Can We Talk About It Now? Recognizing the Optimal Time to Initiate End-of-Life Care Discussions with Older Chinese Americans and Their Families.

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Chinese Americans are one of the fastest growing ethnic groups in the United States, representing the largest subgroup of Asian Americans (Pew Research Center, 2017). More than 4.9 million Chinese Americans now reside in the country. The prevalence of end-of-life (EOL) care discussions among Chinese Americans in the United States ranges from 6% to 37.5%, which is lower than those of the general populations (Gao, Sun, Ko, Kwak, & Shen, 2015; Lee, Hinderer, & Friedmann, 2015). Meaningful EOL care discussions with families is particularly important in Chinese culture, where filial piety is greatly valued and family-centered decision making is common practice (Chen, Simon, Chang, Zhen, & Dong, 2014; Dong, Zhang, & Simon, 2014). Filial piety is the primary duty of Chinese children who are expected to pay respect to and provide the best possible care for their parents or elders. Chinese adult children are expected to care for their parents through the ends of their lives (Nguyen & Seal, 2014). Consequently, family is significantly involved in patients’ decision-making processes at the end of life (Su, McMahan, Williams, Sharma, & Sudore, 2014).

Barriers to EOL care discussions common among Chinese populations are superstition, societal taboos around death and dying, and family objections. Chinese cultural superstition that death-related discussions can bring bad luck has been reported (Lee, Cheng, Dai, Chang, & Hu, 2016; Yap, Chen, Detering, & Fraser, 2017). EOL care discussions are also treated as a societal taboo (Chan & Yau, 2009; Ng, Chan, Ng, Chiam, & Lim, 2013). Although some Chinese may be open to EOL care discussion, their children may have a negative response to the discussion (Ng et al., 2013). Thus, it is important to understand how to discuss EOL care with older Chinese Americans and their families.

Advance care planning (ACP) is defined as “a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care” (Sudore et al., 2017, p. 821). ACP is an evolving concept and an unfamiliar term to some Chinese Americans (Lee, Byon, Hinderer, & Alexander, 2017). In this article, EOL care discussions are defined as any communication related to cardiopulmonary resuscitation; do not resuscitate orders; medical interventions, including full, selective, or
Table 1. Inclusion Criteria for Study Participants.

<table>
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<th>Participants</th>
<th>Inclusion criteria</th>
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<tr>
<td>Older Chinese Americans</td>
<td>• Self-identifying as Chinese or Chinese American</td>
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<td></td>
<td>• 55 years old or older</td>
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<td></td>
<td>• Able to complete the interview in English</td>
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<tr>
<td>Adult children</td>
<td>• Self-identifying as Chinese or Chinese American</td>
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<td></td>
<td>• Older than 18 years old</td>
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<td></td>
<td>• Expected to provide care to their older parents, whose age is 55 years old or older</td>
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<td></td>
<td>• Able to complete the interview in English</td>
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<tr>
<td>Health care providers</td>
<td>• Physicians, nurses, social workers, or chaplains</td>
</tr>
<tr>
<td></td>
<td>• Currently practicing in geriatrics, primary care, or palliative care (hospice excluded)</td>
</tr>
<tr>
<td></td>
<td>• Having regular experience (at least monthly) in facilitating end-of-life care discussions with older Chinese Americans</td>
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comfort-focused treatments; and assignment of durable power of attorney. To increase knowledge about older Chinese American engagement in EOL care discussions, this study explored their preferences, communication, and strategies while including the perspectives of adult children and health care providers (HCPs). This article focuses on older Chinese Americans and adult children’s communication preferences and optimal timing for HCPs to initiate the EOL care discussions.

Method

Focused ethnography explores social and cultural situations and potentially identifies solutions for practical problems with an emphasis on cultural meanings. This approach was used to guide the design, data collection, and implementation of this study (Hammersley & Atkinson, 2007; Higginbottom, Pillay, & Boadu, 2013). The institutional review board of the authors’ university approved the study protocol.

