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"At the End I Have a Say": Engaging the Chinese Community in Advance Care Planning

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Abstract

Context.—Despite the association of advance care planning (ACP) with improved patient and caregiver outcomes, Chinese American elders have low rates of ACP.

Objectives.—Assess ACP facilitators/barriers in the San Francisco (SF) Chinese community and codesign, implement, and test community-based ACP-promoting pilot events.

Methods.—A Chinese Community Committee (N = 19 community-based organization leaders, health system representatives, community members) conducted focus groups in Cantonese and English with Chinese older adults (age ≥55), caregivers, and community leaders. The Committee designed and implemented pilot events in-person and online. We analyzed focus group data using thematic analysis; assessed pre-to-post-event readiness to engage in ACP (validated survey; 14 scale, 4 = most ready); and assessed event acceptability.

Results.—A total of 34 people participated in six focus groups. Themes described Chinese community-specific importance of ACP (e.g., reduces family burden), barriers (e.g., younger generations lack tools to discuss ACP with elders and vice versa), and facilitators (e.g., intergenerational events, culturally/linguistically appropriate materials). Based on focus groups findings, the Committee developed a novel ACP tool and designed intergenerational events. A total of 195 participants attended 10 events; 95% were Chinese, 90% spoke Chinese languages, 80% were women. ACP readiness increased significantly (1.66 [SD 0.84] vs. 2.03 [SD 0.85]; $P < 0.001$); 94% of participants were comfortable attending and 96% would recommend events.

Conclusion.—Community-developed intergenerational events that highlight the value of ACP and address barriers are acceptable and increase ACP engagement in the Chinese community.

Keywords

Advance care planning; Chinese/Asian American; community-based participatory research; health disparities; implementation science

Introduction

The Chinese older adult population in the United States (hereafter referred to as Chinese American elders) is growing rapidly and faces significant disparities in serious illness and end-of-life care, including lower respect by healthcare teams for cultural traditions and spiritual beliefs, higher unmet needs for caregiver support, and lower hospice use compared to White older adults.[1–6] Chinese American elders also have lower rates of advance care planning (ACP), the process by which patients and surrogates prepare for serious illness communication and medical decision-making; the completion rate of advance directives among Chinese Californians specifically is less than half that of White Californians.[2,4,7–10] Given ACP is associated with myriad positive outcomes, including higher patient and family satisfaction with care and lower surrogate distress, increasing ACP among Chinese American elders is critical.[11–13]

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Reasons for low rates of ACP among Chinese American elders include clinician/healthcare communication that is not linguistically and/or culturally appropriate regarding death and dying, cultural preferences concerning intrafamilial decision-making, and low knowledge about ACP.[2,7,8,14–18] Several interventions designed to increase ACP in this population have shown feasibility, acceptability, and higher rates of advance directive completion.[3,19–21] Yet, these interventions have not demonstrated an increase in elders discussing their wishes and care preferences with their surrogate decision-makers—even after completing advance directives—and some require trained health-care personnel for intervention delivery.[20,21] Furthermore, no prior studies have explored interventions that were developed and implemented by the consensus of the Chinese American community. It is possible that filial piety, a virtue focused on respecting parents and elders, impacts families' comfort having intergenerational ACP discussions, but this is unknown.[22] To address this gap in comprehensive ACP engagement and to uplift culturally appropriate, family-centered decision-making, it is imperative to develop and design approaches to ACP with the Chinese community.[23–25]

In this study, we present findings from a community-based participatory research ACP project designed and led by the Chinese community in San Francisco. Our goal was to better understand community-level facilitators of ACP and to use those learnings to develop and implement community-based ACP events.

