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"Advocating for what we need": A CBPR Approach to Advance Care Planning in the Latinx Older Adult Community

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Abstract

Background: Advance care planning (ACP) is low among Latinx older adults. We used community-based participatory research (CBPR) to identify ACP barriers/facilitators and design community-based ACP events.

Methods: In partnership with community-based organizations, clinicians, and local government, we formed a Latinx Community Committee (n=13 community members). We then conducted 6 focus groups with Latinx-identifying, English or Spanish-speaking older adults (age 55), caregivers, and community leaders to assess ACP barriers/facilitators. We analyzed transcripts

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using thematic analysis and, based on these learnings, designed and implemented community-based ACP events. Using a validated survey, we assessed acceptability and pre-to-post-event ACP readiness (4-point scale; 4=most ready; 0.2 change considered meaningful) with Wilcoxon signed-rank tests.

Results: Focus groups included 10 Spanish-speaking older adults, 8 caregivers, and 10 community leaders. Themes highlighted the importance of ACP (e.g., means of advocacy), barriers (e.g., how to start conversations), and facilitators (e.g., trusted community spaces) in the Latinx community. Ninety-seven people attended 5 events targeting 3 Latinx populations (LGBTQI+, intergenerational, and older adults broadly). Overall pre-to-post-event ACP readiness increased (2.62 (SD 0.97) to 2.95 (SD 0.93); P=0.05). Readiness to document wishes increased significantly (2.44 (SD 1.0) to 2.98 (SD 0.95); P=0.003). Most reported being comfortable attending events (85%) and would recommend them to others (90%).

Conclusions: This study describes a feasible, acceptable, and effective CBPR ACP intervention. Co-developed community events represent a promising approach to reducing disparities in ACP among the Latinx population.

INTRODUCTION

Advance care planning (ACP), or the process by which patients and surrogates prepare for communication and medical decision-making, is low among Latinx older adults in the US (defined here as Hispanic or Latino/a/e individuals tracing their descent from Latin America).[1–5] This disparity is concerning because ACP is associated with myriad positive outcomes, including higher satisfaction with care and lower surrogate distress, and gives older adults a voice in decision-making regarding their care.[6,7] Additionally, the Latinx older adult population is growing rapidly and is anticipated to nearly double by 2030.[8] There is an increasing urgency, therefore, to increase ACP and close the gap in ACP inequity among Latinx older adults.[9]

To date, interventions designed to increase ACP in this population have primarily consisted of individual level approaches, originating and/or having been tested in the health system.[9–13] Overall ACP rates have not increased appreciably over time, in part due to lack of access to and lack of trustworthiness of healthcare systems.[9,14–16] Co-development of ACP interventions with the Latinx community has shown promise.[10,17–20] However, among these few interventions, some focus on patients with advanced or chronic disease—rather than Latinx older adults more broadly—and others require facilitation by trained social workers or navigators.[17–20] Thus, employing a fully community-based approach, such as co-development and administration of the intervention in the community by community members, may broaden the reach and sustainability of ACP interventions, and thereby help close the ACP equity gap.[14,21–24]

In this study, we present a community-based participatory research partnership with the San Francisco Latinx community to increase ACP among Latinx older adults. Through this community-initiated process, we identified facilitators of and barriers to ACP, leading to the design and implementation of community-led ACP pilot events.

METHODS

Study Design and Setting

We developed *Learning Journeys*, a community-based participatory research (CBPR) project with communities in San Francisco (SF) experiencing systemic disadvantage (e.g., poverty, racism) and disparities in ACP engagement, including Black, Chinese, and Latinx communities.[25] *Learning Journeys'* goal was to explore facilitators of and barriers to ACP and to design and implement interventions to increase ACP engagement. ACP was identified as a topic of interest and need by the SF Latinx community in partnership with the SF Palliative Care Workgroup (PCWG), a transdisciplinary collaborative led by local government representatives from the SF Department of Disability and Aging Services, clinicians, and community-based organizations (CBOs). This study was approved by the University of California San Francisco Institutional Review Board.

