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"We've Got to Bring Information to Where People Are Comfortable": Community-Based Advance Care Planning with the Black Community

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ABSTRACT

BACKGROUND: People identifying as Black/African American are less likely to engage in advance care planning (ACP) compared to their White peers, despite the association of ACP with improved patient and caregiver outcomes.
OBJECTIVES: Assess facilitators/barriers to ACP in the San Francisco (SF) Black community and co-design/implement/test community-based ACP pilot events.
DESIGN: Community-based participatory research, including qualitative research, intervention development, and implementation.
PARTICIPANTS: In partnership with the SF Palliative Care Workgroup (which includes health system, city, and community-based organizations), we formed an African American Advisory Committee ($n=13$). We conducted 6 focus groups with Black older adults (age ≥ 55), caregivers, and community leaders ($n=29$). The Advisory Committee then selected 5 community-based organizations through a widespread request for proposal. These community-based organizations designed and implemented community-based pilot events to support ACP engagement.
MAIN MEASURES: Two authors analyzed recorded focus group transcripts using thematic analysis. We assessed pre- vs post-event readiness to engage in ACP (validated ACP Engagement Survey; 1–4 scale, 4 = most ready) using Wilcoxon signed rank tests and assessed event acceptability with open-ended questions.
KEY RESULTS: Themes included the importance of ACP to the Black community (sub-themes: strengthens families; preserves dignity, particularly for sexual/gender minorities; is tied to financial planning) and facilitators for increasing ACP engagement (sub-themes: culturally relevant materials; events in trusted community spaces including Black-owned businesses). A total of 114 participants attended 5 events; 74% identified as Black, and 16% as sexual/gender minorities. Readiness to engage in ACP was similar pre- vs post-events; 98% would recommend the events to others.
CONCLUSIONS: Community-based ACP events designed and led by and for the Black community are highly acceptable. Novel insights underscored the importance of financial planning as part of ACP and the role of Black-owned businesses as trusted spaces for ACP-related discussions.

KEY WORDS: Advance care planning; African Americans; Community-based participatory research; Health equity; Sexual and gender minorities

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INTRODUCTION

People identifying as Black or African American are less likely to engage in advance care planning (ACP) compared to their White peers.[1–4] This disparity is thought to be due to a variety of individual, interpersonal, and structural factors, many of which are rooted in systemic racism.[5] These factors include limited knowledge of ACP, differing willingness to discuss death, lack of health insurance and access to medical care, and lack of trustworthiness of healthcare systems.[6–8] Moreover, Black individuals are less likely to receive goal-concordant care and more likely to experience uncontrolled symptoms and surrogate distress at the end of life.[5,9,10] Thus, given ACP's association with agency in medical decision-making and lower surrogate distress, it is imperative to increase ACP engagement in this population to reduce disparities in serious illness and end-of-life care.[11]

Meaningfully increasing ACP engagement may require moving ACP delivery out of healthcare settings, where significant barriers (e.g., lack of access and trust) exist, to community settings, where community strengths and resources can facilitate ACP engagement.[12,13] Existing community-based interventions to increase ACP specifically among Black individuals have demonstrated feasibility, increased knowledge about ACP, and higher rates of advance directive completion.[14–23]

Findings from these interventions suggest that community-based approaches to ACP are promising. To date, many of these interventions have focused on church congregations or used faith-based models,[14–18] which may not reach some groups, such as men and younger generations who attend religious meetings less often.[13,24] Additionally, some of the existing interventions include facilitation by trained clinicians such as nurses, which may not be feasible in some under-resourced settings.[16] While several prior studies assessed multiple facets of ACP (e.g., self-efficacy regarding decision-making),[15,20,21] others focused solely on the completion of advance directives.[14,16,17,19] Yet, it is important to assess the impact of interventions on key components of ACP more broadly, such as communication with surrogate decision-makers.

To broaden the reach of ACP to promote equity and to empower communities to leverage their priorities and assets for sustainable ACP engagement, there is a need for a fully community-based approach to ACP, and specifically, approaches that are initiated, designed, implemented, and tested by the Black community.[25,26] In this study, we present the findings from a Black community-led ACP initiative in San Francisco. Our goal was to partner with the Black community to evaluate facilitators of and barriers to ACP, and to apply those learnings to designing, implementing, and testing tailored community-based ACP events.