Methods

Design and Setting

Working in partnership with the San Francisco (SF) Palliative Care Workgroup, which consists of clinicians, representatives from the SF Department of Disability and Aging Services, and community-based organizations (CBOs) that serve older adults, we developed *Learning Journeys*, a community-based participatory research (CBPR) project focused on ACP. From September 2020August 2021, we collaborated with Black, Chinese, and Latinx communities in SF who experience both systemic disadvantages (e.g., poverty, racism) and disparities in ACP engagement.[26] The Chinese community identified ACP as a priority area for improving health and wellbeing in their community. The SF Palliative Care Workgroup contracted with a bilingual, bicultural Community Ambassador (author CH) to lead this project based on her connection to the community and experience with community engagement and ACP. CH is Cantonese-speaking, as is most of the Chinese community in San Francisco. CH led the formation of a Chinese Community Committee, consisting of 19 paid community members, including leaders of CBOs, representatives from health-related or hospice organizations, and clinicians. The Committee spearheaded each step of *Learning Journeys*, including the overall process, focus groups, event design, and event pilot testing. Fig. 1 provides a timeline and flow-chart of each step of the *Learning Journeys* process and *Learning Journeys* is described in additional detail in a prior publication.[27] This study was approved by the University of California San Francisco Institutional Review Board.

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Methodological and Theoretical Frameworks

We used CBPR as a methodological framework because it reduces health disparities and emphasizes building an equitable partnership between the community and research team.[28,29] We applied the Behavior Change Wheel framework to translate focus group learnings into intervention development.[30] This framework is built upon the Capability, Opportunity, Motivation, and Behavior (COM-B) theory to understand and change targeted behaviors (e.g., ACP engagement) in context (e.g., in a community setting).[31,32] Capability refers to the ability to engage in the process necessary for ACP, opportunity refers to external (e.g., environmental) settings that influence ACP engagement, and motivation refers to conscious and unconscious beliefs that affect ACP engagement. In using this implementation science framework, our goal was to achieve key implementation outcomes, such as acceptability and effectiveness.

Focus Groups

We conducted focus groups to explore ACP facilitators/barriers and identify necessary elements for community-based ACP events. With the Community Committee, authors SN, MW, and RS developed a semi-structured interview guide based on the COM-B model. The Community Ambassador conducted six 90-minute focus groups with English- or Cantonese-speaking, Chinese/Chinese American-identifying older adults (≥55 years old; one focus group in Cantonese, one in English), caregivers (two in Cantonese), and community-based leaders (two in Cantonese). Using e-mail and word of mouth, the Community Committee recruited participants through purposeful snowball sampling (e.g., identifying key informants and asking them to recruit from their networks). We conducted focus groups via Zoom due to the COVID-19 pandemic (Zoom Video Communications, Inc, 2022), and provided Zoom coaching and technical support. Those who were unable to join by video (e.g., did not have a video-capable device) were invited to join by phone. Participants received a $125 stipend.

Event Design

The Chinese Community Committee met 10 times to design community-based ACP events based on focus groups learnings. The design process included choosing partnering CBOs to host and facilitate events, deciding on event content, and developing a novel ACP tool describer further in *Results*. All event facilitators underwent a two-hour “train the trainer” workshop led by an experienced palliative care nurse manager, which included watching the movie *Extremis*, engaging in discussions about “quality of life” and “a good death,” and reviewing existing ACP tools including Go Wish and Prepare for Your Care.[33,34]

Event Pilot Testing

Event participants were recruited via social media (primarily WeChat, a free messaging and social media app, which was identified as the preferred messaging platform for this community), flyers at community and housing centers, and direct outreach via email and phone to clients of partnering CBOs. We used the validated, four-item ACP Engagement Survey with adapted scoring (scores ranging from 14; 4 = most ready) to assess participants’ pre/post-event readiness to engage in ACP.[35] The survey assessed readiness to discuss

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preferences for care with a surrogate decision-maker or with a doctor and readiness to name a surrogate decision-maker or put wishes for medical care preferences in writing. The pre-survey, administered in the week prior to online events and/or immediately before the start of in-person events, included demographic questions (self-identified age, race/ethnicity, gender, sexual orientation). The postsurvey, administered within one week after events, included closed and open-ended questions assessing acceptability (e.g., comfort attending events, willingness to recommend events to others, etc.). Event facilitators completed a post-event survey with open-ended questions assessing feasibility (number of attendees, successes, suggestions for improvement).

Statistical Analysis

Recorded interviews were professionally transcribed; Cantonese interviews were transcribed in Chinese and translated to English through a certified forward-backward translation. SN and MQ analyzed transcripts using thematic analysis (interrater reliability >80%; Dedoose Version 9.0.46, Los Angeles, CA) and met frequently with the coauthor team to discuss emerging themes.[36] We initially analyzed older adult, caregiver, and leader data separately, then combined them because there were no differences in findings between groups. To assess differences between matched pre- and post-surveys in ACP readiness overall and for each question, we used Wilcoxon signed rank tests (R version 4.2.0; alpha<0.05). We repeated analyses, stratifying by event setting (in-person vs online). Based on prior research and validation, a pre to post increase of ≥0.2 is considered clinically meaningful.[35,37] We conducted content analysis on answers to open-ended questions.