Learning Journeys were conducted in full partnership with the community between September 2020 and August 2021 and consisted of five steps: asset mapping, community-wide surveys, focus groups, event design, and event pilot testing. Learnings from each step led to and informed subsequent steps. This paper focuses on findings from the focus groups, event design, and pilot testing with the Latinx community. Author MR (succeeded in July 2021 by author EA) was contracted as a bilingual, bicultural Community Ambassador to lead this project based on her connection to the community, outreach capacity, and experience with community engagement and/or ACP and end-of-life care. Author MR formed a Latinx Community Committee, consisting of 13 paid Latinx community members, including leaders and staff of CBOs, representatives from health-related organizations, and clinicians. The Latinx Community Committee led and oversaw each step of the project. They met on average weekly as a committee, monthly with other members of the authorship team, and more frequently as needed with authors SN and RS during the development of focus group guides and event evaluation surveys. Initial asset mapping and community-wide surveys revealed a need for greater knowledge about ACP, access to ACP materials, and identification of trusted environments for ACP. Based on these learnings, the Latinx Community Committee decided to conduct focus groups for a more in-depth understanding of ACP in their community.

Methodological and Theoretical Frameworks

CBPR strives for equitable partnership with community members throughout the research process, emphasizes community empowerment and capacity-building, and reduces health disparities.[24,26,27] It is therefore an ideal methodological framework for developing tailored, sustainable ACP interventions with a population that experiences significant health inequity. To translate community informants' input into intervention strategies, we applied the Behavior Change Wheel framework, which uses the Capability, Opportunity,

Motivation, and Behavior (COM-B) model to understand targeted behaviors (e.g. ACP engagement) in context (e.g., in a community setting).[28–30] COM-B specifies that changing behavior requires changing individuals' capability, opportunity, and motivation regarding the behavior. Capability refers to the ability to engage in the ACP process, opportunity refers to environmental or social settings that influence ACP engagement, and motivation refers to conscious and unconscious beliefs that affect ACP engagement. By employing this implementation science framework, we aimed to achieve key implementation outcomes, such as acceptability, effectiveness, and sustainability.

Focus Groups

We conducted focus groups to better understand specific facilitators of and barriers to ACP and to identify key factors that would help ensure development of feasible and acceptable ACP interventions. Together with the Latinx Community Committee, we developed a semi-structured focus group interview guide (Supplementary Table S1) based on the COM-B model. The Community Ambassador and members of the Latinx Community Committee conducted six 90-minute focus groups with three key informant groups: two in Spanish with older adults (55 years old), two with caregivers (one in English, one in Spanish), and two in English with community-based leaders working with older adults. Participants were recruited by the Latinx Community Committee through purposeful and snowball sampling via email and word of mouth outreach through Committee members. Focus group participants received a $125 stipend for participation. Due to the COVID-19 pandemic, focus groups were conducted via Zoom, a cloud-based videoconferencing service that offers secure recording of sessions (Zoom Video Communications, Inc., 2022). Author MR provided one-on-one coaching and technical support for using Zoom. Participants were encouraged to join by video but were permitted to join by phone if they did not have video-capable devices.

Event Design Process

On completion of the focus groups, the Latinx Community Committee formed a Design Team to develop and implement ACP pilot events and to build capacity with community partners. To recruit Design Team members, the Latinx Community Committee conducted outreach to creative community members through their own networks and those of focus group participants. Potential designers then applied for the opportunity and were selected based on their availability, connection to the Latinx community, and experience with ACP, event, and curriculum development. The Design Team met 4 times with the Latinx Community Committee and members received a $750 stipend. They underwent a 2-hour "train the trainer" workshop led by an experienced palliative care nurse manager at a local community hospital. The workshop included watching the movie *Extremis*, engaging in discussions about "quality of life" and "a good death," and reviewing ACP tools including Go Wish and Prepare for Your Care.

