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EDUCATION AND TRAINING



A Community Engagement Symposium to Prevent and Improve Stroke Outcomes in Diverse Communities

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Abstract

Background: Racial/ethnic minorities have a higher burden of stroke, but lower awareness and understanding of stroke and its risk factors. Our community–academic collaborative hosted a symposium in South Los Angeles to increase awareness about stroke, provide information on the Los Angeles Stroke Intervention and Research Program (SPIRP), and facilitate bidirectional communication between researchers and community stakeholders.

Objectives: We discuss our partnered approach to increase stroke awareness, elicit community perspectives and perceptions about stroke prevention and research participation, and increase community involvement in research using a community engagement symposium (CES).

Methods: We used a community-partnered participatory research (CPPR) conference framework to guide symposium planning, implementation and analysis. The morning session included clinical lectures, a panel of researchers describing

LA SPIRP, and a panel presentation by stroke caregivers and survivors. In afternoon breakout sessions, attendees identified 1) community-based strategies to prevent stroke and 2) methods to increase recruitment of diverse populations in stroke research studies. Attendees were surveyed about stroke knowledge before and after the morning session. Data from breakout sessions were analyzed using content analysis and pile sorting to identify themes.

Conclusions: We found that the CES based on CPPR principles was effective method to increase short-term stroke awareness and stimulate discussion about stroke research among community members and community stakeholders who serve racial/ethnic minorities.

Keywords

Community health partnerships, health disparities, health outcomes, health promotion, cardiovascular diseases

Racial/ethnic minorities have a higher burden of stroke and worse outcomes after stroke.¹⁻³ These differentials in stroke incidence and mortality are due to a higher prevalence of traditional stroke risk factors at younger ages, greater burden of recurrent stroke, and greater impairment after a stroke.^{1,2}

Despite their higher risk and poorer outcomes, racial/ ethnic minorities have a lesser awareness and understanding of the nature of stroke, its signs and symptoms, the need for urgency of treatment, and risk factors.¹ In a national survey, the proportion of respondents who were able to identify five stroke warning signs and recognize the need to call 9-1-1 was 55.9% among Whites compared with 47.1% among African Americans and only 36.5% among Latinos.² In addition, lack of English proficiency is strongly associated with lack of stroke knowledge among Latinos.⁴ Other contributors to stroke disparities may include differences in access to care, distrust in the health care system, and low participation of racial/ethnic minorities in stroke clinical research studies.^{1,2} Despite emerging evidence that community input into interventions may enhance feasibility and sustainability, few stroke studies have incorporated a community perspective.

The Los Angeles SPIRP is one of four national centers funded by the National Institute for Neurologic Disease and Stroke (NINDS). The goals of SPIRP are to reduce disparities in stroke risk factor control for African Americans, Latinos, and Asian Americans. The center is organized around two community-based interventions to address primary and secondary stroke prevention and an analysis examining trends in stroke risk factor control by race/ethnicity. SPIRP also has three cores for education/training, biomarker collection and analysis, and community engagement.

The Community Engagement, Outreach and Dissemination core of SPIRP consists of community and academic co-leaders and a Community Action Panel (CAP). The core is responsible for conducting five annual community symposia. Symposium planning is guided by leadership and staff from Healthy African American Families II (HAAF), a communitybased organization with a long history of effectively engaging academic investigators in community-partnered research and a co-leader in the SPIRP community engagement core and the CAP.5 The CAP is composed of thought leaders who represent community and cultural organizations in Los Angeles County. Their role is to formally review and advise on projects, promote ways to effectively disseminate the work in the community, and work with center leaders to understand community priorities for research and effectively communicate these priorities to investigators.

For the inaugural event, our community–academic collaborative hosted a 1-day CES in South Los Angeles using CPPR principles. The aims of the first symposium were to increase stroke awareness, introduce SPIRP research projects and cores to the community, and promote bidirectional communication between researchers and community partners from diverse communities. Because the CES was the first entrée into the community by SPIRP, the symposium was intended to introduce and obtain feedback on broad topics around community participation in stroke research, especially from stakeholders from the African American, Latino, Korean American, and Chinese American communities, because these are target groups for SPIRP projects. In this paper, our objectives are to 1) discuss our CPPR approach to increase stroke awareness and elicit community perspectives using a CES and 2) share the main recommendations discussed by community members and practitioners who serve minority communities about stroke prevention and research participation.