Results

Focus Group Findings

All focus group participants identified as Chinese or Chinese American. Eleven elders (six English-speaking and five Cantonese-speaking), 12 Cantonese-speaking caregivers, and 11 Cantonese-speaking community leaders participated in focus groups. Themes highlighted facilitators of and barriers to ACP in the Chinese community, relating to capability, opportunity, and motivation (Fig. 2). Participants shared that ACP is important to the Chinese community because it reduces family burden and helps guide surrogates in decision-making. Participants also said that talking about death and ACP can be inauspicious, doctors do not bring up ACP, and, importantly, younger generations lack the tools or strategies on how to bring up ACP with elders, and vice versa. Themes identified several facilitators to increase ACP engagement, including intergenerational group events to both facilitate discussion between older and younger generations and increase peer influence, and access to culturally, linguistically, and literacy appropriate ACP materials.

Event Design Outcomes

Intergenerational Focus and Development of a Novel Tool.—Based on focus group learnings, the Chinese Community Committee prioritized two key areas: 1) designing intergenerational events to facilitate ACP conversations among families and 2) developing a novel ACP tool and process that would support ACP conversations over time by connecting with a cultural tradition. Specifically, the Committee designed a behavioral

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intervention to increase *Capability* by creating linguistically and culturally appropriate materials, *Opportunity* by facilitating group, intergenerational events, and *Motivation* by drawing on cultural beliefs.[30]

The desire for intergenerational events stemmed from focus group findings and Committee member input, many of whom noted that some Chinese American elders do not talk with their children about their wishes even after completing an advance directive. This discordance between completing advance directives but not talking with surrogates led to the development of a novel ACP tool, "The Precious Blessing—the Conversation" (an idiomatic English translation of "Passing the Blessings from Generation to Generation" in Chinese). "The Precious Blessing—the Conversation" is designed around the *Five Blessings*, which is a millenia-year-old concept reflected upon by many families during the New Year. One of the Five Blessings is *kao zhong ming*, or the desire to have a peaceful death in old age. The Committee developed this novel, culturally tailored ACP tool through an iterative process with community members and by drawing on their personal and professional experiences working with Chinese elders. "The Precious Blessing—the Conversation" takes the form of a pamphlet with questions for reflection and discussion about preparing for medical decision-making and for conversations that support surrogates for decision-making (Fig. 3). The pamphlet art features "Grandma Blessing," a happy, comfortable grandmother surrounded by her family, plants, and cat. This novel tool does not reference any existing ACP tools or materials.

Implementation of Community ACP Events.—The Chinese Community Committee partnered with three CBOs to host a total of ten events (six in person, four online via Zoom). Partnering CBOs were Self-Help for the Elderly, a nonprofit organization that provides services to low-income and racial/ethnic minority older adults, Chinatown Community Development Corporation, an organization that serves primarily the Chinatown neighborhood to enhance quality of life of residents, and the Buddhist Center, a spiritual community in the Bay Area. In-person events were held in the community centers of three housing sites for low-income older adults in Chinatown (Lady Shaw Senior Housing, Bayside Elderly Housing, and the International Hotel). Partnering CBOs promoted the ACP events via WeChat groups, newsletters, radio, and flyers at the housing sites and other CBOs in Chinatown. All events included screening of a freely available video personal testimonial starring well-known Hong Kong film and television actor Chow Chung (age 90), followed by time for questions and sharing of stories among peers and between generations facilitated by "The Precious Blessing" tool, and ending with a review of the Prepare for Your Care easy-to-read advance directive in Chinese. Events also included incentives (e.g., gift cards, raffles with prizes). Events were facilitated by a leader from each partnering CBO and the Community Ambassador (CH), who is a hospice nurse and experienced ACP facilitator.