Event Pilot Testing

The Design Team advertised events to community members via email, telephone, CBOs, flyers, social media, and radio. Due to COVID, events were offered both in-person and virtually. All in-person pilot event participants were asked to complete a pre- and post-

survey (available in English and Spanish). Surveys were developed through an iterative process led by the Community Ambassador (author MR) and with input from the Latinx Community Committee and authors SN and RS. The pre- and post-surveys both assessed readiness to engage in ACP based on the validated, 4-item ACP Engagement Survey. Validated surveys have 5-item responses; however, community members requested modification to 4-item responses for ease of use (scores ranging from 1–4; 4=most ready).[31] The pre-survey included demographic questions (age, race/ethnicity, gender, sexual orientation). Notably, while the Latinx Community Committee chose the term "Latinx" to describe their community, they decided to include "Hispanic or Latinx" and a free response option when asking about race/ethnicity on the pre-surveys. The post-survey assessed comfort attending events and willingness to recommend events to others (on a 4-point Likert scale), as well as open-ended questions assessing acceptability. Participants attending events virtually did not complete surveys. All event leaders and/or partnering agencies were asked to complete a post-event survey with open-ended questions assessing feasibility, including number of attendees, successes, barriers to success, and suggestions for improvement. These surveys were similarly developed by author MR with input from the Latinx Community Committee and authors SN and RS.

Statistical Analysis

Focus Groups—Recorded interviews were professionally transcribed; Spanish interviews were transcribed in Spanish and translated to English through a certified forward-backward translation. Transcripts were analyzed using thematic analysis (Dedoose Version 9.0.46, Los Angeles, CA).[32] After reading and rereading the transcripts, two independent coders (SN, MQ) developed a codebook through an iterative, inductive (i.e., open coding) and deductive (i.e., based on the COM-B theoretical model) process and double-coded 2/6 focus group transcripts (interrater reliability >80%). SN and MQ met frequently with the co-author team, which includes Latinx Community Committee members, to discuss emerging themes. We initially analyzed older adult, caregiver, and leader data separately, then combined them because there were no differences in findings between groups.

Pre/Post Pilot Event Surveys—We conducted descriptive analyses of all measures. We assessed differences in ACP Engagement for each question and overall mean score between the pre- and post-surveys using Wilcoxon signed rank tests. A pre to post increase of 0.2 for each question or for the overall score is considered clinically meaningful.[31,33] We conducted content analysis on answers to the post-survey open-ended questions for participants and event leaders. We used R software for all analyses with alpha <0.05.

RESULTS

Focus Group Findings

Ten Spanish-speaking older adults (2 groups, n=5 and n=5), eight formal and informal caregivers (2 groups, n=5 and n=3), and ten leaders (2 groups, n=5 and n=5) participated. All participants identified as Hispanic or Latinx. Leaders included community-based social workers, senior center managers, patient/family services advocates and care navigators at

CBOs, home health agency staff, and community outreach staff from a national advocacy organization and an academic medical center.

We identified six themes that broadly highlighted the importance of (Themes 1 & 2), barriers to (Themes 3 & 4), and facilitators of (Themes 5 & 6) ACP in the Latinx older adult community. Table 1 describes each theme with supporting quotations. ACP was felt to be important because it allows advocacy for oneself or loved ones and provides surrogate decision-makers with guidance on decision-making, thereby reducing family burden (Theme 1). Participants emphasized that the Latinx community is not monolithic, and that vulnerable groups, including LGBTQI+ and immigrant populations, may have different needs regarding ACP (Theme 2). Barriers to ACP included challenges with the healthcare system (Theme 3) and difficulty knowing how and with whom to have ACP conversations (Theme 4). Facilitators included using culturally, linguistically, and literacy-appropriate ACP materials (Theme 5), and incorporating trusted community spaces, interactive ACP tools, and virtual options into ACP events (Theme 6).