Recruitment, Study Participants, and Setting

Study participants were recruited from a San Francisco Bay Area Chinese American community using purposive and snowball sampling by direct approach, social network media, emails, and flyers (Thomas, 1993). The inclusion criteria included older Chinese Americans, adult children, and HCPs (Table 1). The minimum age (55 years) was chosen to represent community-dwelling older Chinese Americans based on the Housing for Older Persons Act of 1995 requirement for eligibility (U.S. Department of Housing and Urban Development, 2017). The first author verified potential participants’ eligibility after the study was described to them. Exclusion criteria were as follows: vision, hearing, or cognitive impairment; or depression or mental illness sufficient to interfere with the consent process and interviews.

Data Collection

Face-to-face, individual, in-depth interviews guided by open-ended questions, and semistructured follow-up probes were conducted at the participants’ preferred place (e.g., home, a private room at a library, or an office) in 2015 and 2016. A total of 14 older Chinese Americans, 9 adult children, and 7 HCPs were included in the analysis. Six of the 14 older Chinese American participants also provided care to their parents (age 80 years or older). These six older Chinese American participants discussed their experiences as both an older Chinese American and an adult child. The interview topics included (a) EOL care experiences with others, (b) appropriateness of having EOL care discussions with older Chinese Americans, (c) who older Chinese Americans find appropriate to have EOL care discussions with, and (d) the optimal time for EOL care discussions with older Chinese Americans. Original interview questions were tested with five older Chinese Americans in a pilot study; none reported distress or discomfort. The pilot interview guide was revised and discussed with the research team (Table 2). Modifications of interview questions, based on participant responses and results of early data analysis, were made during the data collection period. Informed consent and demographic surveys were obtained prior to the interviews. The interviews took 45 to 90 minutes, were audio-recorded, and were transcribed verbatim by professional transcriptionists. The first author conducted all interviews in English, reviewed transcripts, and verified accuracy. Informal field observations during the interviews, including the environment and interactions between family members, were collected to supplement interview data; postinterview field notes and memos were written. To enhance the analytical process, additional memos of self-reflection were created throughout the study.

Data Analysis

Simultaneous data collection and data analysis were conducted. The goal of ethnographic analysis is to organize large quantities of qualitative data in a systematic and thorough way to understand what people believe in and explain how people behave (Fetterman, 1998; Hammersley & Atkinson, 2007; Roper & Shapira, 2000). Thus, thematic analysis and constant comparative analysis (Charmaz, 2014; DeSantis & Ugarriza, 2000) were used iteratively during and after data collection to explore if older Chinese Americans and their families would be receptive to early EOL care discussions.

Open coding of the interviews and observation field notes was performed in the first phase of analysis. Initial coding was reviewed by a small group of peer researchers for the first 6 months of data collection, and subsequently, the first and the last author met regularly to review analyses and findings. The final findings were discussed with the entire research team. In the second phase, focused coding and constant comparative
methods were conducted to identify the similarities and differences within each group and among all groups (Charmaz, 2014). Major categories were developed by combining data from initial codes and redefining topics of greatest relevance to participants. Data related to the major categories were systematically reviewed and reexamined to develop the overarching theme and then verified by the first and the last author to reach a consensus (DeSantis & Ugarriza, 2000). Major categories and preliminary results were discussed with the research team and other expert nurse-peer researchers. Evolving concepts and interpretations were verified with participants during the iterative data collection process. Study rigor was strengthened by using multiple data collection methods and respondent categories (Kuper, Lingard, & Levinson, 2008). Of note, the first author is of Chinese descent and has worked as a hospice nurse, which facilitated her understanding of the participants’ discussions of Chinese culture and EOL care practices.

Findings
Older Chinese American participants were between 57 and 77 years old. Nine of the 14 older Chinese American participants were foreign-born, were married, were female, and had 30 years or more of U.S. residency and at least a bachelor’s degree. Six of the older Chinese American participants reported caring for parents 80 years or older. Adult child participants were between 31 and 51 years old. One 57-year-old participant chose to be interviewed as an adult child participant instead of as an older adult participant since she was taking care of her 86-year-old mother. Four of the nine adult child participants were U.S. born. Six of the seven HCP participants were of Chinese descent and equally distributed across various health care disciplines (e.g., physicians, advanced practice nurses, and social workers) and specialties (e.g., palliative care and primary care). Although self-identification as a Chinese American was not required for HCP participants, HCP inclusion criteria resulted in most HCP participants being Chinese American.

