

ADVANCE CARE PLANNING AMONG CHINESE AMERICANS

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Advance Care Planning

1) Advance care planning is 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.

(2) 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.

(3) For many people, this process may include **choosing** and preparing another trusted person or persons to make medical decisions in the event the person can no longer make his or her own decisions.

(Sudore, et al. 2018)

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).

Significance

- 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- Many of them received aggressive care that they **may not want** while others may have desired treatments withdrawn (National Health Council,2014).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).

Chinese Culture in EOL Decision-Making

Traditional Beliefs (Wong, 2013)

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

Acculturated Beliefs (Koepke & Denissen, 2012)

- Individuality
- Autonomy
- Not a taboo but a cultural baggage

Gaps

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).

Purpose

The objectives of this study are to:

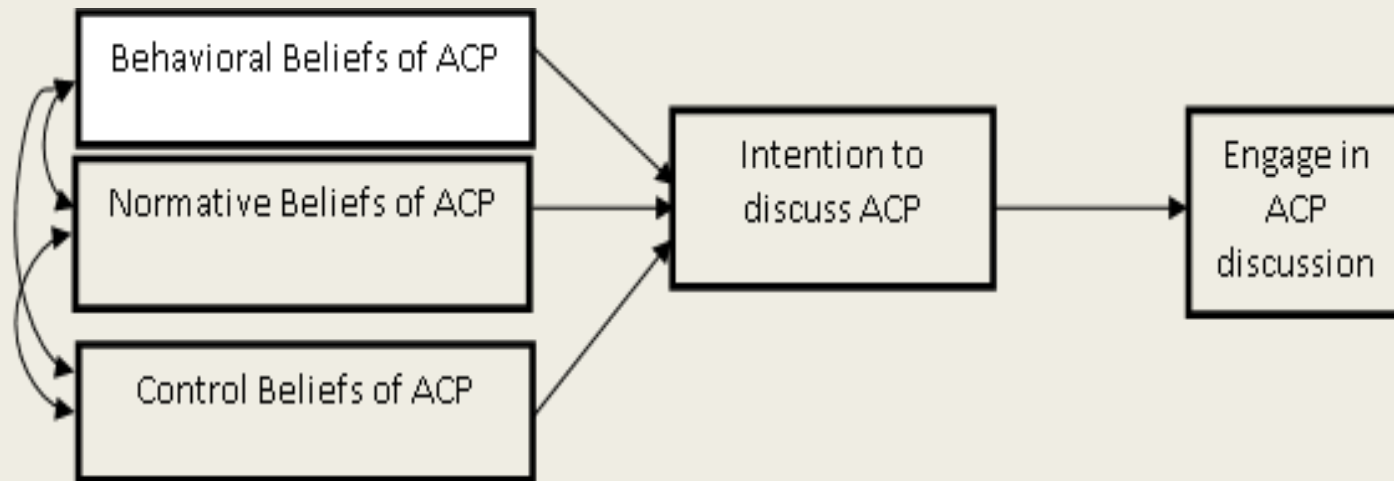
- explore the behavioral, normative, and control **beliefs** in the advance care planning (ACP) discussion among Chinese Americans.
- identify **facilitators, and barriers** of ACP discussion among different generations of Chinese Americans.

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 was 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

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

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

This study is supported by the Center for Health Outcomes Research, University of Maryland Baltimore School of Nursing.

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