Event Design Outcomes

The Design Team used focus group findings to inform their design approach. Design elements derived from each Theme are presented in Table 1; descriptions of the five pilot events are presented in Table 2. Recognizing that the Latinx community is not monolithic, the Design Team identified three distinct target populations: the LGBTQI+ community (2 in-person and 1 virtual event), intergenerational families (1 in-person event that was also live-streamed on social media), and a broad, older adult Latinx population (1 in-person event). They incorporated skill-building for starting ACP conversations, existing culturally- and linguistically-appropriate materials, trusted community spaces, and virtual options into the events. Existing ACP materials incorporated into the events included Prepare for Your Care,[10] Five Wishes,[34] and Go Wish,[35] given focus group findings highlighting the need for step-by-step guides, language framing ACP as *deseos* or "wishes," and games, respectively. They also commissioned a Latinx artist to develop new artwork that was used throughout the outreach process and events themselves (Figures 1 and 2). The art aimed to incorporate cultural imagery, including references to Día de los Muertos, and to highlight the community's diversity by including graphic representations of LGBTQI+ families and people with disabilities. The Design Team members decided to facilitate the pilot events themselves, with support from the Community Ambassador and local ACP experts, such as nurses, physicians, or attorneys, identified through the networks of Latinx Community Committee members.

Pilot Event Assessments

A total of 97 participants attended pilot events in person; 16 attended the Latinx general older adult community event, 64 attended the intergenerational event, and 17 attended the LGBTQI+ events. Of the 97 in-person participants, 71 completed pre-surveys and 59 completed post-surveys. Participants who attended in person were 59 (SD 19) years old; 82% identified as Hispanic or Latinx, 65% reported speaking Spanish at home, and 32% identified as sexual and gender minorities (Table 3). In addition, virtual attendance included

approximately 100 people for the intergenerational event and 1,000 for the LGBTQI+ event (with 35 "likes" and 44 comments on social media).

The overall ACP Engagement score increased from 2.62 out of 4 (SD 0.97) to 2.95 (SD 0.93; P=0.05), Table 4. In addition, the individual question assessing participants' readiness to document in writing their wishes for medical care at the end of life or when faced with serious illness increased significantly (2.44 (SD 1.04) to 2.98 (SD 0.95), P=0.003) and scores for all other individual questions increased beyond the standard clinically meaningful threshold of 0.2 points, Table 4.

For acceptability outcomes, 85% of participants were comfortable attending events and 90% would recommend the events to others. Participants reported attending the events because they were invited and "wanted to learn more about ACP." They liked events primarily because they "learned new information." Some felt the event lengths were too short or too long, and some experienced challenges with communication (e.g., trouble hearing because presenters were wearing masks due to COVID). While event content varied, event facilitators reported that games, testimonials, and including experts (e.g., attorneys, doctors) were the most impactful aspects of the events, and that Prepare for Your Care and Five Wishes were well-received. They reported that more infrastructure support (e.g., finances, personnel) from partnering agencies and more time to promote and plan events were necessary to ensure sustainability. Event leaders also felt that participant engagement would be best facilitated if events were embedded into regularly scheduled gatherings by partner agencies.

DISCUSSION

Our findings demonstrate that a community-based participatory research approach to advance care planning with the Latinx community is feasible, acceptable, and effective. To the best of our knowledge, this is the first study to use CBPR and implementation science frameworks to increase ACP engagement in the Latinx community. Through this community-initiated process and partnership, we were able to identify key target populations, relevant ACP materials, and appropriate intervention design elements, resulting in the implementation of community-wide ACP events that were highly acceptable. Furthermore, participants' readiness to engage in ACP increased after attending the events. Importantly, event facilitators noted that more infrastructure support (e.g., finances, personnel) and time for planning and promoting events were necessary to ensure sustainability and increased reach and effectiveness of these events in future.

Prior research has found that while Latinx older adults report high interest in ACP, they worry that discussing it will burden family members.[5,9,36] Our findings confirmed not only a high level of interest but also an appreciation of ACP reported by Latinx community members as a means of advocacy and guidance for decision-making, and therefore a means of *reducing* family or surrogate burden. Older adults and caregivers alike expressed wanting to learn how to begin ACP conversations with each other. They highlighted the crucial role of Latinx family structure and beliefs, sensitivity to generational differences, and desire for family-based communication that has been described in the literature.[5] It may

be due to these values of family loyalty and wellbeing, or *familismo,* that attendance at the intergenerational event was much higher than at the event focused only on older adults. Our findings suggest that framing ACP as a "gift" or "legacy of love" for surrogate decision-makers and including skill-building on how to begin an ACP conversation contributed significantly to the events' success.

