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Chinese Americans' attitudes toward advance directives: An assessment of outcomes based on a nursing-led intervention

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ABSTRACT

Background: The process of advance care planning (ACP) encompasses learning about and planning for end-of-life (EOL) decisions, documenting preferences through legal forms known as Advance Directives (ADs), and having discussions with loved ones to share these preferences. While most ethnic minority groups have low ACP engagement and AD completion rates, Chinese Americans face additional challenges related to cultural beliefs and ACP.
Purpose: The purpose of this study was to estimate the impact of a culturally tailored nurse-driven educational intervention on the relationship between attitudes toward ADs and AD completion and ACP discussions.
Design: Pre-posttest, repeated measures non-experimental design.
Methods: A convenience sample of Chinese Americans participated in a culturally tailored nurse led AD and ACP workshop in English and Mandarin in a Chinese Community Center. Participants completed surveys before and after the workshop and at one-month follow-up.
Results: Seventy-two Chinese Americans participated in this study. Most were female and born in China. Attitudes toward ADs improved after participating in the workshop and remained consistent at one-month follow-up. There was a significant positive relationship between attitudes and AD completion and ACP discussions.
Conclusions: Nurse-driven interventions improved engagement in the ACP process in Chinese Americans, a population thought to be averse to discussing death and dying and one with lower than average AD completion rates. Using culturally tailored interventions improves engagement in the ACP process.

1. Background

1.1. Advance care planning and advance directives

The process of advance care planning (ACP) encompasses learning about and planning for future medical care at a time of serious or chronic illness or the end-of-life (EOL). Individuals consider and document treatment preferences and ideally share these wishes with loved ones. An important aspect of ACP is having ACP discussions with family and loved ones about treatment desires [Levi & Green, 2010; National Hospice and Palliative Care Organization (NHPCO), 2017]. "The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness" (Sudore et al., 2017, p. 826). Advance Directives (ADs) are legal documents used to share EOL treatment wishes and to guide care when individuals are no longer able to make decisions for themselves (Olick, 2012). Completion of ADs is part of the ACP process (NHPCO, 2017). The United States (US) Patient Self Determination Act (PSDA) of 1990 passed in order to promote ACP (American Bar Association, 2013). The Institute of Medicine (IOM) (2015) report, *Dying in America*, recognized the need for improvements in EOL care, including addressing specific needs of an increasingly diverse US population through increased provider-patient communication and active provider participation in ACP.

In the US, overall AD completion rates are low at best. In a systematic review of 150 studies with 795,909 US participants, AD completion was 36.7% (Yadav et al., 2017). A 2014 study of 7946 individuals found that only 26.3% of Americans had an AD, most citing unawareness of ACP as the key reason for non-completion (Rao, Anderson, Lin, & Laux, 2014). Many AD and ACP studies lack diversity. Overall, Caucasians have higher AD completion rates than individuals from diverse cultural backgrounds. Silveria and colleagues (2014) found much higher AD completion rates, nearing 64%, in a relatively homogeneous sample of 6005 mostly Caucasian individuals. Some studies, particularly those of diverse individuals, including Chinese Americans, show that non-Caucasians are less likely than Caucasians to have an AD and engage in ACP (Gao, Sun, Ko, Kwak, & Shen, 2015).

Reports of AD completion rates in Chinese Americans are varied. A study of 385 Chinese Americans found that 20% of participants had heard of an AD and only 10% had completed one (Gao et al., 2015). Similarly, a study of 2609 Asian Americans found overall AD completion rates of about 14% in Chinese Americans (Jang, Park, Chiriboga,

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Rahhakrishnan, & Kim, 2017). Individuals who have ADs utilize less aggressive treatments at EOL and have lower EOL-related expenditures (Nicholas, Langa, Iwashyna, & Weir, 2011; Silveira, Kim, & Langa, 2010; Silveira, Wiitala, & Piette, 2014). Those with ADs are more likely to receive care consistent with their preferences as outlined in their directives (Silveira et al., 2010, 2014).