METHODS

CPPR Principles in CES Planning

We modeled the CES after the HAAF Community Engagement Conference Model using a CPPR approach.⁵ CPPR principles include having community and academic partners in all phases of research and decision making, having shared leadership and equitable resources, highlighting the importance of evidence while simultaneously valuing the relevance of experience, and developing two-way capacity building for a sustainable partnership that supports research and action that benefits community. A team of eight, composed of community partners (n = 3), researchers (n = 2), staff (n = 1), and students (n = 2), planned the symposium and data collection and analysis strategies over a 10-week period, and members of our team have had a history of collaborations rooted in CPPR.⁶⁻⁸ The CES planning team was co-led by one academic researcher and one HAAF community leader; we met at least weekly by phone or in person at HAAF's office. In addition to shared leadership, HAAF received a subcontract to host the CES, which allowed staff to not only help implement the CES, but also participate in data analysis.

Given HAAF's prior experience and expertise engaging community members and practitioners from resourcechallenged neighborhoods, HAAF had a prominent role in determining the symposium structure and evaluation, but all decisions were made collaboratively. For example, when the researchers suggested raising awareness of stroke warning signs by using the American Heart Association/American Stroke Association (AHA/ASA) FAST acronym (a mnemonic to help detect and enhance responsiveness to stroke victim needs; the acronym stands for Facial drooping, Arm weakness, Speech difficulties and Time) through clinical talks by physicians, HAAF recommended that we complement physician talks with perspectives from patients and caregivers. As such, the CES included a panel of stroke survivors or caregivers to balance the scientific presentations with real-life accounts of stroke warning signs and outcomes. Our team also reviewed all clinical presentations to ensure comprehensibility to non-academic

Table 1. Key Components for Stroke Community Engagement Symposium Based on the HAAF Community Engagement Conference Model

Component	Collaborative Action(s)
Planning: Collaborative planning group that put CPPR principles into action	The Los Angeles SPIRP Community Engagement, Outreach and Dissemination core include staff and leadership from community and academic institutions that have a history of working collaboratively. The group planned and organized the symposium.
Topic selection	We focused on stroke education, racial/ethnic stroke health disparities, and SPIRP research.
	The American Heart Association/American Stroke Association F.A.S.T. acronym was presented in didactic sessions and surveys as an important message to take away from the symposium.
Resources	HAAF received a subcontract to conduct five annual SPIRP community symposia.
	An additional grant was awarded to support translators, translation of materials, and travel for a keynote speaker.
	We solicited in-kind donations for raffle items (blood pressure cuffs and iPad), food (Yogurtland), and conference bags (L.A. CARE health plan) to provide a free conference for attendees.
Attendees: Broad community outreach to enhance the diversity of participants in the conference	We reached out to men, women, African Americans, Latinos, Asian/Pacific Islanders, Whites, health care providers, community-based organizations, social service agencies, academics, students, state and local health departments, state and local government representatives, and media. Outreach was in English, Spanish, Mandarin, and Korean.
Location: Host conference in a non-university site to enhance community participation	The event was held at a large, well-known African American church in South Los Angeles, an area with one of the highest cardiovascular disease and stroke rates in Los Angeles County and California. This venue has been the setting for many multicultural events.
Agenda: Responsive to community needs and includes presentations from both scientific and community perspectives	The keynote presentation was on a cultural adaptation of a stroke prevention intervention in the Korean community using a community-partnered participatory research approach.
	All academic presentations and slides on clinical information about stroke and stroke warning signs were reviewed by community and faculty to ensure they were comprehensible to non-academics.
	A diverse panel (African American, Latino, and Asian) of stroke survivors and caregivers described their experiences with stroke and post-stroke outcomes.
	We had active breaks to promote the stroke prevention message by guiding attendees through Instant Recess® exercises.
	Small group breakout sessions attended by a both community and academic participants provided input on community-based strategies for stroke prevention and for research recruitment.
Materials and other benefits	Simultaneous Spanish translation provided via headphones; Korean and Mandarin translators were available on site.
	The slide presentations, AHA/ASA stroke information, and other conference documents were provided to participants in English, Spanish, Korean, and Mandarin.
	CEU credits provided to licensed professionals.
	Complimentary breakfast, lunch, and health-conscious dessert provided to attendees.
Publicity	Symposium attendees were recruited through ethnic media advertisements, existing list-servs and relationships between the conference planners and SPIRP investigators, local AHA/ASA chapters, community-based organizations, faith organizations, local agencies, health care providers, and community members.
Evaluation: Pre- and post-test evaluations at every conference	An ARS was used to assess baseline and post-conference knowledge.
	A paper survey was used to evaluate the symposium's utility.
	Participation in evaluations was incentivized using raffles for health-related items, including blood pressure monitors.
Follow-up activities	Conference materials were available online and a link was sent to all registered attendees.
	Community members reviewed and helped to interpret the data from breakout sessions.
	Findings were shared with researchers and community members in post-conference meetings.
	Ine CAP reviewed the CES processes, participation and response rates, and attendee evaluations to begin planning for Year 2 activities, including the second symposium.