Pilot Event Assessments.—A total of 195 participants attended events (95 in-person and 100 online); 193 completed pre-event surveys, 156 completed postevent surveys. Their mean age was 62 years old (SD 20; ranging 6 generations from ages 14103); 95% of participants were Chinese/Chinese American, 90% Chinese-speaking (68% Cantonese or Toisanese, 19% unspecified Chinese, 5% Mandarin), 80% women (Table 1).

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Readiness to engage in ACP increased significantly pre vs. post event overall (1.66/4 (SD 0.84) vs. 2.03 (SD 0.85); $P < 0.001$) and for each individual question ($P < 0.001$ for each; Table 2). When stratified by event setting (in-person vs. online), the increase in ACP readiness remained clinically and statistically significant in both groups (Supplementary Material A).

Nearly all participants were comfortable attending events (94%) and would recommend events to others (96%). Participants' reasons for attending events included curiosity, wanting to increase their knowledge about ACP, and wanting to plan for the future for themselves or their families. Participants liked learning more about ACP (an "unfamiliar" topic), and "sharing with other participants"; they described events as "a rich experience," "clear," and "useful." Several participants requested more time for dialogue and peer-to-peer sharing in future events, and called for events in Mandarin. While some participants noted that talking about death and therefore ACP is "uncomfortable," they also expressed appreciation for these events as spaces to prepare for these "taboo topics."

Event facilitators from partnering organizations shared that giving participants time to discuss ACP with their peers, reviewing the Prepare for Your Care advance directive, and using culturally appropriate materials such as the video testimonial were the most effective elements of the events. They noted that more time, a higher facilitator to participant ratio, and more one-on-one outreach to participants prior to events would help improve events in future, which they hoped would continue on an ongoing basis. They also noted that event evaluation in the form of surveys was a distraction to the event content, and was particularly cumbersome for the oldest-old, many of whom had literacy and visual challenges that required one-on-one support to complete surveys.

Discussion

In this study, we found that community-based, intergenerational, group events using a community-designed culturally-aligned tool reflecting a millennia-year old concept of the Five Blessings are feasible, acceptable, and effective at increasing ACP engagement in the SF Chinese community. The Chinese community drew on their strengths such as close intergenerational relationships, existing culturally and linguistically appropriate ACP materials (e.g., Prepare for Your Care), and cultural traditions to design and implement events that were well-received by the community and that increased ACP engagement. To the best of our knowledge, this is the first community-based participatory research project focused on ACP among Chinese American elders.

The community ACP events developed in this project increased ACP engagement in several key areas, including readiness to put wishes into writing as well as readiness to talk about wishes and care preferences with families and doctors. The latter is critically important, as the goal of ACP is to equip people and their surrogates with skills and preparedness for serious illness communication and medical decision-making—in other words, ACP is a process that encompasses much more than completing an advance directive at a single point in time.

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As demonstrated in prior research, Chinese/Chinese American older adults recognize the importance of ACP and are motivated to engage in this process.[2,23] In addition, some of our findings are unique and promising, as other existing ACP interventions have not demonstrated an increase in discussions between Chinese American elders and their loved ones, even while resulting in higher advance directive completion rates. Moreover, similar to other studies we found that Chinese/Chinese American older adults want to discuss ACP with their doctors but lack the opportunity.[14,23] Our team's work has indicated that health system ACP interventions in primary care settings have resulted in increased advance directive completion rates among Chinese American elders (results unpublished). However, it is unknown whether increased advance directive completion correlates with more ACP conversations between older adults and their clinicians or families. Introducing ACP in a community event that increases older adults' readiness to discuss ACP with their doctors may empower them to initiate these conversations.

Specific design elements of the community ACP events, derived using the COM-B framework, likely contributed to the events' effectiveness. The increase in readiness to discuss wishes with loved ones may be influenced by the intergenerational design of the community ACP events, which increased both *capability* and *opportunity* of participants to engage in ACP. While prior studies have established the importance of family participation in decision-making in the Chinese population, there has been limited understanding thus far of how best to incorporate family into ACP.[23] In line with Jia et al.'s[23] finding of harmony as a key value in this population, it is possible that community ACP events that intentionally create space for intergenerational conversations may promote harmony both within families and across the community in regards to ACP discussions. The Chinese Community Committee also created a novel ACP tool based on the concept of a peaceful death in old age, one of the Five Blessings that many families reflect on at least yearly during the New Year. Developing a tool that is rooted in this tradition, which includes reflection with family in a non-stressful setting, may have increased *motivation* by reinforcing the importance of talking about ACP with loved ones. Finally, group events provided both *opportunity* and *motivation* for ACP discussion among families by increasing peer-to-peer sharing of stories and experiences, thereby normalizing a taboo or inauspicious topic like ACP.[38,39]

