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Brief Report

Advance Care Planning Engagement and End-of-life Preference Among Older Chinese Americans: Do Family Relationships and Immigrant Status Matter?

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A B S T R A C T

Objectives: To examine how immigrant status and family relationships are associated with advance care planning (ACP) engagement and end-of-life (EOL) preference in burial planning among older Chinese Americans, the largest subgroup of Asian Americans.
Design: Cross-sectional survey.
Setting: Communities in Honolulu, Hawai'i.
Participants: Participants were 430 older Chinese Americans aged 55 years and older.
Measures: Measures included ACP contemplation, ACP discussion, and EOL preference in burial planning, immigrant status, family cohesion, family conflict, demographic information, and health status.
Results: Results show that in comparison to foreign-born Chinese Americans, US-born Chinese Americans were more likely to have ACP contemplation [odds ratio (OR) 2.80, 95% confidence interval (CI) 1.39-5.63], ACP discussion (OR 3.02, 95% CI 1.50-6.08), and preferences for burial plans at the end of life (OR 4.56, 95% CI 2.04-10.18). Family conflict increased the possibility of having ACP contemplation (OR 1.21, 95% CI 1.07-1.38), ACP discussion (OR 1.22, 95% CI 1.07-1.39), and EOL preference in burial planning (OR 1.22, 95% CI 1.04-1.42), whereas family cohesion was not associated with these study outcomes.
Conclusions and Implications: This study suggests that ACP should be adapted to be more culturally appropriate, especially in a time of coronavirus and xenophobia, such as framing ACP as a tool to help families reduce stress while fulfilling filial obligations, in order to ensure equitable access to ACP.

Advance care planning (ACP) is a process of understanding and communicating individuals' values, goals, and preferences regarding end-of-life (EOL) care.[1,2] Contemplation of individuals' EOL wishes and discussions with families can be as important as discussions with physicians and completion of an advance directive in guiding care.[3,4] ACP is a social process built on relationships and alleviation of burden on others, a means to prepare for death, and a measure to exercise the ethical principle of patient autonomy.[5] Burial planning can ensure individuals' wishes are executed and relieve the burden of loved ones to determine what the deceased would have wanted during the time of grief. In this sense, burial planning is an important element of ACP.[6] Therefore, it makes sense to examine ACP contemplation, ACP discussion with family, and EOL preference in burial planning together.

ACP can improve quality of EOL care for individuals, including less in-hospital death and increased hospice use.[7] Despite the benefits of ACP, the participation rate of ACP remains low, especially among older adults of racial and ethnic minorities. Studies found that in the United States, Blacks and Hispanics are less likely to have an EOL discussion, a durable power of attorney, and an advance directive than their White counterparts,[8,9] but there is a lack of knowledge on ACP engagement among Chinese Americans, the largest subgroup of Asian Americans and the fastest-growing minority group in the USA.[10]

Compared with native-born Chinese Americans, foreign-born Chinese Americans may face more cultural and logistical challenges in ACP engagement because of their limited English proficiency, greater cultural burden in discussing death and dying and accepting individual autonomy, and lack of ACP knowledge.[11,12] In addition, the effectiveness of ACP may rely on the involvement, knowledge, and

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cooperation of family members[13]; however, because of the lack of rich and comprehensive measures of family relationships in previous research on ACP, few studies have examined the extent to which family relationships influence individuals' ACP engagement. To fill this knowledge gap, this study aimed to examine how immigrant status and family relationships are associated with ACP contemplation, ACP discussion with family, and preference in burial planning among older Chinese Americans.

Methods

Data

Data were derived from a survey conducted in Honolulu, Hawai'i, where approximately 4.7% of the total population is composed of Chinese Americans, and 44% of the adult population are immigrants.[14] We used snowball sampling and convenience sampling to identify and recruit key informants from local Chinese groups, social organizations, businesses, and faith-based agencies based on their capacity of accessing Chinese communities and their willingness to assist in recruiting Chinese older adults in the community. We collaborated with key community leaders. This is a common and effective strategy to recruit respondents from minority populations,[15] as random sampling is challenging because of the unfeasibility of constructing a completed sampling frame, cultural appropriateness, time, and expense.[16] The inclusion criteria for the survey participants included Honolulu residents, aged 55 years and older, who self-identified as Chinese. The detailed recruitment and data collection methods were reported in previous studies.[17] The participants provided informed consent prior to the data collection. This study was approved by the institutional review board at the university with which the second author was affiliated. A total of 430 participants were recruited from January 2018 to September 2018.

Measures

Dependent variables: ACP engagement and EOL preference in burial planning

ACP engagement includes ACP contemplation and ACP discussion. ACP contemplation and ACP discussion was assessed by asking respondents if they previously (1) had thought about their end-of-life care plan with family and (2) had discussed the plan with family, respectively.