Notes. AHA/ASA, American Heart Association/American Stroke Association; ARS, Audience Response System; CAP, Community Action Panel; CEU, continuing education unit; CES, community engagement symposium; HAAF, Healthy African American Families II; SPIRP, Stroke Prevention and Intervention Research Program.

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attendees. In another example, HAAF wanted to ensure that the CES allowed for community input and interaction with researchers. To facilitate these interactions, we had breakout sessions in the afternoon with a mix of academic and community stakeholders in each group. Table 1 illustrates other key components of the CES and resulting collaborative actions.

CES

The CES took place in July 2013 in South Los Angeles, an area with one of the highest cardiovascular disease and stroke rates in Los Angeles County and California.⁹ To enhance community participation, the symposium was intentionally held at a highly regarded and easily accessible African American church that had hosted other multicultural events. The CES consisted of morning plenary presentations to disseminate information about stroke and afternoon small group sessions to obtain ideas on strategies important for stroke research.

The CES was free for attendees and intended for community members, health care providers, social service providers, community and faith-based organizations, health organizations, students, and researchers with an emphasis on engaging those who are or work with African Americans, Latinos, Chinese Americans, and Korean Americans. We provided conference materials (i.e., agenda, presentations, survey, informational brochures) in Spanish, Korean, and Mandarin and had on-site translators. Materials were also made available on a webpage after the conference (https://sites.google. com/site/laspirp/). Attendees were asked to complete a paper survey evaluating the utility of the CES, and those that did were entered into a raffle for several prizes, including blood pressure cuffs. We received approval from the University of California, Los Angeles, Institutional Review Board and CES hosts reviewed a written informed consent given to all attendees at the start of the symposium.

Stroke Awareness Presentations and Survey

To increase stroke awareness and introduce SPIRP projects to attendees, the CES morning session included lectures about stroke risk factors, warning signs, and disparities from stroke neurologists and a hypertension-focused primary care physician. This was followed by a presentation by stroke survivors and caregivers from African American, Latino, and Korean racial/ethnic backgrounds. In addition, a panel session introduced SPIRP investigators and research projects and answered audience questions about the research.

We used an electronic Audience Response System (ARS) to conduct an anonymous survey that was administered at the beginning and end of the morning presentations to assess changes in stroke awareness in the short term. The ARS promotes community engagement by providing immediate feedback on correct and incorrect responses (we provided correct responses after the second round of the ARS survey) and encouraging discussion about the range of responses.¹⁰ The survey questions were adapted from the presentations, the stroke literature, and several evidence-based online resources (NIH/NINDS,¹¹ National Stroke Association,¹² AHA¹³).

Collaborative Input on Stroke Research

To elicit community perspectives, we had afternoon breakout sessions to obtain input on community-relevant questions about stroke prevention and research. Attendees were divided into six groups, led by a facilitator, and summarized by a note taker. Five were facilitated in English, and one in Spanish. One week before the symposium, HAAF staff with expertise in facilitator training led a 3-hour session to prepare university and community-based organization staff and undergraduate and graduate students to serve as facilitators and note-takers.