Similarly, incorporating culturally, linguistically, and literacy-appropriate ACP materials into events was a strong priority for the community, and event leaders noted these materials were well-received. Research has documented the need for and success of culturally, linguistically, and literacy-appropriate materials in increasing ACP engagement among Latinx populations.[5,10,11,13,18,19] As such, well-studied, culturally adapted ACP materials, including Prepare for Your Care, Five Wishes, and Go Wish were used in all events.[10,34,35] The development of original artwork, intentionally sourced and designed with a Latinx artist, to promote ACP events was a unique approach in this study and responded directly to the community's suggestion of incorporating visual cultural ties into the ACP process.

A novel component to our approach was holding events in trusted community spaces, facilitated by community leaders and professionals from the community itself. While other interventions for Latinx populations have held ACP discussions outside of clinical settings,[17,37] our approach was unique in that we were able to fully leverage trusted community agencies and design interactive, group events that included music, food, and games in spaces with which community members were familiar. Interestingly, due to the COVID-19 pandemic two of the partnering agencies included virtual event options that were very well attended, suggesting that ACP events held virtually are feasible. The desire to move ACP from healthcare to community settings is likely a result of several factors, including the lack of trustworthiness of the healthcare system due to racism and discrimination, the fragmentation of the healthcare system and its impact on low-income older adults, and incompatible patient-clinician communication styles—all of which were noted in our findings and are known to be experienced disproportionately by Latinx populations.[13] We chose to employ CBPR methods in part because it is an approach that is known to reduce health disparities.[24,26,27] While we cannot assess these pilot events' impact on equity, it is notable that the Latinx community purposefully designed ACP interventions outside of traditional health systems.

Immigrants and LGBTQI+ populations within the Latinx community were identified as particularly vulnerable to inequity in ACP. Concerns for immigrants included not having local family or surrogate decision-makers, lower access to senior services, and challenges beyond the norm in navigating burial and financial planning. These findings are consistent with literature describing lower rates of ACP, mistrust, and lack of local support systems among some immigrant populations to the US, particularly among undocumented immigrants.[38–41] ACP-related concerns for LGBTQI+ populations similarly included challenges identifying surrogate decision-makers—noting that "family" often does not refer to biological family—and lower access to local services. While literature in this area is limited, studies have demonstrated lower rates of ACP and discomfort discussing ACP with clinicians among LGBTQI+ individuals, especially among gender diverse compared to cisgender individuals.[42–45] Although intersectionality has been identified as an important

framework for public health,[46,47] there is as yet no other research exploring ACP in the Latinx LGBTQI+ community specifically. Community leaders identified the Latinx LGBTQI+ community as a target population for ACP outreach because of the higher proportion of LGBTQI+ older adults in San Francisco compared to the rest of the country[48] and because of their own experiences with end-of-life issues in this community during the AIDS epidemic.

The generalizability of this work to other Latinx communities is unclear. However, by including Latinx older adults, caregivers, and leaders in the focus groups, themes may apply to other Latinx older adult populations. By describing our research process, we hope to demonstrate the feasibility and replicability of this work in other communities. To some extent, CBPR may have greater external validity than controlled studies, since outcomes are assessed in a "real world" setting.[49] Despite these concerns, CBPR is a proven method to reduce health disparities, build local capacity, and result in sustainable change—thus, its benefits are substantial. Survey attrition rates were high, and surveys were not administered to participants attending events virtually. The overall increase in ACP readiness was of a similar magnitude to that in prior studies,[31,33] but not statistically significant, possibly due to small sample size and variation in event types. Nevertheless, participants' readiness to document their wishes in writing increased significantly. Thus, while our primary focus was on assessment of feasibility and acceptability, these findings suggest that the events were also effective in at least one key area of ACP readiness.[50] We did not follow-up with participants beyond the post-event surveys, and therefore do not have data on whether and how they ultimately engaged in ACP.

