something red as a sign of ''bringing good wishes'' to the patient/family.
	Black and White	Black and White are considered colors of mourning. Chinese usually avoid wearing or sending gifts in those colors during holidays such as CNY.
Numbers	4	The number ''4'' is an unlucky number because it rhymes with the Chinese word for death—''sǐ'' (死).[22] Some Chinese American patients may not wish to be admitted to the 4th floor or to a room that contains #4.
	8	The number ''8'' is a lucky number since it rhymes with the Chinese word for prosperity.
	Clocks	Clocks are considered unlucky since the Chinese translation—''zhōng'' rhymes with the word for ''end'' or ''death.''
Talking about death during certain holidays	It is considered inauspicious to talk about death during CNY. Some Chinese American families may request to defer such conversations until after CNY.	

CNY, Chinese New Year; PC, palliative care.
Source: Chinese American Coalition for Compassionate Care (CACCC),[21] Coy,[23] and Panesar et al.[24]

from pain,'' ''to pray,'' to ''not being a burden to my family.''[27] Also, individual knowledge of and experience with EOL care varies widely. In one community-based study, less than half of Chinese Americans were familiar with hospice.[28] Acculturation may influence adherence to traditional beliefs around death.[12,26] Compared to Mandarin and Cantonese speaking focus groups, predominantly English-speaking focus group participants had greater familiarity with EOL planning and practices.[12] Given the heterogeneity of values and preferences among Chinese Americans, clinicians should avoid stereotyping and, more importantly, engage patients on these topics to better inform their decisions and EOL care.

Tip 7: Providing Food at EOL Represents Filial Responsibility, Hope and Expression of Affection

Historically, famine was common in Chinese life. The provision of food holds emotional, filial, and psychological significance for Chinese patients and their families at EOL.[29] Patients and families share similar views about feeding with three themes: filial piety, source of hope, and expression of affection.[29] The fear of suffering and death by starvation may result in requests for artificial nutrition and hydration. A survey of Chinese elders in Singapore showed that a majority desired artificial feeding at EOL with as many as 55.8% wanting nasogastric feeding and 65.1% wanting intravenous hydration.[30] In Chinese culture, food has important symbolic meaning, including an expression of support, group cohesion, and identity.[31] Thus, a family caregiver's agreement to patient's refusal of treatment, or acceptance of anorexia and weight loss, may be perceived as violating filial responsibilities.[32]

Family members may have limited understanding of life-sustaining treatments.[33] Chinese family caregivers of older people with dementia showed limited understanding of surrogate decision making and life-sustaining treatments, including tube feedings.[34] Chinese caregivers relied more on their own views rather than the perceived wishes of the person with dementia, reflecting the Chinese families' tendency to make collective decisions.[34] Concerns about the lack of Chinese food and the perceived unsuitability of ''Western food'' were shown to be major issues regarding hospitalization.[35]

PC providers can (1) proactively educate Chinese patients and family caregivers on expected changes at EOL, including decreased oral intake and lack of hunger, (2) address the misconception that dying patients require artificial nutrition to stop them from starving to death, and (3) promote oral comfort feeding as the recommended approach for patients with advanced serious illnesses, including dementia, rather than feeding tube insertion.[36]

Tip 8: Many Chinese American Patients Are Open to Hospice Care if Explained in a Practical Way

Compared to White, Black, and Hispanic Americans, Asian Americans (including Chinese) underutilize hospice services.[37] Contributing factors may include lack of knowledge, language barriers, lack of access to hospice services, and lack of providers' recommendation for hospice.[28] Providers should be aware that Chinese patients may have already heard of hospice, but lack personal experience with it. Hospice is often explained as a ''philosophy of care'' that is ''holistic'' and cares for the ''whole patient and family.'' These terms may be vague and unclear to Chinese patients. A more effective way of explaining hospice care is to discuss hospice in terms of practical support.

Strategies to begin these conversations include using another person's EOL experience, so it is less direct, and to frame the conversation as a standard approach for discussing EOL planning with all patients. It is important to acknowledging their cultural framework and asking permission to move forward and ask questions.[9] Through starting the conversation, the health care provider may begin to obtain the patient and family's wishes, fears, or concerns about the EOL experience. Connecting this conversation to practical aspects of what hospice care can provide is helpful. For example, if a patient or family member mentions that ''I want to talk about what I've done in my life'' or ''I want to be free from pain,'' a provider can mention that hospice services include culturally appropriate care services that can assist with physical and existential pain and a nurse who can help with physical pain management.[38]

It can be helpful to discuss practical services that hospice can provide such as home health aides and home care equipment (e.g., hospital bed, oxygen). Engaging in this practical approach to discussing hospice care will increase Chinese American patients and family's openness to hospice services. Refer to Table 2 for updated translations of EOL-related terms.