The overarching theme throughout all interviews was that older Chinese Americans and their families would engage in EOL care discussions at an “optimal time” and with appropriate people. Two major categories related to this theme were (a) communication preferences and (b) recognition of the optimal time. Communication preferences included intrafamilial communication and patient-provider communication. Participants stated that they had or would recognize the optimal time for EOL care discussions after triggering events, with changes in health status or with advancing age.

Communication Preferences
Variation in communication preferences was found within and between older Chinese American and adult child groups. The salient communication preferences were intrafamilial communication (i.e., discussions between family members) and patient-provider communication. Patient-provider communication was defined as discussions involving any type of HCP participation, which included, but was not limited to, physicians, nurses, and social workers.

Older Chinese American Preferences. Older Chinese Americans were more engaged in intrafamilial communication than patient-provider communication with regard to EOL care discussions. They preferred that face-to-face and in-depth EOL care conversations occur within their family, preferably between spouses, before disclosing their EOL care decisions to their adult children and nonfamily members (see Figure 1). Half of the 14 older Chinese Americans had conducted EOL care discussions with their families, and five had begun EOL care discussions with their spouse. The other two participants had started EOL care discussions with their
adult children instead of a spouse because of an estranged relationship or the spouse being physically out of the country. For example, a 72-year-old participant discussed EOL care with her husband after they had attended an ACP seminar following retirement, and later, they completed advance directives together and only then informed their children of their EOL care decisions. This older Chinese American had a strong feeling that EOL care decisions were hers alone and did not want to involve her children until after the advance directive was complete; “It’s none of their business. Then, after we [she and her husband] did everything, then we told them [their children] that this is our wish.” Similarly, a 68-year-old participant said, “Actually [I discussed EOL care] only with my husband, it’s not as if I’ve spoken to my children about it. Although I just assumed that I wouldn’t have to because my husband and I would handle all that between us.”

Older Chinese Americans, who were caring for a single older parent, did engage in EOL care discussions with their parents. For example, a 67-year-old older Chinese American whose mother was in her 90s said,

At that time, I wasn’t the primary care person [for my deceased father]. It was my mother. Like in most Chinese generation, it’s the spouse. They work out things together. Then coming down to children. Right now, with my mother’s care, I do talk about that.

No older Chinese American voluntarily initiated an EOL care discussion with his or her HCP, although the two had had an EOL care discussion with their primary care physician after a health care facility encouraged them to complete an advance directive. Consequently, they brought the advance directive form to their physician. All older Chinese American participants expressed being open to patient-provider communication if the HCP took the initiative (see Figure 1). A Chinese primary care physician’s experience reinforced these findings although she did not expect them. She said,

One patient who said, “I’m so glad you brought this up because I’ve just been talking to my son about it . . .” Earlier I think I would’ve thought that Chinese don’t like to talk about it, that’s not true. A lot of them are like, “Thank God you’re asking me.”

In the above exemplar, patient–provider communication was preceded by intrafamilial communication. Although Chinese patients wanted to have EOL care discussions with the HCP, they did not initiate them; instead, they waited for the HCP to take the initiative (see Figure 1). Strikingly, no older Chinese American’s HCP had initiated an EOL care discussion, though some older Chinese Americans had completed advance directives themselves.

**Adult Children’s Preferences.** Adult children of older Chinese Americans would like HCPs to initiate EOL care conversations with their parents. Adult children were also open to EOL care discussions if their parents would initiate the discussion (see Figure 1). No adult child had voluntarily initiated an EOL care discussion with a parent. Eight of the nine adult children stated that they would engage in the EOL care discussions with their parents, but they would prefer to obtain guidance from HCPs or to have HCPs initiate the conversation. A 31-year-old participant whose parents were in their 70s and 80s explained, “I feel like we needed a source of authority to say ‘you should have this conversation when you turn this age or are going through this life experience.’” A 37-year-old participant said, “I would like for the provider to initiate it first and then we will follow up with the topic with the parents.”