This study describes a feasible, acceptable, and effective CBPR ACP intervention approach using co-developed community events to engage communities and reduce disparities in ACP among the Latinx population. Pilot ACP events used existing ACP materials and leveraged trusted community centers, leaders, and tailored, culturally appropriate messaging and visual cues, to help ensure acceptability, and effectiveness. Based on feedback from event participants and facilitators, next steps include refining the pilot interventions and incorporating them into routine meetings held by partnering agencies to promote sustainability. Our findings also identify necessary areas of further research, including further exploration of ACP among Latinx immigrant and LGBTQI+ populations.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

ACKNOWLEDGMENTS

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Key Points:

- Community-based participatory research (CBPR) to advance care planning (ACP) in the Latinx older adult community was feasible.

- Older adults' readiness to document wishes increased.

Why does this matter?

This is the first study to use CBPR, which reduces disparities, to increase ACP in the Latinx community.
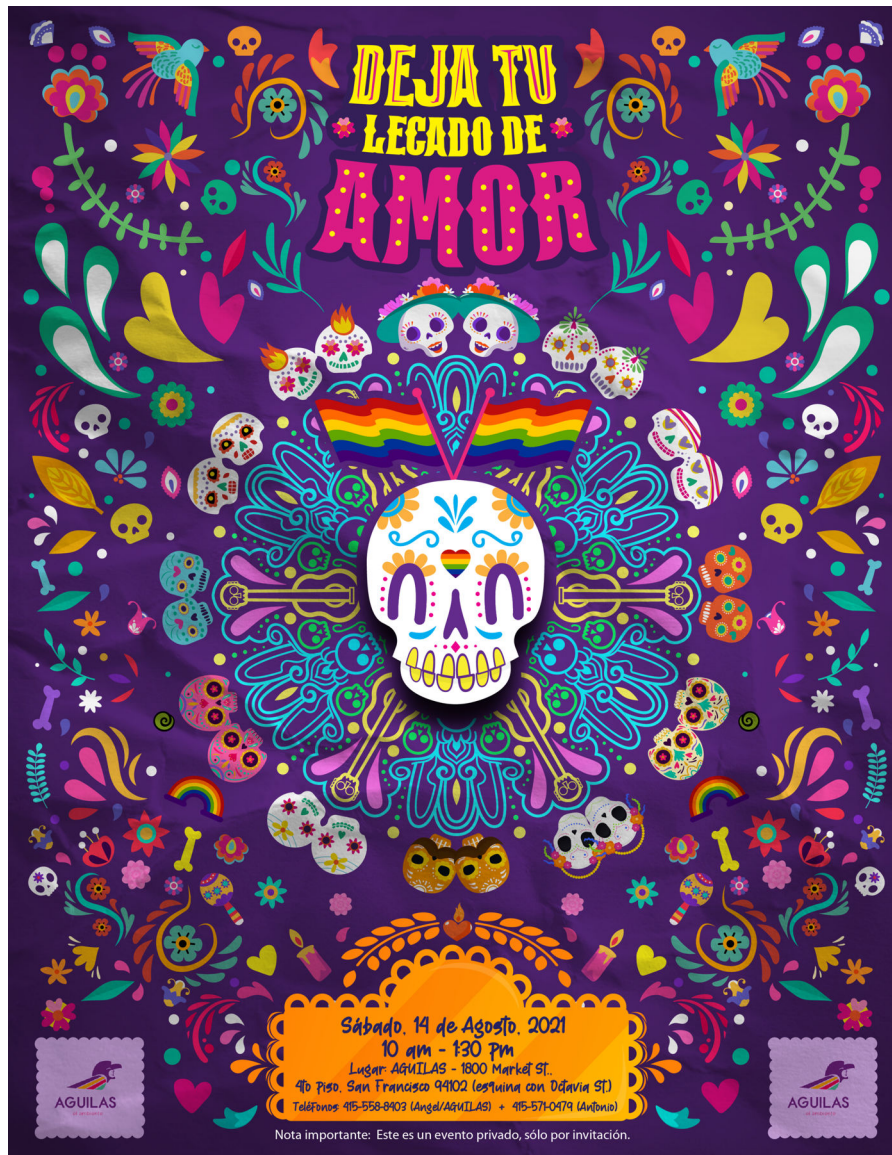
Figure 1.
Original art by Abner Recinos, commissioned by the Latinx Community Design Team, incorporating cultural imagery and advertising one of the community-based ACP events.