Conflicts between cultural beliefs, norms, and practices in regard to EOL care and ACP are prevalent in specific Asian American cultural groups, including Chinese Americans (Chew, 2012). There are approximately 4.9 million Chinese Americans in the US (Pew Research Center, 2017a), representing the largest subgroup of Asian Americans, and one of the most rapidly growing cultural groups of the US population (Pew Research Center, 2017b). Chinese Americans bring a rich history and culture that has a strong influence on their healthcare decisions. Chinese values, steeped in Confucianism, hold a strong focus on beliefs of importance of family (Wong, 2018).

1.2. Culture

Culture, as defined by Bates and Fratkin (2003) is “a system of shared beliefs, values, customs, behaviors, and artifacts that the members of society use to cope with their world and with one another, and that are transmitted from generation to generation through learning” (p. 390). Individuals who are not from Western or Euro-Caucasian cultural backgrounds have additional factors and cultural considerations that influence ACP participation [United States Department of Health and Human Services (HHS), 2008]. Chinese culture, influenced by Confucianism, holds the central virtue of filial piety. Some considerations of filial piety include that children are expected to live with their parents and are responsible for making their aging parents' healthcare decisions. Filial piety may lead to withholding information from family members regarding illness to “protect” them, rendering informed decision-making impossible. Filial piety also leads to a reluctance to place elders in long-term care and disinclination to discuss ACP (Lee, Hinderer, & Kehl, 2014; McLaughlin & Braun, 1998).

Discussions regarding ACP are rare among Chinese families because discussions related to death and dying are taboo for traditional Chinese. Although ACP is not only related to planning for EOL care, many Chinese believe discussions around treatments for serious and chronic illnesses are unwise, as such discussions will hasten death or bring bad luck to the family (Chen et al., 2017; Hsu, O'Connor, & Lee, 2009; McLaughlin & Braun, 1998; Wong, 2018). In an effort to remain respectful of elders, adults may not discuss ACP with their aging parents (Hsu et al., 2009). These cultural beliefs greatly hinder conversations and planning for EOL care in the family, particularly for family elders. In contrast, some studies have demonstrated that Chinese elders are not opposed to discussing death and EOL issues (Chu & Woo, 2004; Lee, Byon, Hinderer, & Alexander, 2018). They may prefer to hold these discussions in a more indirect manner, using hypothetical scenarios and examples of others to share their own treatment preferences (Yonashiro-Cho, Cote, & Enguidanos, 2016). Increased acculturation into Western society and educational efforts on the topics of ACP and ADs improved acceptance of EOL care planning by Chinese Americans (Lee, Hinderer, & Kehl, 2014; Sun et al., 2017). In one study, level of acculturation and knowledge predicted AD completion (Jang et al., 2017). Overall, few studies exist that are specific to Chinese Americans and the unique influence Chinese culture has on ACP, including attitudes toward discussing EOL issues in Chinese residing in the US (Gao et al., 2015).

1.3. Attitudes

Attitudes, or beliefs, toward ACP can influence ACP engagement and AD completion (Nolan & Bruder, 1997). In a diverse sample of 256 low-income older adults, 20% of individuals had an AD, and attitudes regarding ADs varied by racial group. As compared with African Americans and Hispanics, Caucasians were more positive about ADs and had higher AD completion rates. Predictors of AD completion included intensive care unit admission and positive attitudes toward ACP. A one-point increase in attitude score improved the odds of completing an AD by 20% (Ko & Lee, 2014). Likewise, in a sample to 331 diverse individuals, including Caucasians, Hispanics, African Americans, and mixed races, older age, religious affiliation, and knowledge about hospice predicted positive attitudes toward EOL care (Ruff, Jacobs, Fernandez, Bowen, & Gerber, 2011). Using a faith-based educational intervention with Chinese and Korean Americans, attitudes toward ADs and ACP improved with education (Sun et al., 2017). Limited available research and conflicting results related to ADs, EOL discussions, and ACP create the need for further research of ACP in Chinese Americans.