Importantly, aside from the novel tool "The Precious Blessing—the Conversation," much of the event content consisted of existing culturally, linguistically, and literacy appropriate ACP materials, suggesting that leveraging existing materials to introduce ACP in a community setting is feasible, even in resource-limited settings. Like prior research, our findings demonstrated that Chinese/Chinese American older adults have a strong desire for linguistically and culturally tailored material.[3] The Chinese Community Committee directly responded to this request by incorporating the Chinese language easy-to-read advance directive by Prepare for Your Care and a freely available video about ACP featuring a well-known Hong Kong actor. In their postevent acceptability evaluations, event participants responded to both of these materials favorably. Notably, in stratified analyses, online and in-person events were similarly effective at increasing ACP readiness, underscoring that even with the constraints of the COVID pandemic, community ACP events remain feasible and effective.

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This study has several limitations. Focus groups and in-person events were conducted in Cantonese and “The Precious Blessing—the Conversation” is written using traditional rather than simplified Chinese, reflecting the Chinese/Chinese American population in San Francisco. Both prior to the Chinese Exclusion Act of 1882 and after the Magnuson Act of 1943, most Chinese immigrants to San Francisco were working-class people from Cantonese-speaking Guangdong province, China, and Hong Kong. While the use of traditional Chinese may limit generalizability of the novel ACP tool specifically, San Francisco has a large (21% of the San Francisco population with 19% speaking Chinese languages at home), multigenerational, and socioeconomically diverse Chinese population relative to other cities in the United States, suggesting the intervention and research process more broadly may be generalizable to other Chinese/Chinese American communities in the US. There is a risk of selection bias, with people who are already interested in or curious about ACP being more likely to participate in focus groups or attend events. Still, we found relatively low ACP readiness scores at baseline among participants that increased after the events. Survey attrition rate was high, and event facilitators noted significant challenges in survey completion particularly among the oldest-old, suggesting the need for alternative forms of evaluation in future work. Prior research has suggested that Chinese older adults defer ACP until they are facing advanced illness or death.[40] To minimize survey burden, as noted, we did not assess participants’ health status, and therefore do not know how that may have impacted their engagement.

This CBPR initiative demonstrated feasibility, acceptability, and effectiveness of community ACP events that were designed and implemented by the Chinese community in San Francisco. These events were successful in motivating participants to speak with their family members and clinicians about their care preferences. We found that an intergenerational approach to ACP events aligned with cultural values in decision-making is highly desired and aligns with cultural values in decision-making. This preliminary work led to the development of a novel ACP tool for the Chinese community and simultaneously reinforced the importance of leveraging existing culturally, linguistically, and literacy appropriate ACP material to increase ACP engagement. Based on participant feedback, next steps include refinement of the novel ACP tool, event format (e.g., event duration, facilitator-to-participant ratio, etc.), and implementation strategy at community-based organizations. This collaborative project lays the groundwork for continued research designed to increase ACP among Chinese/Chinese American older adults, which is critical in this rapidly growing population that faces significant disparities in serious illness and end of life care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Key Message

The Chinese older adult population in the US is rapidly growing, has low rates of advance care planning (ACP), and faces disparities in serious illness care. A community-based participatory research approach to ACP in the San Francisco Chinese community was acceptable and effective at increasing readiness to engage in ACP.