Two questions were asked in each group: 1) What can we do as a community to prevent stroke? and 2) How can we recruit more diverse populations into stroke research studies? Attendees were instructed to write their first response to each question on a notecard before the facilitated discussion of that question. The notecards and discussion notes were collected for later analysis. When the large group reconvened, two volunteers—one researcher/physician and one community member/agency representative—presented a summary of the top three recommendations from their breakout group.

Data Analysis

We collected demographic and stroke awareness data with the ARS, and conducted descriptive analyses using cross-tabulations and frequencies. We used qualitative research methods to analyze the breakout session data. Using content analysis methods, we read through notecards and discussion notes several times in an iterative process to identify recurring concepts for each breakout session question.¹⁴ We continued the process until we reached consensus on concepts, labeled as categories and subcategories. Our team then classified individual ideas or quotes by pile sorting them into our categories.¹⁵ To ensure face validity of our pile sorted quotes and categories, we assembled 10 community members who attended the symposium and asked them to review the categories and linked examples of quotes for each breakout session question. Community members had good agreement with the CES team's categories and pile-sorted quotes (kappa = 0.83). We also conducted debriefing sessions during which members of the planning team and the CAP reflected on the symposium and reviewed data about the characteristics of attendees, participation rates, and attendee evaluations of the CES.

RESULTS

Demographics

Of the 236 CES attendees, more than 70% lived or worked in South/South Central Los Angeles based on registration zip code. More than one-half of the attendees responded to the surveys, which is typical of response rates for similar community symposia.¹⁶ Specifically, 54% (n = 126) of the attendees responded to the CES evaluation and 53% to 59% (n = 124-140) responded to individual ARS questions. ARS respondents were mainly female (65%), greater than 50 years old (51%), and included community residents (37%), researchers (12%), and personnel from local clinical (22%), social service (23%), and faith (8%) organizations (Table 2). More than one-half were African American, 17% were Latino; 12% Asian/Pacific Islander; and 9% White.

Stroke and SPIRP Awareness

Stroke knowledge before and after the didactic sessions increased from 6.0% to 38.3%, with an average 14.5% increase in knowledge across the 11 questions (Table 3). We did not find significant differences by age or race/ethnicity among respondents who changed from the incorrect response in the pre-session to the correct response in the post-session. Eighty-five percent of the CES evaluation respondents strongly agreed (70.7%) or agreed (14.6%) that the CES increased their knowledge about stroke.

Collaborative Input on Stroke Research

The community/academic breakout sessions brainstormed several ideas for stroke prevention and research participation. Eighty-one percent of the CES evaluation respondents found

Table 2. Demographics of Symposium Respondents				
Characteristic	n	(%)		
Gender (<i>N</i> = 127)				
Male	41	(32.3)		
Female	83	(65.4)		
Transgender	3	(2.4)		
Age, y (<i>N</i> = 127)				
18-29	25	(19.7)		
30-49	37	(29.1)		
50-64	40	(31.5)		
≥65	25	(19.7)		
Race/ethnicity ($N = 129$)				
Black or African American	73	(56.6)		
Hispanic or Latino	22	(17.1)		
Asian, Native Hawaiian or other Pacific Islander	16	(12.4)		
White	11	(8.5)		
Multiracial	4	(3.1)		
Other	3	(2.3)		
Affiliation ($N = 124$)				
Community member	23	(18.6)		
Community-based organization	28	(22.6)		
Faith-based organization	10	(8.1)		
Academic/researcher	15	(12.1)		
Health care provider	27	(21.8)		
Other	21	(16.9)		
Main source of information on risk factors/warning signs for stroke ($N = 132$)				
Family member or friend	35	(26.5)		
American Heart Association/ American Stroke Association	21	(15.9)		
Medical books	21	(15.9)		
Doctor	16	(12.1)		
Television	10	(7.6)		
Newspaper or magazine	4	(3.0)		
None of the above	25	(18.9)		

Note. Sample size is indicated for each category and based on the Audience Response System.

the breakout sessions useful because it provided a forum for community stakeholders to share their priorities and perceptions with researchers.