The purpose of this study was to explore the relationship between a nurse-led AD/ACP educational intervention, AD/ACP completion, and attitudes toward ACP in community-dwelling Chinese Americans. This paper focuses specifically on Chinese Americans' attitudes toward ACP and the relationship between attitudes and AD completion and ACP discussions. The research questions for this study were: 1.) Is there a difference in attitudes of Chinese Americans regarding ADs before, immediately after, and at a one-month follow-up after attending a nurse-led educational workshop on ACP; and 2.) Is there a relationship between attitudes about ADs and completion of ADs and ACP discussions in Chinese Americans? This paper addresses a population and a study area with a paucity of research. It explores the role of nursing interventions on attitudes toward ACP and lends insight into Chinese American ACP engagement.

2. Methods

2.1. Design

The study design was non-experimental pre-test post-test repeated measures.

2.2. Sample and setting

Subject recruitment began after the investigators received Institutional Review Board approval from the Committee on Human Subjects at the university. We recruited a convenience sample of Chinese Americans from a Chinese community center with over 2000 Mandarin speaking Chinese American members in the metropolitan area of Washington, DC. Subjects were recruited using flyers, announcements in community center publications, and through word of mouth. Power analyses revealed the need for a sample size of 71 to meet 80% power, alpha of 0.5, with a medium effect size. Seventy-two individuals participated in this study. The study setting was the Chinese community center.

2.3. Instrumentation

The instruments used in this study were bilingual (Chinese and English). To ensure accuracy, two separate individuals fluent in both Mandarin and English reviewed and back translated all instruments. Feedback from this process informed corrections made to the instruments to assure proper translation.

2.3.1. Background survey/demographic instrument

We developed a bilingual (Chinese and English) background survey/demographic instrument for this study. The 13-item survey included open-ended questions that assessed demographic characteristics of the sample, as well as, questions about previous EOL experiences.

2.3.2. Advance Directives Questionnaire

The advance directives questionnaire (ADQ), a ten-item instrument with 7 multiple-choice items and 3 open-ended items, assessed

individuals' experiences with AD and ACP. Multiple-choice items included yes/no responses or responses on a 4-point Likert scale ranging from very likely (4) to not very likely (1). It specifically asked questions about having an AD (Do you have an advance directive?), intent to complete an AD (How likely are you to complete an advance directive?), and having discussions with family members about ACP (How likely are you to talk to your family or friends about your end of life wishes?). Open-ended questions evaluated the workshop (How could this educational workshop be improved?). The study authors developed this instrument, based on theory, clinical expertise, previous research, and the literature, as no other instruments were available (Hinderer & Lee, 2014). The current study yielded a Cronbach's alpha of 0.51 for the multiple-choice items, and the instrument is currently undergoing further revision and testing.

2.3.3. Advance Directives Attitudes Scale

The ADAS, a 16-item instrument, assessed attitudes toward ADs (Nolan & Bruder, 1997). Individual Likert-style item responses ranged from 1 (strongly disagree) to 4 (strongly agree), scores ranged from 16 to 64. Higher scores on the ADAS indicated a more favorable attitude toward ADs. In previous studies of adult populations, alpha coefficients ranged from 0.74 to 0.86 (Douglas & Brown, 2002; Nolan & Bruder, 1997). With permission, the second author translated the ADAS into Chinese. Cronbach's alpha in the present study was 0.82.

2.4. Procedures

Prior to the start of the program, we informed participants about the purpose of the study. We assured confidentiality and informed participants of the voluntary nature of the study. Individuals could choose not to take part in the study but still participate in the workshop. Participants acknowledged consent to participate through survey completion. A one and one-half hour interactive workshop, conducted in both English and Mandarin by two registered nurses, incorporated a culturally sensitive approach to ACP (Table 1). This included sensitivity to Chinese cultural beliefs about EOL and focused on the importance of the family as the decision-making unit. We designed the workshop using health-literacy principles and plain language recommendations of the U.S. Department of Health and Human Services Office of Disease Prevention and Health Promotion (n.d.). The workshop included an interactive session that guided participants through AD completion (Lee, Hinderer, & Friedmann, 2015).

The document used for the workshop was the *Five Wishes*®, a type of AD known as a living will. Available in English and Chinese, *Five Wishes*®, accepted as a legal AD in 42 states, included traditional AD content and an area to document a durable power of attorney for health care (DPAHC). Uniquely addressed within the *Five Wishes*® were individual spiritual, physical, and emotional concepts and EOL requests (Aging with Dignity, 2018).