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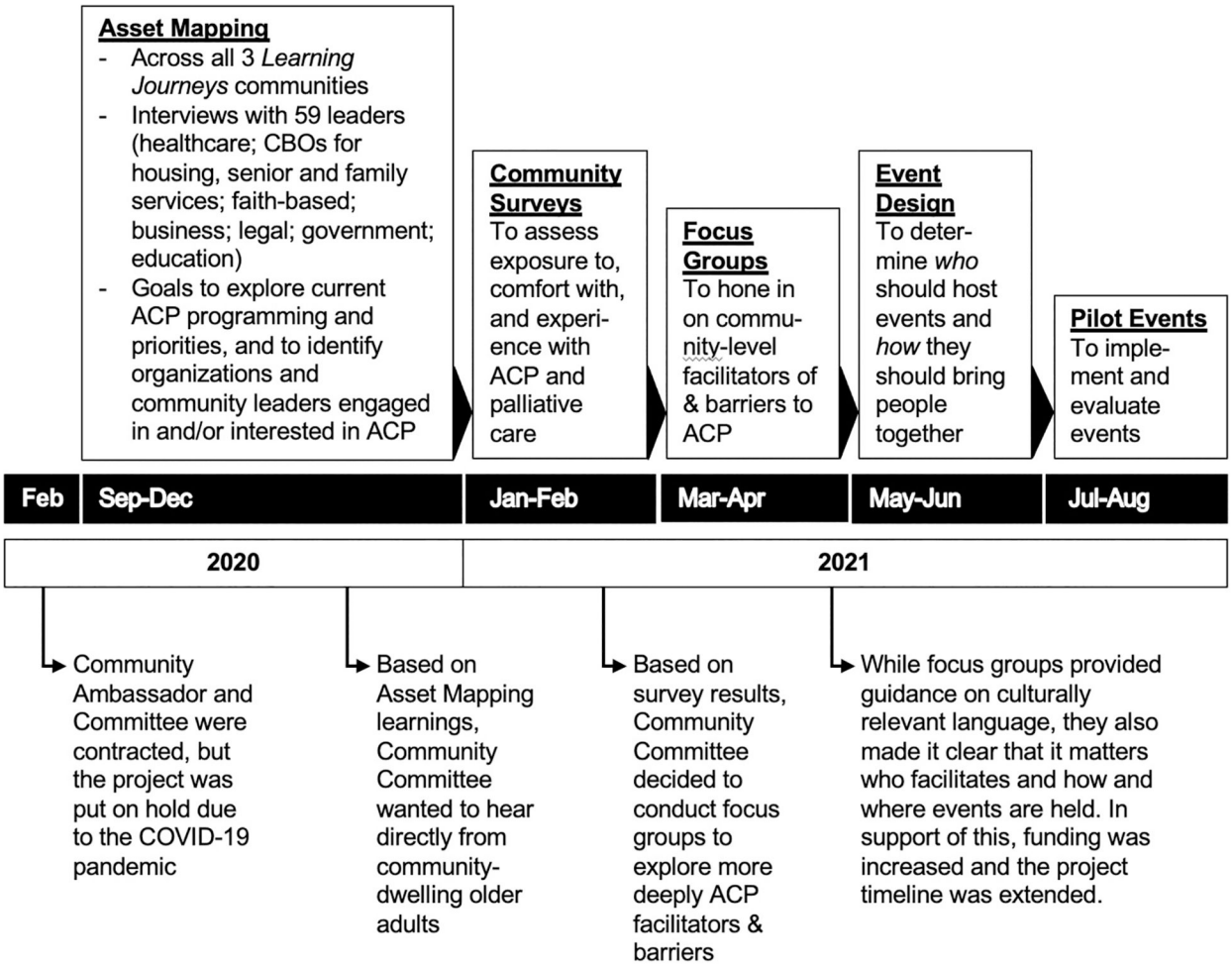

Fig. 1.
Timeline and flow chart of the *Learning Journeys* process.