Overall, older Chinese Americans favored in-depth conversations with their spouse first, followed by disclosing their now-determined EOL care decisions to their adult children. Furthermore, older Chinese Americans were open to discussion initiation by HCPs; however, no older Chinese American’s HCP had initiated this EOL care discussion. Both older Chinese Americans and adult children preferred

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**Figure 1.** End-of-life care communication preferences. A dashed square indicates a desired action that did not occur yet. Arrows indicate preferred orders.
that HCPs take the initiative first, which could lead to family discussions. The initiation of EOL care discussions by HCPs can ensure that older Chinese Americans’ EOL care preferences are documented in a medical system and guide future care plans. In general, parents expected their adult children to honor their EOL care preferences, but adult children were not expected to initiate EOL care discussions. EOL care discussions only occurred when the older Chinese Americans took the initiative to discuss EOL care with their adult children. Adult children were reluctant to initiate the discussion with their parents. Adult children strongly preferred to have HCPs initiate the conversation with their parents, so that their parents would subsequently discuss EOL care with their adult children.

### Optimal Time

Considerations of the optimal time to discuss EOL care were a key component of how EOL care should be discussed. Optimal time is defined as a particular temporal window or a specific opportunity considered as appropriate and helpful to engage individuals in EOL care discussions. Participants said that the optimal time for the EOL care discussions is conditioned by triggering events, health status, and age. Interview excerpts elucidating notions of optimal timing are recorded in Table 3.

### Triggering Events

Older Chinese Americans were more likely to engage in EOL care discussions when they had encountered triggering events, such as death events, hospitalization, fall accidents, retirement, and change in a health care condition. For example, a 67-year-old participant had had a fall the day before the interview. This event increased the older Chinese American’s sense of urgency in engaging with ACP. She said, “I fell . . . I tumbled right on top. That tells me that . . . I better start putting things together . . . That’s when I have a sense of urgency.” Various life events may trigger older Chinese Americans to discuss EOL care with their families. To some, retirement was a trigger and eventually led to ACP action. A 72-year-old’s retirement prompted her to become a hospital volunteer, which led her to attend an ACP seminar she had not considered before retirement. She eventually arranged to have EOL care discussions with her children and HCPs; “When you’re retired, then you have more time to think about it, or maybe they might say, ‘Yeah, my brother in law just got a big stroke, so now he’s in a nursing home and he can’t talk or anything. I never want to be like that.” Something like that. I wait for those types of opportunities to show up. [a primary care physician]

### Table 3. Data Examples to Support Optimal Time.

<table>
<thead>
<tr>
<th>Category</th>
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<tr>
<td>Triggering events</td>
<td>He (her husband) really is willing to talk about it (EOL care), especially he had experience of hospitalization where he was put a stent in his artery . . . He was kind of forced to feel the possibility of life and death. I think that kind of experience impacted him quite a lot. He's more than willing to think about and talk about this topic now. [62-year-old, female, older Chinese American] Both my sister and I we haven't really broached that topic. The only time it did come up was when she (her mother) was hospitalized and that was under the professional medical staff would bring up the topics or social worker. [57-year-old, female adult child] It [EOL care discussion] really takes opportunities. We take each opportunity as a breaking through point. If there's an infection comes up, if hospitalization comes up, if there is a fall, if there is a care giving breakdown, so any of those little moments to us it's an opportunity . . . It really takes that timing because if nothing's changed, they're not going to take any new information because they feel like, “Oh, things are the same. I'm maintaining everything well.” Only when there are crises I will say that's the opportunity that we can readress goals of care, treatment options or things like that. [a palliative care social worker]</td>
</tr>
<tr>
<td>Health status and age</td>
<td>Maybe do it early on. Maybe do it when they're in their 50s and 60s and not wait until they're 80 or 90. Then, it's like, you will get older, grouchier and feel like, what is this person's intent? They don't want to take care of me anymore or whatever . . . I think early is better. [65-year-old, female, older Chinese American] More often 80s, but if they're in their 70s and let's say we have a discussion and I get a clue that they've thought about it, or maybe they might say, “Yeah, my brother in law just got a big stroke, so now he's in a nursing home and he can't talk or anything. I never want to be like that.” Something like that. I wait for those types of opportunities to show up. [a primary care physician]</td>
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Note. EOL = end of life.
Older Chinese American perspectives. Some older Chinese Americans stated that the EOL care discussion should be conducted “the earlier the better.” A 72-year-old participant said, “I really don’t know [when is the right time], but I think the earlier you do it the better.” Aligned with this statement, a 68-year-old participant felt that an EOL care discussion should be conducted when people were still healthy; “As long as people are still healthy, I think you can ask this question. As people get very frail, it feels very awkward. That’s partly the problem.” She felt less comfortable about having an EOL care discussion with very frail people. A 65-year-old participant commented that it would be better if the EOL care discussion took place earlier (e.g., 50s or 60s). She mentioned that waiting until older Chinese Americans were in their 80s and older would make the discussion challenging due to potential cognitive decline and emotional sensitivity.