Figure 2.
Original art by Abner Recinos, commissioned by the Latinx Community Design Team, incorporating cultural imagery and representing the diversity of the Latinx community.

Table 1.

Focus group findings among Latinx older adults, caregivers, and community leaders, and associated design elements of ACP pilot events.

Themes	Sub-Themes and Supporting Quotes	Design
1. ACP is an important means of advocacy and can relieve family burden	ACP is a way to empower and advocate. *"It's also about empowering and advocating for what we need." (Leader)*	Tailor messaging to reflect ACP as an opportunity for advocacy and reducing family burden (e.g., "leave a legacy of love").
	ACP provides surrogates decision-making guidance and reduces family burden. *"[my daughter will] have more courage to be able to do what's written." (Older adult)*	
	Prior experience with serious illness or death and the COVID pandemic reinforce the importance of ACP. *"My father has Alzheimer's and so we started all this process of making decisions." (Older adult)*	
2. The Latinx community is not monolithic. Vulnerable groups within the community may have different ACP needs	There is an assumption that surrogate decision-makers must be close family members. *"[…] many clients don't have anyone that […] can speak on their behalf, because they're here alone." (Leader) "For LGBT seniors you know that we have a different sense of what family is to us, it may not be blood family." (Leader)*	Identify 3 target populations for ACP events: LGBTQI+, intergenerational, and Latinx older adults more broadly.
	Vulnerable populations are less likely to have access to health-related services. *"The LGBTQ elders, including in the Latino Community, they reach about 50% less senior services than any other community and it happens a lot with immigrants [...]." (Leader)*	
3. Challenges with and within the healthcare system present barriers to engaging in ACP	People want to talk about ACP with their doctors, but inadequate access precludes this. *"I think it's important for us to have a conversation with the provider." (Caregiver) "The reality in the US is that we hardly have access to a doctor. Many of us are low income, uninsured, underinsured, [doctors] change every 6 months." (Leader)*	Build community-based events in trusted spaces and include professional facilitators (e.g., doctors, attorneys) from the Latinx community.
	The healthcare system is not trustworthy. *"For those low-income communities, it's hard to really trust, you know, put basically your life to a provider." (Leader)*	
	Clinician communication may be overly direct. *"I know at first when they brought it up […] it sounded a little bit insensitive, they just threw it out." (Caregiver)*	
4. Starting an ACP conversation can be hard	Older adults struggle with discussing ACP with their younger surrogates and vice versa. *"I don't know how to talk with my children, […] they are in denial." (Older adult)*	Incorporate teaching on facilitation of ACP discussions.
	Teaching surrogates skills can facilitate ACP discussions with older adults. *"If we are saying that our children are the ones we're really having the problem with, why not educate them also so that the topic can be brought up with everyone more easily?" (Older adult)*	
5. There is a need for tailored ACP materials and programs	Low literacy, culturally, and linguistically appropriate materials are essential. *"[ACP] went from being something strictly legal to something personal. But there was never a transition […] to create a cultural bridge. Because this is a very American thing, right?" (Older adult) "I think it'll be really important to have very concrete step by steps. […] particularly if it's in a language that is not your native language, [...] these are very difficult to read." (Leader)*	Include cultural imagery, Spanish-language materials, and step-by-step guidance.
6. Elements for ACP events to boost ACP engagement	Community-based events can increase trust. *"People at the senior center [...] maybe they don't trust everyone there - but there's an established sense of trust, about the space, and the people." (Leader)*	Conduct events in trusted community spaces (e.g., senior centers) and include interactive components and virtual options.
	Interactive tools can increase engagement and information-sharing. *"With the cards it is more personal and people can sort out [...] what's most important." (Caregiver) "[an app] makes it easier to share, whether with family, doctors or agencies." (Older adult)*	
	Virtual events may be preferred due to privacy. *"We can mute and have side conversations privately in our home, while being part of this group engagement." (Leader)*	

Table 2.