EOL preference in burial planning was measured by a hypothesized question. Respondents were asked whether formulating a burial plan was one of the most important things for them to consider if they were diagnosed with a terminal illness and only had 6 months to live, among several other options. Other mentioned options included having religious beliefs/support, alleviating pain, reducing care and financial burden on family, and extending their life.

Independent variables

Immigrant status was measured by asking respondents whether they were US- or foreign-born.

Family relationships were measured by 2 reliable and valid existing scales—family cohesion and family conflict. The index of family cohesion was assessed by asking respondents whether (1) family members like to spend free time with each other, (2) family members feel very close to each other, and (3) family togetherness is very important.[18]

Family conflict was measured using the 5-item Family Cultural Conflict scale, which assesses cultural and intergenerational conflict perceived by respondents in their family.[19]

Covariates

Sociodemographic variables included gender, age, marital status, education, financial strain, living arrangement, and social activity participation. Health need factors included self-rated health, comorbidity (a continuous variable that examines the existence of at least 9 chronic conditions including heart diseases, stroke, cancer, diabetes, hypertension, high cholesterol, thyroid disease, arthritis, liver-related diseases, and others), disabilities in activities of daily living, and psychological distress. Psychological distress was assessed by the Kessler Psychological Distress Scale (K10).[20]

Analysis

First, we summarized the sample characteristics. Then, we used logistic regression models and calculated odds ratios (ORs) to test whether immigrant status, family cohesion, and family conflict were associated with ACP engagement and EOL preferences. All the analyses were conducted using Stata, version 15.1.

The missing rates for ACP contemplation, ACP discussion, and EOL preferences in burial planning were 13%, 15%, and 23%, respectively. To reduce sampling errors and attain more stable analytical results, we conducted multiple imputations (MIs) for each model. All the dependent variables were imputed, and the imputed values were retained in the analysis. We used 25 imputed data sets as there were high levels of missingness on the dependent variables.[21] For sensitivity analysis, a dependent variable was imputed, and imputed values were deleted for analysis (MID). The MID method produced ORs that were almost identical to those in the model where the imputed values were retained.

Results

Table 1 summarizes sample characteristics. It shows that less than half of the participants had ACP contemplation (48.5%) and ACP discussion (43.3%). Only 24.1% had EOL preference in burial planning in the hypothesized situation.

Table 2 shows ORs with 95% confidence intervals (CIs) from logistic regressions. The US-born Chinese Americans were more likely to have ACP contemplation (OR 2.80, 95% CI 1.39-5.63), ACP discussion (OR 3.02, 95% CI 1.50-6.08), and preference in burial planning (OR 4.56, 95% CI 2.04-10.18) than the foreign-born. Higher levels of family conflict were associated with higher likelihood of ACP contemplation (OR 1.21, 95% CI 1.07-1.38), ACP discussion (OR 1.22, 95% CI 1.07-1.39), and preference in burial planning (OR 1.22, 95% CI 1.04-1.42), whereas family cohesion was not significantly related to these outcomes.

Discussion

This study aimed to examine the roles of immigrant status and family relationships in the associations between ACP engagement and giving EOL preferences to burial planning among older Chinese Americans. The US-born Chinese Americans were more likely to have ACP contemplation and ACP discussion than the foreign-born. This may be because the foreign-born Chinese Americans have lower socioeconomic status, less English proficiency, lower levels of acculturation, and less knowledge about ACP and the US healthcare system than their US-born counterparts.[11,12,22] In addition, these individual-level differences may be mixed with other system-level barriers within the US healthcare system to worsen the disparities in ACP engagement.[23] For example, Chinese American immigrants may have a stronger belief that family and society are held in higher regard than individuals, and attribute a higher value to collectivism of family and society rather than patient autonomy in EOL decision making.[12] Moreover, because traditional Chinese culture expects children to carry the role of protecting their parents' health, safety, and general well-being, many Chinese children may construe this responsibility as

Table 1
Characteristics of the Study Sample of Chinese Americans (N = 430)

	% or Mean (SD)	Coding
ACP engagement		
ACP contemplation	48.45%	0 (never and don't want to/never but want to/reluctant to), 1 (yes)
ACP discussion	43.27%	0 (never and don't want to/never but want to/reluctant to), 1 (yes)
EOL preferences in burial planning	24.12%	0 (no), 1 (yes)
US-born	27.60%	0 (no), 1 (yes)
Family Relationships		
Family cohesion	9.21 (1.99)	0 (least cohesive)–12 (most cohesive)
Family conflict	1.63 (2.10)	0 (least cultural conflict)–10 (most cultural conflict)
Female	58.94%	0 (male), 1 (female)
Age	73.62 (9.87)	52-99
Married	69.47%	0 (unmarried), 1 (married)
Education	11.58 (4.96)	0-26
Financial strain	0.85 (0.86)	0 (not at all)–3 (a great deal)
Living alone	31.36%	0 (no), 1 (yes)
Participation in social activities	69.50%	0 (no), 1 (yes)
Self-rated health as excellent/good	62.01%	0 (no), 1 (yes)
Number of chronic disease	1.25 (1.14)	0-7
ADL disability	3.51%	0 (no help needed), 1 (needs help)
Psychological distress	1.67 (0.73)	1 least distressful–5 most distressful