The recommendations for community-based strategies to prevent stroke focused on education of community members and lifestyle activities. Awareness campaigns included using low-tech and high-tech strategies: "we should advertise on billboards and bus-stops with FAST slogans" and "use social networking sites and text messaging to share stroke information with friends and families." Recommendations for educational content stressed awareness of stroke warning signs (i.e., FAST) and the recognition of the family's role in prevention by researchers and health care providers. Several groups discussed training community members or persons

Table 3. Stroke Knowledge Questions Before and After Didactic Sessions Using ARS ^a				
	ARS Before Sessions	ARS After Sessions		
Question	n (%)	n (%)		
Stroke is the fourth leading cause of death in the United States and a leading cause of serious, long-term disability in adults				
Correct answer (true)	88 (69.3)	121 (89.0)		
Incorrect answers or don't know	39 (30.7)	15 (11.0)		
What does the FAST acronym stand for?				
Correct answer (face, arm, speech, and time)	94 (74.6)	128 (93.4)		
Incorrect answers	32 (25.4)	9 (6.6)		
What are warning signs of stroke?				
Correct answer (all of the above: dizziness, headache, numbness on one side, slurred speech, vision problems)	117 (87.9)	127 (94.1)		
Incorrect answers	16 (12.0)	8 (5.9)		
What would you do first if you thought someone else was having a stroke?				
Correct answer (call emergency medical services [EMS] or 911)	126 (92.7)	139 (99.3)		
Incorrect answers or don't know	10 (7.4)	1 (0.7)		
What is the number one risk factor for stroke?				
Correct answer (hypertension or high blood pressure)	111 (82.2)	130 (92.9)		
Incorrect answers	24 (17.8)	10 (7.1)		
Which racial/ethnic group has the highest prevalence of high blood pressure?				
Correct answer (African Americans)	124 (88.6)	134 (97.1)		
Incorrect answers	16 (11.4)	4 (2.9)		
African Americans have almost double the rate of first ever or initial strokes compared to Whites.				
Correct answer (true)	110 (83.3)	129 (93.5)		
Incorrect answers or don't know	22 (16.7)	9 (6.5)		
Studies show that Hispanic/Latino women are significantly less aware of stroke symptoms than White women.				
Correct answer (true)	107 (79.9)	117 (86.7)		
Incorrect answers or don't know	27 (20.2)	18 (13.3)		
Which racial/ethnic group is more likely to suffer from a hemorrhagic stroke?				
Correct answer (Hispanics/Latinos)	9 (6.6)	17 (12.6)		
Incorrect answers	127 (93.4)	118 (87.4)		
Korean Americans most at risk for stroke are the least likely to recognize stroke symptoms.				
Correct answer (true)	78 (55.7)	126 (94.0)		
Incorrect answers or don't know	62 (44.3)	8 (5.9)		
Among which group is there the least amount of data or literature about stroke risk?				
Correct answer (Asian American)	69 (51.5)	100 (78.7)		
Incorrect answers	65 (48.5)	27 (21.3)		

^a ARS, Audience Response System. Pre-sessions ARS, N = 124-140; Post-sessions ARS, N = 127-140.

who have an affiliation with a particular community (through race/ethnicity, culture, language, faith) to conduct culturally sensitive stroke awareness workshops in community venues, such as churches, schools, and senior centers. Session participants emphasized the role of partnerships with trusted community stakeholders, such as local organizations, businesses, and government to facilitate stroke education to respective members, especially among limited English proficiency ethnic communities. There was a strong emphasis to educate primary and secondary students about stroke risk factors.

The recommended lifestyle activities to prevent stroke in community settings focused on nutrition, physical activity, and blood pressure screening. Nutrition comments ranged from "having more fast food healthy restaurants" to creating "community gardens and making healthy food economical." Groups also discussed physical activity strategies such as walking groups and "[having] no to low cost exercise facilities that are easily accessible." Blood pressure screening in churches or through mobile vans was advocated as a way to provide both information and medical treatment. Participants in the Spanish speaking group emphasized similar themes, but also discussed the need for Spanish language-specific education and incorporation of specific cultural elements (i.e., foods, customs, and family and community values) in education efforts. Additional ideas are presented in Table 4. 155

The recommendations to enhance minority recruitment into clinical studies encompassed outreach/incentives and methods to gain trust. In addition to venues for outreach, session participants advocated for storytelling as an appealing recruitment method. One group suggested having a "Speaker's Bureau of stroke survivors from the community that could share their experiences and encourage recruitment