Prior to the start of the workshop (time 1), participants were asked to complete paper and pencil surveys that included the background/demographic instrument, the ADQ and the ADAS. At the completion of the workshop (time 2), survey data including the ADQ, and ADAS were collected. One month after workshop completion (time 3), participants received follow-up ADQ and ADAS surveys via the mail.

2.5. Analyses

Descriptive statistics (means, frequencies) described sample characteristics, ADAS scores, and explored AD completion and ACP discussions. Repeated Measures Analysis of Variance (RMANOVA) compared differences in ADAS scores from time 1, time 2, and time 3. Correlations examined relationships between AD completion (yes/no), ACP discussions with family/friends (yes/no), and attitudes toward ADs (ADAS score). We used IBM SPSS Statistics version 19.0 (IBM Corp., 2010) for data analysis.

3. Results

Of 72 participants, the overall response rate at baseline (time 1) was 99% (n = 71) and post-intervention (time 2) was 100% (n = 72). The response rate at the one-month follow-up (time 3) was 88% (n = 63).

3.1. Demographics

Participant age ranged from 32 to 87 years (M = 61.1 ± 12.2). The majority of the sample was female (n = 46, 63.9%). All participants were foreign born. Of the 72 participants, 45 (62.5%) reported completing college or graduate school (see Table 2). Within this group, 25 (34.7%) reported having a history of a chronic illness. Very few had previous EOL experiences with one previously on life support, one acted as a surrogate decision maker, and one made previous EOL decisions for another person.

Table 1
Overview of the interactive workshop[a].

Component	Topics Addressed
Part 1: Welcome and Pre-test	Introduction to the workshop and welcome Overview of the study, description of confidentiality and voluntary nature of the study Time to complete the pre-test materials
Part 2: Advance Directives (power point presentation and discussion)	Advance Directives (ADs) – topics included: definition, names for ADs, terminology, types of forms, logistical aspects of ADs, purpose of ADs, seeking legal advice Local resources for further information Introduction to the *Five Wishes*® Break/time for reflection
Part 3: *Five Wishes*® (power point presentation, discussion, hands-on approach with booklets, video clips)	Guided *Five Wishes*® Review – go through each of the sections of the five wishes booklet Special attention and discussion around considering family and the decision to select a healthcare agent Who can witness or sign the forms What to do after the forms are completed – share with medical doctor, hospital, family, and/or surrogate How to talk with family about ADs– open discussion and video clips from the *Five Wishes*® Discussing advance directives with family, discussion of ways to have conversations with family (including examples of indirect discussions)
Part 4: Complete Post-test	Complete post-test Time after workshop to answer additional or individual questions, help with ideas for how to complete or communicate with family

[a] The entire workshop was delivered in English and Mandarin, translation time was included in the presentation.

Table 2
Description of study participants (n = 72)[a].

Variables	Frequency (percentage)
Gender	
Female	46 (63.9)
Male	25 (34.7)
Place of Birth	
China	47 (65.3)
Taiwan	17 (23.6)
Hong Kong	5 (6.9)
Other	2 (2.8)
Highest level of education	
Less than high school	9 (12.5)
Completed high school	15 (20.8)
Completed college	32 (44.4)
Completed graduate school	13 (18.1)
History of chronic illness	
Yes	25 (34.7)
No	45 (62.5)

[a] Not all respondents answered every question.

3.2. Advance directives, advance care planning discussions, and attitudes

At the time of the workshop (time 1/time 2), 21 of 71 participants (29.5%) had an AD and 26 of 71 (36.6%) previously engaged in a discussion with friends and/or family about their ACP wishes. One month following the workshop (time 3), of those who did not have an AD or no previous ACP discussion, an additional 10 participants reported having an AD and an additional 16 individuals had an ACP discussion.