METHODS

Design and Setting

The San Francisco (SF) Palliative Care Workgroup (PCWG), a collaborative of representatives from the healthcare community, the SF Department of Disability and Aging Services, the faith community, and community-based organizations (CBOs) whose aim is to improve local access to palliative care, launched *Learning Journeys*, a project about how best to implement ACP in the community. This community-based participatory research (CBPR) project was conducted from 9/2020 to 8/2021 with Black, Chinese, and Latinx communities in SF—communities who experience both systemic disadvantage (e.g., poverty, racism) and disparities in ACP engagement.[27] We used CBPR as a methodological framework because it strives for an equitable partnership between the community and research team, emphasizes community empowerment, and reduces health disparities.[25,28,29] *Learning Journeys* is described in more detail in a prior publication.[30]

PCWG representatives from the SF Black community identified ACP as an area of need and identified community champions. To start, the PCWG contracted with a Community Ambassador (author BND) based on her connection to the community and experience with community engagement. She then formed an African American Advisory Committee ($N = 13$ community members) to lead each step of the project, including focus groups, event design, and event pilot testing. The community invited a research team from the University of California San Francisco (UCSF) to collaborate on the evaluation of the programs. This study was approved by the UCSF Institutional Review Board.

Focus Groups

With the Advisory Committee, authors SN, MW, and RS developed a semi-structured focus group interview guide (Appendix 1) to explore ACP facilitators/barriers and identify elements that could contribute to successful community-based ACP events. The Community Ambassador and members of the Advisory Committee conducted six 90-min focus groups with Black-identifying older adults (≥55 years old; 2 focus groups), caregivers (2 focus groups), and community-based leaders (2 focus groups). The Advisory Committee recruited participants through purposeful snowball sampling (i.e., identifying key informants and asking them to reach out to their networks) through email, word of mouth, and their organizations' clients. We conducted and recorded focus groups via Zoom due to the COVID-19 pandemic (Zoom Video Communications, Inc., 2022). We provided Zoom coaching and technical support to all participants. Participants were paid $125 for their time.

Event Design

Based on focus group findings, the Advisory Committee developed and widely distributed a Request for Proposal (RFP) for community members and CBOs to design and implement ACP events. Applicants were evaluated based on the following criteria: how they would recruit participants, their reach into the population, and how they would approach event design and implementation. The RFP offered training on ACP and serious illness communication and a $2,000 stipend for each participating applicant to develop their own ACP event and include their own desired target population.

Event Evaluation

Recruitment methods varied by event and included newsletters, social media posts, and personal invitation/street outreach. All event participants received pre/post-event surveys. The pre-survey included demographic questions (self-identified age, race/ethnicity, gender, sexual orientation). Pre- and post-surveys assessed readiness to engage in ACP based on the validated, 4-item ACP Engagement Survey.[31] Validated surveys have 5-item responses; however, community members requested the responses be truncated to 4 items for ease of use (not at all/somewhat/mostly/completely; scores analyzed on a scale of 1–4 with 4 = completely ready). The post-survey also assessed comfort with attending events and willingness to recommend events to others (on a 4-point Likert scale), and open-ended questions about acceptability. Partnering organizations 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. Transcripts were analyzed using thematic analysis (Dedoose Version 9.0.46, Los Angeles, CA).[32,33] Two independent coders (SN, MQ) read and reread the transcripts, developed a codebook through an iterative, inductive process, and double-coded 2/6 transcripts. SN and MQ met frequently with the co-author team to discuss emerging themes. We combined older adult, caregiver, and community leader data because the findings were similar across groups. We used Wilcoxon signed rank tests to assess differences in pre-to-post ACP readiness for each question and overall mean scores (R version 4.2.0; alpha < 0.05). We conducted conventional content analysis on answers to open-ended questions, reading and rereading answers to inductively identify codes.[34]

RESULTS

Focus Group Findings

Nine older adults (2 groups, $n = 5$ and $n = 4$), 11 caregivers (2 groups, $n = 6$ and $n = 5$), and 9 community-based leaders (2 groups, $n = 5$ and $n = 4$) participated in focus groups; all identified as Black or African American. We identified the following themes: (1) ACP is important to the Black community and (2) a culturally relevant approach to ACP can facilitate engagement (Fig. 1).