Description of five community-based advance care planning pilot events in the Latinx community in San Francisco.

Event Name	Partnering Agency	Focus Population	Event Model	Event Contents	Outreach strategies
"Deseos" (n=16)	On Lok (provides healthcare and support services for older adults)	General Latinx older adult community	2-part in-person event at On Lok	Session 1: music, gift cards and raffle, Go Wish, review of a completed AD and distribution of Prepare for Your Care AD to complete at home. Session 2: music, gift cards and raffle, swag bags, a recap of Session 1, a testimonial about writing an AD, and a step-by-step AD review by an attorney.	Email, telephone
"Noche de tus 5 deseos" (n=64 in person; n=100 via live-stream)	Family Caregiver Alliance (provides services for caregivers) & Calle 24 (preserves, enhances, advocates for Latino culture)	Intergenerational Latinx community	In-person at the Mission Neighborhood Center and live-streamed on Facebook and Instagram	Dinner, an intergenerational video presentation about starting an ACP discussion, followed by a presentation about Five Wishes, ADs, and opportunity for Q&A with a physician and attorney	Social media, community distribution, radio
"Deja tu legado de amor" (n=9)	AGUILAS (provides a supportive environment and health promotion for gay/bisexual Latinos)	Spanish-speaking LGBTQI+ Latinx community	In-person at AGUILAS	Interactive presentation about values, conversations, and surrogates, shared testimonials and stories. Participants were provided time and guidance to start completing the Prepare for Your Care AD.	Email, telephone
"Mis últimos deseos" (n=6)	El/La Para Translatinas (builds programs to promote survival and quality of life for translatinas)	LGBTQI+ Latinx community	In-person at facilitator's home with staggered attendance	Intimate discussion about ACP, including a palliative care nurse.	Personal invitation
"Mis últimos deseos" (virtual) (n>1,000 with 35 "likes" and 44 comments)	El/La Para Translatinas	LGBTQI+ Latinx community	Live-streamed on Facebook as part of a regular group meeting for the partnering agency	Presentation about Five Wishes, why ACP matters for the LGBTQI+ community, and the importance of completing ADs.	Social media

AD = advance directive.

Table 3.

Characteristics of participants who attended advance care planning pilot events.

Characteristic	Participants (N = 71)
Age, mean (SD), range	59.4 (19.2), 16–87
Race/ethnicity, *n (%)	
Hispanic or Latinx	58 (81.7%)
Black or African American	4 (5.6%)
Asian	6 (8.5%)
White	1 (1.4%)
Missing	5 (7.0%)
Language spoken at home, *n (%)	
Spanish	46 (64.8%)
English	34 (47.9%)
Tagalog	1 (1.4%)
Missing	9 (12.7%)
Gender, *n (%)	
Woman	43 (60.6%)
Man	23 (32.4%)
Transgender	2 (2.8%)
Missing	4 (5.6%)
Sexual orientation, n (%)	
Heterosexual/straight	39 (54.9%)
Gay/lesbian	17 (23.9%)
Bisexual/pansexual	5 (7.0%)
Something else	1 (1.4%)
Missing	9 (12.7%)

*
Participants could select more than one option. Percentages may add to >100%.

Table 4.

Pre- and Post-Event readiness to engage in ACP, using the validated ACP Engagement Survey.

	Pre-Event, mean (SD) (N = 71)	Post-Event, mean (SD) (N = 59)	Wilcoxon signed rank test
Mean overall score	2.62 (0.97)	2.95 (0.93)	p = 0.05
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?	2.66 (1.1)	3.00 (0.96)	p = 0.2
How ready are you to put your wishes into writing about the person or group of people to make medical decisions for you?	2.73 (1.1)	3.00 (1.0)	p = 0.3
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?	2.66 (1.1)	2.89 (1.1)	p = 0.5
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?	2.44 (1.0)	2.98 (0.95)	p = 0.009

Scores ranged from 1–4; 4=most ready.