Adult child perspectives. Adult child participants suggested various health status markers as the optimal time to discuss EOL care. Eight of the nine adult children thought that the best time was when their parents had declined health, including chronic or terminal illnesses or physical disability. Strikingly, more than half of the adult children used words such as serious, drastic, and terminal to identify the optimal time. As a 41-year-old adult child participant stated, “I think the right time would be if either of them had a serious incapacitating condition or accident.” He elaborated by emphasizing physical disability, “like if something happened that was clear that their activity level’s going to change drastically.” A 31-year-old adult child participant whose parents were in their 70s and 80s commented that the optimal time was when his parents had either mental or physical disabilities and required more care, “like mentally or physically drastically disabling issue like Alzheimer’s, for example. Like anything that you need more care around you that is pointing to a degradation of quality of life.” Neither older Chinese Americans nor HCP groups mentioned a level of physical capability or relevant care needs as an optimal time for an EOL care discussion.

Health care provider perspectives. HCP participants acknowledged the theoretical importance of initiating an EOL care discussion early in life, but they attempted to do so with their Chinese American patients only when they were older, which they defined as 70s or 80s. A Chinese primary care physician stated that she tried to have EOL care discussions with her older and sicker patients (e.g., a serious illness or onset of cognitive impairment); “I try to do it for people over 70, right? Some of them obviously are sick enough that even in their 60s you need to start doing it . . . I prioritize the ones who are obviously older, the ones who are obviously sicker.”

In summary, older Chinese Americans stated that they would engage in EOL care discussions if the subject was introduced at the optimal time by appropriate people. The optimal time to initiate EOL care discussions varied both within and among participant groups. However, all three groups expressed that it is crucial to have EOL care discussions with older Chinese Americans before their decision-making capacity is impaired.

Discussion

Four salient findings for EOL care discussions with older Chinese Americans and their families were presented in this study. First, although EOL care discussion rates are low among Chinese Americans (Gao et al., 2015; Lee et al., 2015), this study showed that older Chinese Americans and their families would engage in the EOL care discussions if introduced by appropriate people and at an optimal time. In this study, a variety of perceived optimal times for EOL care discussions with Chinese Americans were identified indicating that variations of openness toward EOL care discussions exist among acculturated Chinese Americans. Similar findings have been reported across general populations in systematic reviews (Barclay, Momen, Case-Upton, Kuhn, & Smith, 2011; Sharp, Moran, Kuhn, & Barclay, 2013). Despite variation, optimal times identified in this study offer opportunities for HCPs to assess older Chinese Americans’ readiness for EOL care discussions and to initiate them.

Second, older Chinese Americans often preferred to have an initial in-depth EOL care conversation with their spouse and then disclose their decisions to their adult children. This finding differs from typical descriptions of Chinese or Asian culture, in which family-centered decision making or heavy involvement of firstborn children has been found to be the norm (Su et al., 2014). A potential explanation for this finding is that older Chinese American participants were highly acculturated and independent, and autonomy was greatly emphasized in the interviews. As a result, adult children were expected to honor their parents’ EOL care wishes instead of actively participating in their parents’ initial decision-making process. Research shows that Chinese populations are inclined to trust and rely on their physicians’ decisions because physicians are highly regarded and respected in Chinese health care culture (Lee, Hinderer, & Kehl, 2014). In contrast, from the perspectives of older Chinese Americans and adult children in this study, the physician’s authority did not automatically grant a trusting relationship. Instead, these two groups emphasized the importance of establishing a trusting patient-provider relationship for EOL care discussions.

