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ADVANCE CARE PLANNING IN CHINESE AMERICANS

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Purpose

The objectives of this study are to:

- explore the behavioral, normative, and control **beliefs** in the advance care planning (ACP) discussion among Chinese Americans.
- identify **facilitators, and barriers** of ACP discussion among different generations of Chinese Americans.

Advance Care Planning

Advance care planning is a process used to discuss and determine treatment goals that are consistent with a patient's preferences for care at the end-of-life.

Background

- More than **133 million** (40% of the total US population) Americans were living with chronic progressive diseases.
- Many of them received aggressive care that they **may not want** while others may have desired treatments withdrawn (National Health Council,2014).

Chinese Americans

- Among all Chinese Americans, three-quarters (76%) of adults are foreign-born(National Consensus Project, 2013).
- Their values and beliefs strongly shaped and influenced by the traditional Chinese culture.
- These cultural beliefs may conflict with the overarching American culture of ACP (Chew, 2011).

Advance Care Planning

- It improves **patients'** quality of life by assisting them in recognizing their goals and preparing for end-of-life.
- It reduces **family members'** psychological burden when they need to make decisions for patients (CDC, 2013).

Chinese Culture in EOL care

Traditional Beliefs (Wong, 2013)

- Family and society versus individuals
- Truth-telling
- Taboo
- Filial Piety

Acculturated Beliefs (Koepke & Denissen, 2012)

- Individuality
- Autonomy
- Not a taboo but cultural belief

Significance

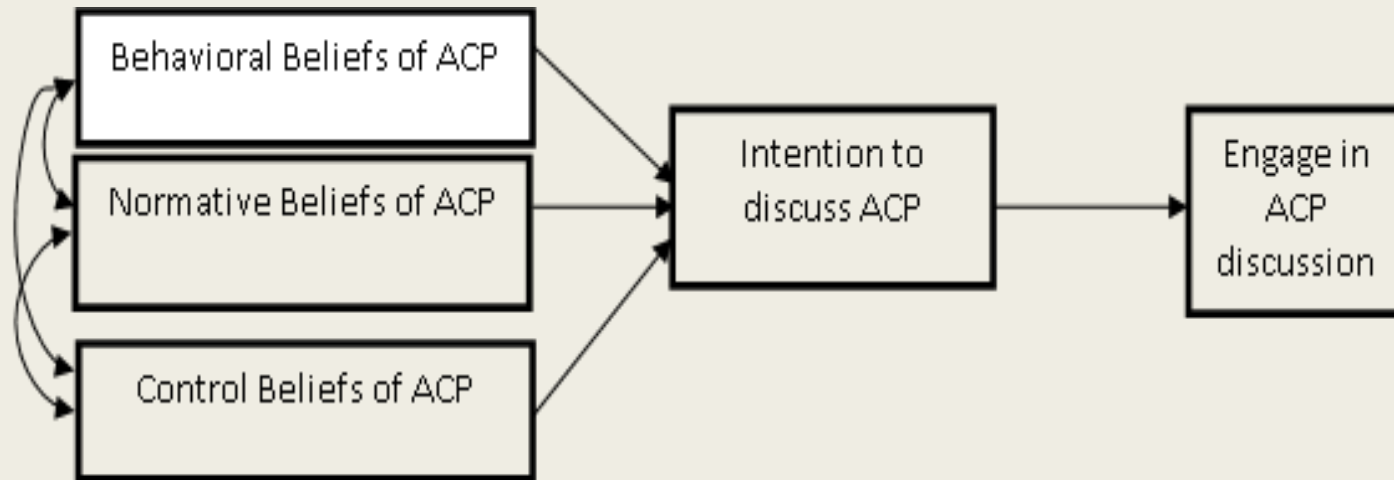
intergenerational differences exist in traditional values and beliefs. These conflicts and confusion between generations may **hinder honest communication** of ACP among Chinese family members (Lin, Bryant, Boldero, & Dow, 2015).

Theory of Planned Behavior

Behaviors are the outcomes of a set of self- perceived beliefs (Ajzen, 2006)

- Behavioral beliefs (beneficial)
- Normative beliefs (desirable)
- Control beliefs (achievable)

Theory of Planned Behavior in ACP, modified from the Theory of Planned Behavior



Study Design

Method: Qualitative-focus groups discussion

Sample: Purposive sampling

- Adult who are above 18 years old
- Self-identified as Chinese Americans
- Speak either Mandarin or English.
- N= 60 (older and younger groups)

Study Design

Step1: Question Development

- A list of questions were constructed based on the Theory of Planned Behavior and literature review.

Step 2: Develop Script and Prompts for interview guide

Step 3: Pilot Test the questions to ensure the questions are understood as intended.

Study Design

- Sample questions:
 - *Is advance care planning important?*
 - *What do you see as the benefit of having the discussion of advance care planning?*
 - *Do most of the people who are important to you think that advance care planning discussion is needed/not needed?*
 - *Do you think you could bring up the topic of advance care planning with your family?*
 - *All questions are open-ended to promote discussion.*

Procedure

- IRB approval
- Ten focus group discussion (5 for older and 5 for younger groups)
- Each focus group had about 2-7 participants.
- Each group discussion was about 2 hours.
- Verbal consent
- audio-typed

Data Analysis

- Line by line analysis of the transcripts will be guided by thematic approach (Van Manen, 1990).
- The Framework Method was used (Gale, Heath, Cameron, Rashid, & Redwood, 2013).
- Open coding was also employed to allow for independent groups of themes to develop beyond the three constructs.
- NVivo software was used to organize the data.

Results

- The sample had a mean age of 53 ($SD = 18.33$), range from 29 to 79 years old.
- Three-quarters of the sample (75%) were females.

Older Chinese Americans (>65)

- ACP is good and needed
- ACP discussion is a taboo
- Children do not want to discuss ACP
- Discussing ACP with children will upset them
- Not capable to discuss ACP
- Lack of information about ACP
- Lack of English proficiency
- Lack of ACP tool that is sensitive to Chinese culture.

Younger Chinese Americans (<65)

- ACP is important
- ACP discussion is a taboo
- Not supported by the Chinese society
- Easier to have ACP conversation with younger generation
- Discussing ACP with parents will be criticized, labeled as no filial and disrespectful
- Not capable to discuss ACP
- Afraid to be a surrogate and make wrong decisions
- Being a surrogate decision maker is a huge responsibility

Results

Facilitators for ACP

- Prior experience
- Small group discussion
- Indirect approach such as case study
- **Safe opportunity** to start the conversation

Discussion

- The finding that older participants had a positive attitude about ACP in this study was **encouraging**: despite the traditional cultural beliefs about death and dying, introducing and promoting the ACP in Chinese Americans could be feasible and practical.
- This study revealed an interesting intergenerational phenomenon likely caused by and **cultural beliefs & social expectations**.
- More resources and support are need to engage Chinese Americans in ACP discussion.

Acknowledgement

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