Table 4. Community E	ngagement Symposium Recommendations for Community-Based Stroke Prevention Strategies	
Category/Subcategory (Frequency)	Example Quote	
	Education	
Awareness campaigns	Designate the 5th Sunday to talk about stroke on the radio.	
(128 quotes)	We should have a community-based health activist who would go door-to-door with information about stroke events or education.	
	Partner with health care providers and community-based organization to offer free education classes.	
	Have community participate in AHA/ASA stroke media campaigns.	
Content and cultural considerations	Emphasize age is not a factor because a lot of young people have strokes but feel immune; youth's current lifestyle behaviors will cause more problems as they age.	
(79 quotes)	Provide contact information for organizations that are available in the communities: resources for follow-up, treatment, prevention.	
	Make sure stroke education is cultural relevant and sensitive; hold meetings in Spanish, Korean, or the common language that is spoken by the community.	
Venues (65 quotes)	Have TV/video presentations at places where people wait, like doctor's offices, beauty shops, grocery lines, banks, and airports.	
Partnerships (34 quotes)	Churches could provide health fairs for the community.	
	Have strategic partnerships with major corporations that contribute to causes of stroke.	
	Politicians could help disseminate the information and utilize staff to develop focus groups and symposia throughout.	
Audience (30 quotes)	Education sessions for everyone, i.e., churches, senior housing and schools.	
Lifestyle Activities		
Nutrition (50 quotes)	Having more fast food healthy restaurantsI'm getting tired of Subway.	
Physical activity (26 quotes)	Implement walking groups at workplace, churches, schools, senior housing.	
Blood pressure screening (14 quotes)	Have blood pressure trucks in the community and have a physician or health care provider educate, screen, and provide treatment.	

Notes. Quotes may be included in more than one category. AHA/ASA, American Heart Association/American Stroke Association.

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into stroke research studies." Other groups suggested "using social media, like Facebook and Twitter, to raise awareness of stroke research studies" or "having a gallery exhibit with pictures of stroke survivors to tell stories about how they dealt with stroke and then distribute information about stroke and research participation." Although most groups discussed the use of monetary incentives to help recruitment efforts, some groups also discussed non-monetary incentives, such as comprehensive health care or free blood pressure monitors.

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The need to gain trust between community members and researchers was implied in recommendations by all groups. Groups discussed lack of trust from racial/ethnic communities and a lack of willingness to participate in research due to "previous abuses and mistreatments (e.g., Tuskegee Syphilis Study)" and a "lack of knowledge about research or transparency from investigators about the research study." Communicating research objectives in layman's terms was brought up by participants, as was using endorsements from trusted medical professionals and non-medical community groups to aid recruitment efforts. Several participants discussed making participation in research more accessible by bringing studies away from academic medical centers and into more local settings, like the CES. Participants in the Spanish-speaking small group brought up fear of deportation and a lack of legal documents

Category/Subcategory (Frequency)	Example Quotes		
Outreach and incentives			
Outreach methods (116 quotes)	Outreach at community clinics and doctor's offices where patients with high blood pressure could be recruited into stroke research studies.		
	Outreach at health conferences like this one.		
	Have leaders at community centers and churches ask for volunteers in at-risk populations.		
	Recruit at block club meetings and senior centers.		
	Have a gospel concert or something that speaks to the public interest and then inform them of the research at that event.		
	Put recruitment brochures or flyers in public areas like the Department of Public Social Services or Social Security.		
	Outreach at schools to focus on students with a family history of stroke.		
Incentives (48 quotes)	Give out free blood pressure cuffspeople like free stuff.		
Methods to gain trust			
Communication strategies (72 quotes)	We [community members] are guarded because we lack knowledge about research. Start with the basic definition what is research.		
	Some people are embarrassed to say that they don't understand. Take the time to answer questions instead of running through it really quick.		
	Inform community members of potential outcomes and how it would benefit them and others to participate.		
	Have culturally-sensitive recruitment campaigns based on which groups you are trying to recruit. Be sensitive to education and age.		
Partnerships with trusted stakeholders (51 quotes)	Have churches and senior housing facilities promote research and researchers to recruit ethnic groups. Encourage stroke survivors to spread the word and share their own personal stories (e.g., support groups). Partner with local neighborhood groups and go to monthly community block meetings to recruit people for research studies. Have a celebrity from that ethnic group promote and recruit for research studies.		
Community relevance (11 quotes)	The community does not know what was done with the information collected from the community.		
Location of study (11 quotes)	Time and location prevent people from participating in research. We need to bring the research to where people live.		