Tip 9: Engage Chaplaincy to Help Support Patients Through Using Plain Language and a Practical Approach When Introducing the Service

Chinese American patients have diverse spiritual/faith needs.[39] They might not use ''God-centered'' language that is usually associated with spirituality. In contrast to Catholicism where the priest visits patients in the hospital, the same expectation may not exist in Buddhism and Taoism. Chinese American patients might associate ''emotional support'' with psychological and psychiatric treatment, or ''spiritual care'' with proselytization or religious rituals.[40] Thus, it can be challenging for PC clinicians to introduce spiritual care or chaplaincy to patients.

A better approach is to use contextualized plain language when introducing chaplaincy or spiritual care. For example, a PC clinician might say: ''It's a lot of information to take in. You may find it helpful to have our chaplain sit with you after we leave and talk through what's on your mind.'' Chaplains might find it helpful to introduce themselves based on a role that is familiar to Chinese American patients. For example: ''You can think of me as a friend who has experience with helping people through decision making or life transitions.''

For Chinese American patients, there is a wide range of practices and beliefs on dying and after-life. Some patients and families may wish to play religious chanting, request monastics to recite scriptures, speak with Chinese funeral planners, dress patients in specific clothes after death, or not move patients within a certain time-period. Clinicians should consult with family regarding EOL rituals and postmortem care and make possible accommodations. If families request lighting incense or candles at the bedside, clinicians should remind them to use electric candles for safety reasons.

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Tip 10: Chinese Culture Inherently Respects Physicians, so It Is Important for Clinicians to Build a Trusting Relationship, Provide a Safe Space to Discuss Difficult Topics or Mediate Conflicts, and Feel Comfortable Making Medical Recommendations

Traditionally, physicians are highly respected in Chinese culture and are able to work with the Chinese family in making medical decisions on behalf of the patient. As described, filial piety emphasizes the role of the family over individual rights and medical decision making involves the patient-family-physician triad.[41,42] Children may resist disclosing bad news to parents to protect them and fulfill their filial responsibilities (Tip 4).[43,44] Likewise, Chinese providers traditionally practice nondisclosure at the request of families. Some Chinese patients and families expect physicians to make medical decisions on behalf of the patient-family unit.

PC clinicians can practice commonly acceptable cultural behaviors related to respect and trust.[27] Respectful behaviors include knocking on the door before entering, handing business cards or documents with both hands while slightly bowing, using titles and honorifics (i.e., Mrs. Li rather than the first name), and conferring with the family before speaking with the patient. Trust-building behaviors include being accessible and following up on commitments made (i.e., phone calls and prescriptions).[45] When bringing up sensitive topics, clinicians should balance direct/verbal and indirect/nonverbal communication. Examples include ''I read that Chinese American patient prefers to avoid taking morphine even if they have severe pain. Does that apply to you?'' or ''Sometimes patients require the breathing machine to stay alive artificially. What are your thoughts?''

Many Chinese American patients and families may expect physicians to make medical decisions or recommendations, including life-sustaining treatment decisions. Unlike the United States where the Patient Self-Determination Act prioritizes autonomy for individuals to state their life sustaining treatment and EOL preferences, most Asian countries do not have such a law. It is not uncommon in China for the physician to make medical decisions on behalf of the patient. PC physicians in the United States need to be aware of this practice in Asian countries and emphasize our role in shared decision making over that of making actual decisions.

Conclusion

Chinese Americans are a heterogeneous group with different geographical, cultural, educational, socioeconomic, and dialectic backgrounds. Cultural values such as family harmony and filial piety may place family preferences above those of the individual. In contrast to Western communication styles, Chinese American patients may respond better to indirect communication approaches. Chinese American patients value physician-patient relationships based on respect and trust. Chinese American patients may lack knowledge of and access to PC services but are open to EOL communication and planning if approached from a culturally sensitive, respectful, and practical perspective. Knowledge of these cultural values and preferences can improve ACP and EOL discussions, preserve dignity, and reduce suffering.

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Address correspondence to:
Cynthia X. Pan MD
Division of Geriatrics and Palliative Care Medicine
Department of Medicine
NewYork-Presbyterian Queens
Weill Cornell Medicine
56-45 Main Street
Flushing, NY 11355
USA

E-mail: cxp9001@nyp.org

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