Importance of ACP: Subthemes. We identified 3 subthemes highlighting why ACP is important to the Black community. (1) Financial planning is a critical component of ACP because it preserves dignity and intergenerational wealth: *"In our community, we take care of each other because we have been left out of a lot of things. Insurances have ripped us off. So here again we're talking about intergenerational wealth and social economic gains and disparities"* (older adult). (2) ACP unifies and strengthens families: *"This is about family and making it easy for whoever needs care"* (older adult). (3) ACP provides agency and upholds the wishes of those who lack trust in healthcare systems or personal networks (e.g., people who are minoritized within the community based on sexual orientation or gender identity) or who face competing priorities for survival and well-being (e.g., young Black men). Participants highlighted the particularly critical role of ACP as a tool for agency among Black people identifying as transgender, since mistrust in both the healthcare system and

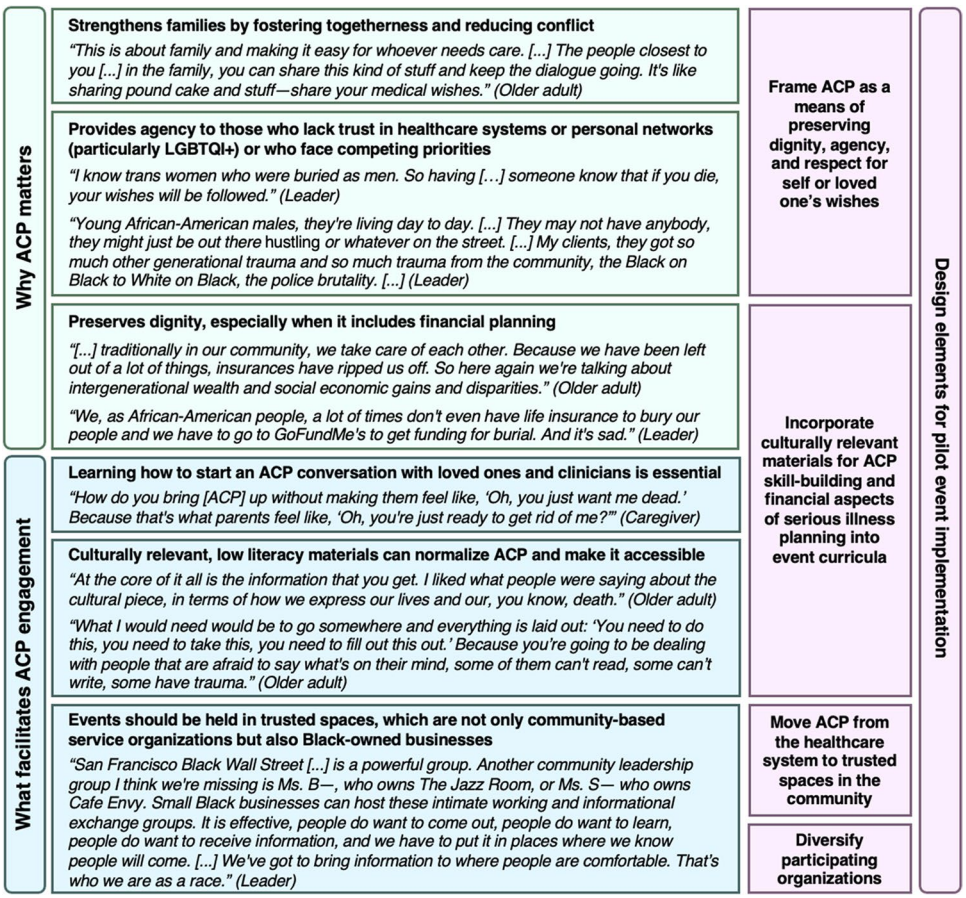

Figure 1 Focus group findings, including themes, subthemes, and key event design elements, among Black older adults, caregivers, and community leaders.

biological family raised concern among this population of not having their wishes honored at death: *"I know trans women who were buried as men. So having […] someone know that if you die, your wishes will be followed"* (community leader).