A third finding revealed that Chinese American adult children in this study were not expected to initiate EOL care discussions with their parents. This is similar to previous research (Yonashiro-Cho, Cote, & Enguidanos, 2016) that found that Chinese Americans believed that parents should initiate the discussion. Some older Chinese Americans in this study, who cared for a single older parent, actively participated in their parent’s care and EOL care discussions. Nevertheless, older Chinese Americans did not initiate EOL care discussions with their older parent until HCPs had taken the initiative. Nguyen and Seal (2014) found “a shift from
traditional interpretations of filial piety in regards to the interdependent roles between parent and child and an emphasis on personal independence” (p. 168). In our study, older Chinese Americans who were more acculturated valued autonomy over collectivism. As a result, they were willing to discuss their own EOL care preferences with their spouse and adult children to ensure that their final wishes were honored. Although older Chinese Americans who had adapted to American culture (e.g., individualism) were open to discuss their own EOL care, they still maintained some conditions of Chinese culture (e.g., collectivism) and were therefore sometimes reluctant to initiate an EOL care discussion with their parents. Older adult child participants or those whose parents were older (80+ years) felt that an EOL care discussion should be conducted early. In contrast, younger adult child participants did not have the same sense of urgency.

Finally, in the current study, adult children emphasized that declining physical capabilities and increased health care needs were the optimal time to begin EOL care discussions; however, these conditions were not mentioned by either older Chinese Americans or HCPs. Filial piety, a Chinese cultural custom, which demands that adult children care for their parents, may explain this finding (Dong et al., 2014; Hsu, O’Connor, & Lee, 2009). Since family objections have been reported to be a major barrier to EOL care discussions (Ng et al., 2013; Wong et al., 2012), an emphasis on changes in physical capacities or care needs may be a starting point to engage older Chinese Americans and their adult children.

Overall, older Chinese Americans, adult children, and HCPs in this study failed to initiate critical EOL care discussions. However, both older Chinese Americans and adult children welcomed HCP initiation of these challenging conversations. Given Chinese cultural norms discouraging adult children from initiating EOL care discussions with their parents, HCPs should proactively identify the optimal time to initiate discussions with their patients.

**Limitations and Suggestions for Future Research**

This study has several limitations, including small sample size, lack of monolingual Chinese participants, and one geographic location. Further research is required to assess whether the identified optimal times apply to monolingual Chinese Americans living in other geographic locations. Since all participants consented to participate in this study, they were receptive to EOL care discussions. The majority of older Chinese American participants were well-educated and had resided in the United States for at least 30 years, which indicated a high level of acculturation. Therefore, the findings cannot be applied to more recent migrants. Older Chinese American participants were community-dwelling and physically active, so our findings should be applied cautiously to older Chinese Americans with serious illnesses. Finally, the majority of the participants were female and married, more male and single participants should be recruited.

**Conclusion and Implications for Practice**

Older Chinese Americans and their families are willing to discuss EOL care when introduced at an optimal time and by appropriate people. Older Chinese Americans are open to an initiation of EOL care discussions from HCPs. Adult children rely on HCPs’ guidance on initiating EOL care discussions. HCPs can foster EOL care discussions in this community by initiating ACP consultations during patient visits and offering public education about ACP.

The promotion of ACP discussions with patients and their family members is the responsibility of all HCPs. HCPs should proactively seek the optimal time to introduce the ACP concept or to engage patients and their families in EOL care discussions. Since the optimal time to discuss EOL care varies individually, HCPs should assess patients’ readiness for the discussion before launching into an in-depth conversation. Furthermore, since family objections are one of the major barriers to EOL care discussions, HCPs should explore how to successfully engage family members in such discussions. For instance, adult children perceived that the optimal time to begin EOL care discussion is when hands-on care for their parents is necessary. Thus, HCPs can better engage adult children in EOL care discussions by emphasizing their parent’s increased care needs and provide support and care to meet the challenges of the new level of care. Consequently, HCPs can help adult children recognize the urgency and importance of having EOL care discussions with their parents. Additionally, HCP tailoring of EOL care discussions to address older Chinese American patients’ specific needs builds a trusting relationship with them and their families.

Given that older Chinese Americans prefer intrafamilial communication over patient-provider communication, HCPs can also promote ACP by suggesting that their older Chinese American patients discuss EOL care with their spouses and then follow up with their patients at a later time. Nurses often spend the most time with patients compared with other HCPs. Therefore, it is beneficial for health care systems to educate and empower nurses in discussing EOL care with Chinese Americans and other minority ethnicities as well, so that they are able to initiate such discussions and advocate for these growing patient populations.

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**Declaration of Conflicting Interests**

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