Prior to the workshop (time 1), attitudes toward ADs, as assessed by the ADAS, ranged from 45 to 59 with a mean score of 49.96 (± 4.16). Immediately after the workshop (time 2), ADAS scores ranged from 43 to 76 with a mean score of 51.98 (± 5.94). At the one-month follow up (time 3), ADAS scores ranged from 44 to 61 with a mean of 52.23 (± 5.62) (see Fig. 1).

Repeated Measures Analysis of Variance (RMANOVA) was used to examine the effect of time on attitudes as measured by the ADAS at 3 levels: pre-intervention (time 1), immediately after intervention (time 2), and one month after intervention (time 3). Mauchly's test indicated that sphericity was not violated (p = 0.361). Contrasts with Sidak adjustments for multiple comparisons evaluated differences between ADAS scores at specific time points.

In the RMANOVA, there were significant differences in attitudes as measured by the ADAS according to time [F(2,112) = 6.243, p = 0.003]. Contrasts revealed that attitudes were significantly higher immediately after the intervention (time 2) than before (time 1) (p = 0.014). There was no significant difference between ADAS scores from immediately after the intervention (time 2) to one month later (time 3) (p = 0.975), indicating that attitudes remained stable for this period.

3.3. Relationship of attitudes toward advance directives (ADAS scores), completion of advance directives, and advance care planning discussions

Of those who responded at the one-month follow-up (time 3), there was not a significant relationship between ADAS scores and AD completion (n = 62, p = 0.09) but a significant relationship was found between ADAS scores and ACP discussions (n = 62, p = 0.029). Of those individuals who did not have an AD prior to the workshop, there was not a significant relationship at the one-month follow-up (time 3) between ADAS scores (attitudes) and ACP discussion (p = 0.189), but a significant relationship was found between ADAS scores and AD completion (p = 0.019).

4. Discussion

The current study lends support to nursing-driven, culturally tailored educational interventions for Chinese Americans to improve attitudes and engagement in ACP and AD completion. This study supports the relationship between attitudes and AD completion and ACP discussions in Chinese Americans. The sample of Chinese Americans in this study was relatively healthy and well educated, with most reporting college or graduate education. The majority of the sample were female and from China. This population of Chinese Americans was not averse to participating in the AD/ACP educational session or to engaging in ACP activities.

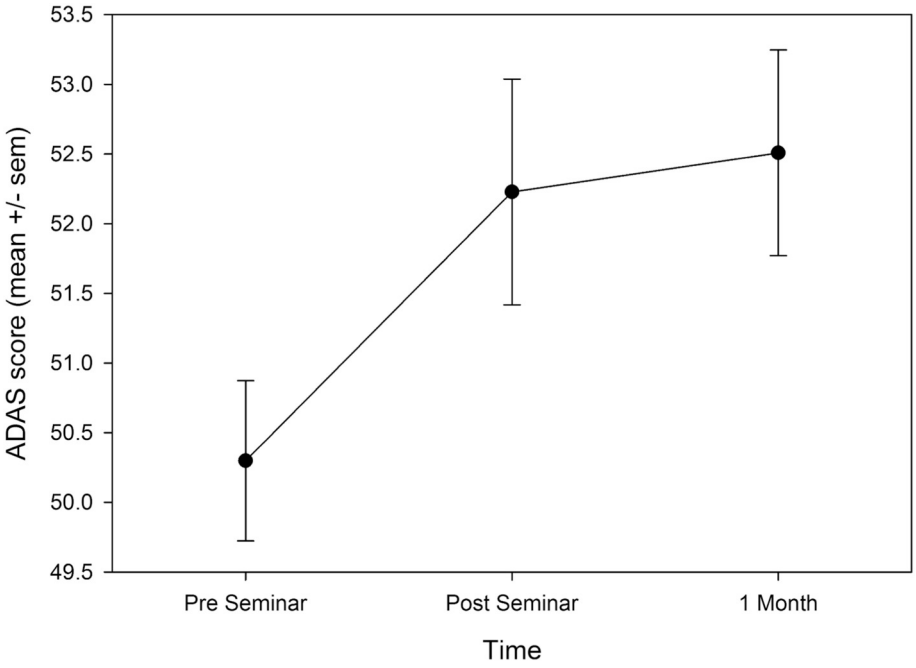

Fig. 1. Mean ADAS Scores Before (Time 1), Immediately After (Time 2), and One Month Following (Time 3) the Workshop.