Facilitators for Increasing ACP Engagement: Subthemes. We identified 3 subthemes revealing key facilitators to increasing ACP engagement: (1) skill-building in how to start an ACP conversation with loved ones and clinicians, (2) community-based events featuring culturally and literacy-appropriate content, and (3) holding events in trusted spaces and led by trusted community leaders. Notably, trusted community spaces and leaders included not only social service organizations but also small Black-owned businesses where people gather, such as restaurants: *"Small Black businesses can host these intimate working and informational exchange groups. It is effective […] and we have to put [information] in places where we know people will come. […] That's who we are as a race"* (community leader).

Event Design Outcomes

Responding to focus group findings that trusted community leaders may extend beyond social service organizations, the Advisory Committee opened the call for community events via an RFP broadly to community members with or without the backing of an organization. Nine organizations/individuals responded to the RFP and five were selected to host events in SF: three church-affiliated (Alameda County Care Alliance, Jones Memorial United Methodist Church, Third Baptist Church of San Francisco), one that provides housing assistance and homelessness services to older adults (Curry Senior Center), and one that partners with Black-owned eateries to organize catered hikes coupled with discussions about health-related topics (Big + Black + Brunch). All five partnering organizations underwent a 2-h "train the trainer" workshop led by an experienced palliative care nurse manager. The workshop included watching the movie *Extremis*, engaging in discussions about the quality of life, death, and dying and reviewing ACP tools. Events were tailored to the preferences of each organization. Based on focus group findings, all events were held in trusted spaces, framed ACP in terms of dignity and agency, and aimed to achieve cultural relevance through testimonials by community members and incentives such as meals catered by Black-owned eateries (Table 1).

Pilot Event Assessments

A total of 114 participants attended 5 events; 69 completed pre-surveys and 56 completed post-surveys. Participants were 57 (SD 17) years old; 74% identified as Black or African American, 54% as women, and 16% as sexual or gender minorities (Table 2). Overall readiness to engage in ACP was similar pre- vs post-events (3.01 (SD 1.0) vs 3.10 (SD 1.0); $P = 0.8$; Table 3). Readiness to identify a surrogate decision-maker in writing increased from 2.90 (SD 1.1) to 3.21 (SD 1.0), although not significantly ($P = 0.3$).

Acceptability was high: 96% were mostly or completely comfortable attending events and 98% would recommend events to others. Participants reported coming to events because they were invited or informed about events by trusted people like neighbors. They appreciated learning more information and described events as "inspirational," "encouraging," and "organized," though some reported events were too short and would have welcomed longer events as they were "comfortable" and facilitated "camaraderie." Organizations felt testimonials, peer-to-peer sharing of stories and culturally competent ACP or palliative care experts were key to events' success and specifically to building trust.

DISCUSSION

In this CBPR approach to ACP with the Black community in San Francisco, we learned that community-based ACP events designed and led by the community are both feasible and highly acceptable. Discussions with older adults, caregivers, and community leaders identified critically important and unique facets of ACP in this population: incorporating financial planning into ACP to preserve intergenerational wealth and reaching out to vulnerable groups within the community, such as people identifying as LGBTQI + and young Black men. Focus group participants also identified Black-owned businesses as trusted institutions within the community. Readiness to engage in ACP did not increase significantly after the events, possibly due small sample size in this pilot study, selection bias, and heterogeneity of event content. These ACP programs, initiated and led by the Black community in an urban community setting, demonstrate that CBPR is a promising and welcomed approach to increasing ACP engagement. Drawing from the community's assets, including trusted networks of community leaders and spaces, helped ensure that community-based ACP events were both feasible and highly acceptable.