Table 5. Community Engagement Symposium Recommendations to Increase Racial/Ethnic Minority Participation in Stroke Research

Note. Quotes may be included in more than one category.

as reasons why some immigrants choose not to participate in research studies or travel to a university. The group suggested passing on research study information through institutions and stakeholders trusted by immigrants. Table 5 shows additional ideas to foster minority participation in research.

CAP Debriefing Sessions

After the CES, members of the planning committee and CAP debriefed about the symposium. Based on the CES evaluations, 85% of respondents strongly agreed or agreed that the CES increased their knowledge about SPIRP and 75% strongly agreed or agreed the CES was valuable to their work. The most suggested comment in the CES evaluation was to have more symposia on similar health topics. However, one concern raised during the debriefing session was the lower than expected participation of Latino Americans, Chinese Americans, and Korean Americans and those with limited English proficiency. The CAP had several recommendations: hosting the next large symposium in a more central location that was more accessible for these communities, extending the recruitment period and the approaches to outreach in different communities, increasing the representation of these groups on the CAP, and using materials from the symposium to conduct smaller workshops in Spanish, Mandarin, and Korean in ethnic enclaves. The CAP also discussed approaches to increasing the ARS and CES evaluation response rates in future symposia; among them clearer orientation to the ARS devices and to the survey questions and encouragement to complete the surveys at regular intervals. The CAP also recommended the future symposia focus on successful community-partnered strategies for stroke prevention.

DISCUSSION

We found that the CES based on a CPPR approach was an effective forum to increase community awareness about stroke in the short term, elicit community perspectives and perceptions about stroke prevention and research participation, and increase community involvement in research. Although not the explicit purpose of this symposium, our planning team did feel that it was a missed opportunity to get community stakeholders to better understand, participate in, and potentially modify existing SPIRP project designs. As such, future symposia will focus on specific SPIRP research and/or community efforts with an emphasis on collaboration and integration of community input into methods and/or dissemination of results. In the interim, SPIRP investigators have presented their work at CAP meetings for feedback.

Although not intentional, SPIRP research projects were influenced by the CES. For one project, investigators recruited an occupational therapist from the community in the intervention, modified educational materials to simplify the language, and used venue recommendations from the CES to recruit in the Asian/Pacific Islander communities. In another project, investigators decided to culturally adapt the AHA/ASA FAST message for Latinos and Asian Americans. In addition, our local AHA/ASA collaborated with SPIRP to conduct an annual Spanish-language conference. The CES also served as an opportunity to enhance the diversity of the CAP by recruiting new community members and representatives from key stakeholder organizations.

Based on the recommendations from the breakout sessions, clinicians and investigators that are aware of community resources and develop partnerships with community-based organizations may be more effective advocates of stroke prevention and minority recruitment in research, respectively. For our collaborative health partnership based in CPPR principles, we will continue to modify the CES to be effective in disseminating health information to minority communities, facilitating community involvement in research, and sharing strategies for community–academic partnerships. Findings from the first CES were shared with community members and other attendees in the subsequent CES.

Description of Partnership

The Community Engagement Core of SPIRP includes community and academic co-leaders and a CAP that formally reviews and advises on center projects, promotes ways to effectively disseminate the work in the community, and works with center leaders to understand community priorities for research and effectively communicate these priorities to center investigators. To enhance public engagement in stroke research, our community–academic collaborative hosted a 1-day symposium.

Drs. Nazleen Bharmal and Arleen Brown have collaborated on research and service projects with HAAF, the main community partner for this study, for the last 10 years. They have conducted and published studies and presented at research and community meetings together. Dr. Brown (UCLA researcher) and Ms. Loretta Jones (CEO HAAF) are the co-directors for the Community Engagement, Outreach and Dissemination Core of the Los Angeles Stroke Prevention and Intervention Program for Health Disparities.

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