4.1. Advance directives, advance care planning discussions, and attitudes

Attitudes toward ADs improved with participation in the educational intervention. The current study demonstrated a positive relationship between attitudes and AD completion. In all participants, participation in the workshop increased overall ACP engagement, whether that signified AD completion, ACP discussions, or some combination of both. Ethnic minority groups are generally less engaged in ACP, with identified barriers of knowledge deficits and cultural beliefs (HHS, 2008; IOM, 2015). As compared with the general US population, there is a lower completion rate of ADs and participation in ACP in ethnic minorities (Yadav et al., 2017), including Chinese Americans (Jang et al., 2017). In the current study, Chinese Americans were not opposed to planning for EOL care and saw value in having a plan in place for future decisions. In addition, a nurse-driven, culturally tailored educational program can support ACP engagement and AD completion in Chinese Americans. Attitudes toward ACP were higher after attending the workshop, and, in this sample, positive attitudes did not diminish at one-month post-intervention. Likewise, Sun et al. (2017) and Jang et al. (2017) found improved attitudes toward ACP from a culturally tailored educational intervention with Chinese Americans.

4.2. Relationship of attitudes toward advance directives, completion of advance directives, and advance care planning discussions

As one of the most collectivistic Asian cultures, Chinese cultural beliefs and values pose challenges with relationship to engagement in ACP discussions (Cheng, 2018). Participants in the current study who did not have an AD prior to the workshop demonstrated improved, positive attitudes toward ACP and had a significant increase in AD completion. However, in this group, there was not a significant increase in ACP discussions, potentially highlighting that ACP is a process and that individuals may be moving toward comfort with ACP but are not yet ready to have a discussion. Ko and Lee (2014) suggested favorable attitudes predicted completion of ADs in Chinese Americans. Like the present study, Sun et al. (2017) found that although many Chinese Americans completed ADs, few participated in ACP discussions with proxy decision makers. With Chinese Americans, indirect communication related to EOL care and ACP, such as through discussions about circumstances of others or hypothetical scenarios may be a preferred method of ACP discussions (Cheng, 2018).

5. Limitations

This study had several limitations that need to be considered. The study sample was recruited from a single site located in a metropolitan area of the Eastern US. The sample had a high proportion of college graduates. Social desirability bias cannot be ruled out due to the survey method of data collection. In order to lessen survey burden, we chose not to measure acculturation level, although this may influence attitudes toward ACP (Gao et al., 2015). We noted during the workshop and in subsequent follow-up, many of the participants did not speak English and preferred to communicate in Mandarin. Therefore, the sample may represent individuals not well acculturated to western values. Despite this, we did see positive attitudes toward ADs. Future research should include a measure of acculturation to assess the relationship of acculturation to ADs and ACP.

6. Nursing implications

As opposed to traditional health-care settings, a culturally tailored, community-based, nursing-driven approach to ACP had a positive influence on attitudes toward and completion of ADs in Chinese Americans. Nurses can use therapeutic and sensitive communication to have ACP discussions with patients and families. In clinical settings, nurses should not shy away from addressing ACP and ADs with their patients, especially those of diverse cultural backgrounds (IOM, 2015). Since ACP is considered a process rather than a single event (Sudore et al., 2017), nurses should regularly address ACP with their patients, thus increasing the number of contacts regarding ACP and opportunities to educate and encourage patients to work through the process. Addressing specific preferences in Chinese Americans, such as the preference to have a peaceful death and the desire not to burden family with EOL decisions, may be ways to broach this important topic (Gao et al., 2015; Lee, Hinderer, & Alexander, 2018). The current study showed positive outcomes through nurses educating clients in a culturally sensitive manner, highlighted that ACP is a shared responsibility among healthcare providers and clients, and reinforced the concept of ACP engagement. Future studies could include the use of interprofessional healthcare providers in educational interventions. In our experience, Chinese elders are open to ACP discussions. Future studies should explore how to encourage individuals of diverse backgrounds to have increased engagement in the entire ACP process.

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