Through focus groups, we learned that the Black community in San Francisco strongly desires ACP engagement regardless of age; this was reflected in the average age of event participants. In fact, the community identified a particularly critical need for ACP for vulnerable groups within the Black community, such as young Black men and people identifying as sexual or gender minorities. These groups are targets of severe and disproportionate violence that is inextricably linked to anti-Black racism, includes social, economic, and structural (e.g., healthcare, police) violence, and results in shorter life expectancy and intergenerational trauma.[35–39]

Table 1 Description of Five Community-Based Advance Care Planning Pilot Events in the Black Community in San Francisco

Organization	Population ($N=114$)	Event model	Event contents	Outreach strategies
Alameda County Care Alliance (ACCA)*	Black or African American residents of the SF Bayview/Hunters Point neighborhood ($N=26$)	In-person and live-streamed on a Wednesday evening	Testimonial by a community member, prayer by a reverend, and information about ACCA's Advanced Illness Care Program by healthcare navigator. Included hot lunch and Target gift cards for participants	Personal invitation through ACCA and Greater Life Church congregation
Big + Black + Brunch	Adults identifying as Black or African American ($N=23$)	In-person on a Saturday	Urban hike followed by presentation and discussion about ACP led by local palliative care nurse. Healthy lunch was provided by a local Black-owned business	Social media
Curry Senior Center & Cadillac Hotel (Single-Residence Occupancy)	Black older adults with low-income and/or experiencing homelessness ($N=30$)	In-person on a Tuesday and a Wednesday afternoon	Testimonials by event facilitators followed by open discussion with participants; review of advance directive with opportunity to ask questions. Lunch and gift cards provided	Flyers, personal invitation and phone calls by case managers, street outreach
Jones Memorial United Methodist Church	Church-based, older adults ($N=27$)	In-person on a Sunday	Testimonials by church congregants; ACP presentation and discussion by local palliative care chaplain who is also a congregant. Coffee, food, and gift cards provided	Invitation during online church services
Third Baptist Church of San Francisco	Church-based, any adult ($N=8$)	Virtual (Zoom) on a Saturday	Movie screening (Extremis) and discussion with testimonials facilitated by the church's health/wellness minister and local palliative care nurse. Raffle with cash prize included	Church bulletin and newsletter, social media

AD, advance directive

*The ACCA event was held at the Greater Life Church in San Francisco

Because of this injustice, the community identified these groups as benefiting from ACP as a means of having agency not only in their end-of-life care but also in outlining wishes for their burial and memorial services.

Additionally, the community felt financial planning for end-of-life care must be part of ACP, not only to account for burial and insurance costs but also to preserve intergenerational wealth. The impact of racism on this issue cannot be overstated: redlining in the USA has resulted in persistent and growing inequities in the Black-White wealth gap, as well as related inequities in health, housing, education, insurance, and financial services (e.g., student loans), and retail (e.g., food deserts).[40–43] For the Black community in San Francisco, ACP that includes financial planning is an opportunity to address these disparities. An advantage of ACP delivery in the community rather than the healthcare system is the possibility of including and leveraging the existing work of community lawyers, with whom patients engage in ACP at much higher rates than with their clinicians or health systems. Compared to ACP in a health system context, community lawyers' approach to ACP includes broader financial, serious illness, and end-of-life planning and considers people's socioeconomic context.[44] Despite these findings, none of the pilot events included information about financial planning. This may be because the standardized ACP training for partnering organizations through the Learning Journeys program did not include financial information.

This ACP study was unique in that it was entirely initiated by the community. Academic partners were subsequently invited to help with data collection and analysis. All other aspects of the events and pilot were decided on and led by community members. Other studies among Black or African American populations have also shown promise in community-based ACP approaches.[14–23] Approaches for other public health endeavors involving Black-owned businesses have been tremendously successful in increasing reach and improving outcomes among Black or African American populations, such as for hypertension management.[45] Our CBPR approach similarly revealed that trusted community

Table 2 Characteristics of Participants Who Completed Pre-surveys at Community Advance Care Planning Pilot Events