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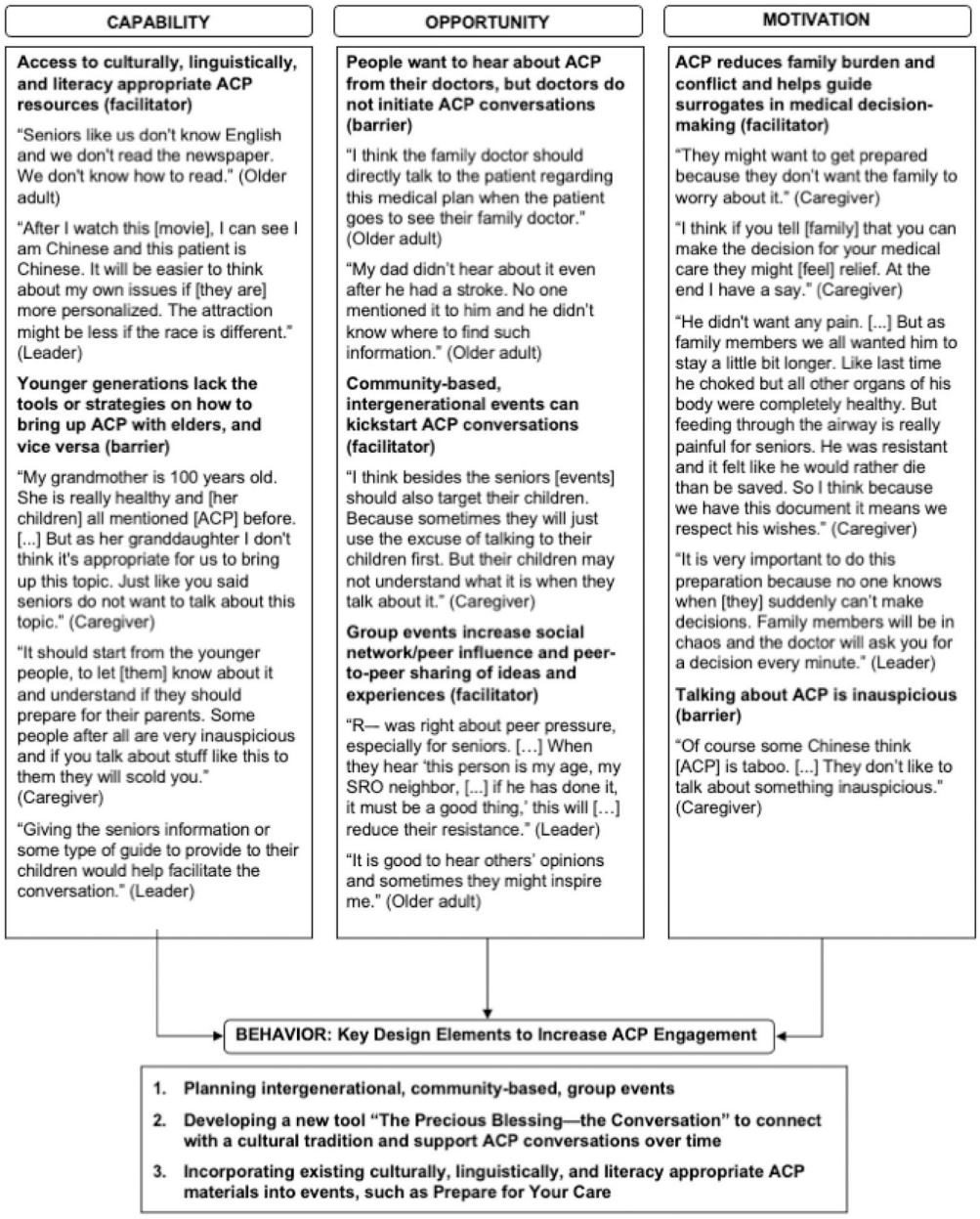

Fig. 2.

Findings from focus groups with Chinese or Chinese American older adults, caregivers, and community leaders presented by Capability, Opportunity, Motivation, and Behavior (COM-B) theory.