ADL, activities of daily living.

making every effort to prolong their older parents' life, which may sometimes be in opposition to their parents' own wishes.[24] These potential factors surrounding older Chinese immigrants may help explain this population's lack of engagement in ACP. Healthcare providers, in turn, should pay closer attention to these factors in order to thoroughly evaluate patients' EOL wishes. It is noted that the US-born Chinese Americans were far more likely to have preferences in burial planning than the foreign-born. The finding is consistent with a previous study in that decisions such as EOL care and funeral and burial preplanning are impacted by similar factors.[25] Indeed, EOL care decision making and burial planning are 2 integrated processes at the end of life,[26] and burial plan is included in some advance directive documents in practice. Future studies on ACP need to consider burial planning.

Second, family cohesion was not associated with ACP contemplation, ACP discussion, and EOL preference in burial planning, whereas family conflict increased the possibility of ACP contemplation, ACP discussion, and EOL preferences in burial planning. The finding is inconsistent with 1 previous study conducted among White older adults, revealing that the positive family relationship encourages, whereas problematic family relationship hinders, ACP engagement.[27] The inconsistency is likely due to the fact that Chinese Americans value family in the process of EOL decision making.[28,29] The lack of association between family cohesion and ACP engagement may be because older adults with higher levels of family cohesion have to balance between the potential benefit and harm of ACP engagement. On the 1 hand, older Chinese Americans may have positive attitudes about ACP engagement and believe that ACP engagement is important and necessary because it allows them to witness their loved ones' death and dying experience.[12] On the other hand, close-knit familial relationships may make both older Chinese Americans and their families feel more uncomfortable to start a conversation on EOL care because discussions about death and dying are often considered a taboo in Chinese culture.[30] In this sense, strong family ties may have limited impact on ACP engagement. An explanation for the significant relationship between family conflict and ACP engagement could be that higher levels of family conflict may indicate a greater need for ACP engagement. This is because the members in these families are less likely to know about the EOL care preferences of older adults and be trusted in the EOL decision making.[13] These findings suggest that culture may play an important role in the complex association between family relationships and ACP engagement.

Several limitations of the study deserve mentioning. First, the cross-sectional data from a small region limit our ability to generalize findings to older Chinese Americans living in other parts of the United States, as well as to make causal inferences. Second, the ACP engagement in our study only included ACP contemplation, ACP discussion, and preference in burial planning. Future studies need to include more ACP options, such as the completion of living wills or advance directives, and the selection of a durable power of attorney for health care to understand more about ACP engagement in Chinese American families. Third, ACP knowledge is an important confounding variable for both immigrant status and ACP engagement. Future studies on ACP engagement need to consider this variable.

Conclusions and Implications

Despite these limitations, this study sheds light on how immigrant status and family relationships shape ACP engagement among older Chinese Americans. It is found that immigrant status decreases whereas family conflict increases the likelihood of having ACP contemplation, ACP discussion, and preference in burial planning.

Table 2
Factors Associated With Advance Care Planning Engagement: Results of Logistic Regression (N = 430)

	ACP Contemplation, OR (95% CI)	ACP Discussion, OR (95% CI)	EOL Preferences in Burial Planning, OR (95% CI)
US-born (ref = foreign-born)	2.80 (1.39, 5.63)	3.02 (1.50, 6.08)	4.56 (2.04, 10.18)
Family relationships			
Family cohesion	1.08 (0.93, 1.25)	1.06 (0.92, 1.22)	1.14 (0.99, 1.31)
Family conflict	1.21 (1.07, 1.38)	1.22 (1.07, 1.39)	1.22 (1.04, 1.42)

All models adjusted for age, gender, marital status, education, financial strain, living alone, social activity participation, self-rated health, number of chronic disease, activities of daily living, and psychological distress.

Health care providers may consider patients' immigrant status and family relationships to better serve ethnically diverse populations. Given that cultural factors play an important role in ACP engagement, ACP should be adapted to be more culturally appropriate among Chinese Americans, especially in a time of coronavirus and xenophobia, such as framing ACP as a tool to help families reduce stress while fulfilling filial obligations, in order to ensure equitable access to ACP.

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