Characteristic	Participants ($N=69$)
Age, mean (SD), range	56.8 (17.3), 12–88
Race/ethnicity,*† n (%)	
Black or African American	51 (73.9)
Hispanic or Latinx	7 (10.1)
Asian	1 (1.4)
White	4 (5.8)
American Indian or Alaska Native	2 (2.9)
Something else	1 (1.4)
Missing	5 (7.2)
Language spoken at home,* n (%)	
English	57 (82.6)
Spanish	5 (7.2)
Missing	7 (10.1)
Gender,*‡ *n* (%)	
Woman	37 (53.6)
Man	28 (40.6)
Non-binary or Something else	2 (2.9)
Missing	2 (2.9)
Sexual orientation, *n* (%)	
Heterosexual/straight	57 (82.6)
Gay/lesbian	3 (4.3)
Bisexual/pansexual	2 (2.9)
Something else	4 (5.8)
Missing	3 (4.3)

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

†Response options also included Native Hawaiian/Pacific Islander, Middle Eastern/North African

‡Response options also included transgender and gender non-conforming

leaders can come from a variety of places, including not only social services or faith-based organizations but also local Black-owned businesses. Moreover, leveraging this wide range of leaders allowed for broader reach to people across the community (e.g., young Black men, people without housing), rather than reaching only members of a particular group within the community (e.g., church congregants) or a health system. Also consistent with prior literature, perceived "barriers" to ACP in this population, such as family decision-making or mistrust, were actually noted by participants to be motivators for encouraging ACP engagement so they could retain their own agency.[46] Reframing ACP as a means of preserving dignity, agency, and respect for one's wishes may therefore help increase engagement in this population. This framing aligns with current definitions of ACP that emphasize preparation for communication and medical decision-making, with known positive outcomes of ACP such as lower surrogate distress.[11,47,48]

The request for a proposal sponsored by a local foundation allowed for the five distinct organizations to create their own heterogenous ACP events. This heterogeneity in events and target populations, while an expected and encouraged outcome of the CBPR process, precludes us from assessing the acceptability or effectiveness of specific event elements across all participants. Yet, we were able to identify key elements that participants found acceptable and leading organizations found effective: building trust (through the use of trusted spaces, organizations, and people), incorporating peer testimonials/stories and culturally competent experts into event content, and using incentives such as food and gift cards. While focus group participants did not specifically recommend faith-based organizations as targets for ACP events—and rather emphasized including Black businesses and non-faith-based organizations—three of the five participating organizations were faith-based. Prior studies of community-based ACP in the Black or African American population have occurred primarily in faith-based settings, and, importantly, the Black Church continues to serve as a source of community support, empowerment, and action, including in end-of-life care.[49–51]

Limitations of this study include the limited sample size, low survey completion rates, and possible selection bias, with people already interested in ACP more likely to attend focus groups and events and to complete surveys. Additionally, this work was conducted with the San Francisco Bay Area community so its generalizability to other communities is unknown. As described above, the heterogeneity of events' models, contents, and leaders impacted our evaluation.

Our findings from this community-driven and community-led study strongly suggest that ACP is perceived to be valuable among minoritized Black or African American

Table 3 Pre- and Post-Event Readiness to Engage in ACP, Using the Validated ACP Engagement Survey. Scores ranged from 1 to 4; 4 = most ready

	Pre-event, mean (SD) ($N=69$)	Post-event, mean (SD) ($N=56$)	Wilcoxon signed-rank test
Mean overall score	3.01 (1.0)	3.10 (1.0)	$P=0.8$
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?	3.12 (1.1)	3.16 (1.0)	$P=0.8$
How ready are you to put your wishes into writing about the person or group of people to make medical decisions for you?	2.90 (1.1)	3.21 (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?	3.13 (1.1)	3.00 (1.1)	$P=0.3$
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?	2.85 (1.1)	3.04 (1.0)	$P=0.4$

people who experience systemic racism, including structural violence from the US healthcare system. What constitutes ACP may vary depending on context, population, and priorities. Novel findings in this study, for example, were that the Black community prioritizes including financial planning as part of ACP to protect intergenerational wealth, reaching all members of the community regardless of age, and targeting outreach to LGBTQI + populations. The next steps include incorporating these key learnings into community-based ACP interventions through continued work with community partners and evaluating interventions' impact on ACP engagement across a larger population and over a longer period of time. This preliminary pilot study lays the groundwork for continued work in building sustainable and impactful community-based ACP in Black communities across the US.

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Data Availability *The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.*

Declarations

Conflict of Interest *The authors have no conflicts of interest to disclose.*

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