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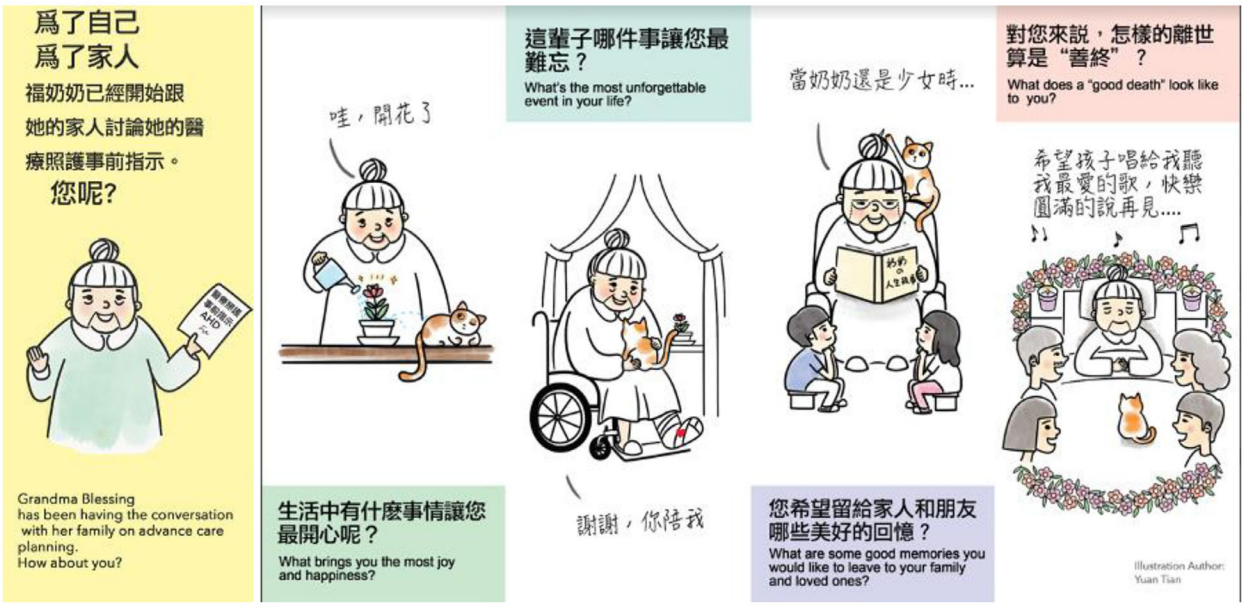

Fig. 3.

(Color). “The Precious Blessing—the Conversation” pamphlet, a novel tool for advance care planning engagement. The pamphlet features “Grandma Blessing,” a happy and comfortable grandmother, surrounded by her family, plants, and cat, and poses questions for reflection and discussion with surrogates about medical decision-making.

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Table 1

Characteristics of Participants Who Attended Advance Care Planning Pilot Events

Characteristic	Participants (N = 193)
Age,[a] mean (SD), range	62.0 (19.6), 14103
Race/ethnicity,[b,c] n (%)	
Asian	184 (95.3)
Black or African American	2 (1.0)
Hispanic or Latinx	1 (0.5)
White	1 (0.5)
Missing	5 (2.7%)
Language spoken at home,[b] n (%)	
Cantonese	109 (56.5)
Toisanese	21 (10.9)
Mandarin	10 (5.2)
Chinese (did not specify)	36 (18.7)
English	5 (2.6)
Missing	14 (7.3)
Gender,[b,d] n (%)	
Woman	154 (79.8)
Man	35 (18.1)
Gender nonconforming	1 (0.5)
Missing	4 (2.1)
Sexual orientation,[e] n (%)	
Heterosexual/straight	167 (86.5)
Bisexual/pansexual	6 (3.1)
Something else	5 (2.6)
Missing	15 (7.8)

[a] Participants from six generations were in attendance: Generation Z (n = 6), Millennial Generation (n = 42), Generation X (n = 23), Baby Boom Generation (n = 81), and the Silent Generation (n = 34), and the Greatest Generation (n = 9).

[b] Participants could select more than one option. Percentages may add to >100%.

[c] Response options also included Native Hawaiian/Pacific Islander, American Indian or Alaska Native, Middle Eastern/North African, and Something Else.

[d] Response options also included non-binary, transgender and Something Else.

[e] Response options also included gay/lesbian.

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Table 2

Pre- and Postevent Readiness to Engage in ACP, Using the Validated ACP Engagement Survey. Scores Ranged From 14; 4 = Most Ready

	Pre-Event, Mean (SD) (N = 193)	Postevent, Mean (SD) (N = 156)	Wilcoxon Signed Rank Test
Mean overall score	1.66 (0.8)	2.03 (0.9)	$P < 0.001$
Individual questions			
How ready are you to talk to your decision maker about the kind of medical care you would want if you were very sick or near the end of your life?	1.71 (1.0)	2.03 (0.9)	$P < 0.001$
How ready are you to put your wishes into writing about the person or group of people to make medical decisions for you?	1.73 (1.0)	2.04 (0.9)	$P < 0.001$
How ready are you to talk to your doctor about the kind of medical care you would want if you were very sick or near the end of your life?	1.63 (1.0)	2.01 (0.9)	$P < 0.001$
How ready are you to put your wishes in writing about the kind of medical care you would want if you were very sick or near the end of your life?	1.59 (1.0)	2.05 (0.9)	$P < 0.001$