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The Effectiveness of Community-Based Outreach Events for the Promotion of African-American Research Participation

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Abstract

Introduction: African Americans (AA) are disproportionately affected by Alzheimer's disease and related dementias, yet are underrepresented in clinical research. Outreach events for AA are offered to encourage research participation; however, this approach's effectiveness remains largely unexplored.

Methods: To explore the effectiveness of AA focused versus general audience events, we examined attendance data over five years, encompassing ten general audience and four events focused on AA. For each individual, we searched center records for recruitment contacts and research enrollment. Summary scores for attendance at AA focused events, general audience events, and total events were compared between those with and without research involvement.

Results: Out of 773 unique AA that attended one or more event, 88 became or were involved in research (11.4% engagement). AA focused events achieved greater AA attendance than general audience events. While research engaged individuals were more likely to have ever attended an AA-focused event than a general audience event, attendance at AA focused events did not statistically relate to research engagement. In contrast, attendance at events focused on the general public was related to an increased likelihood of research participation.

Discussion: These findings have important implications for designing and implementing community events to encourage AA research participation.

Keywords

Outreach Events; African Americans; Research Participation

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Background

African American (AA) individuals are disproportionately impacted by Alzheimer's disease (AD) and related disorders, yet are underrepresented in research^{1,2}. Many AD research sites use local community outreach events to build relationships and increase research participation³. To supplement these efforts and increase AA enrollment in studies, many sites create events designed for local AA communities⁴. The Institute of Medicine suggests adjusting existing approaches based on the group of focus when broader efforts are not leading to the desired successes⁵. Events that are planned to engage AA individuals are designed to increase perceived relevance of the events and enable a focus on beliefs and attitudes towards AD and research participation that may be more prevalent among the AA community; the hope is that through greater identification with the event and its content, efforts to encourage research participation will be more effective. While some research suggests that such focused events may lead to increased AA research involvement, information regarding effectiveness is rather limited^{6,7}.

Event effectiveness can be evaluated in various ways. 1) Using attendance data to demonstrate successfully reaching the population of interest. 2) Counting attendees indicating research interest following an event (however, stated interest is frequently a significant over-estimate of actual engagement in research, possibly due to perceived barriers to research participation)⁸. 3) Exploring immediate post-event outcomes, e.g. did attendees follow up and get involved after the event.

The barriers to research involvement within the AA community are often deeply entrenched due to a history of research mistreatment and a subsequent lack of research trust⁹. Additional barriers may include perceived risks, unclear benefits, and the lack of culturally appropriate information about research opportunities¹⁰. Despite these barriers, some research suggests that AA willingness to get involved in research is similar to willingness among Caucasian individuals, highlighting the importance of ensuring AAs are also equally aware of research opportunities^{11,12}. For individuals who are hesitant to get involved with research, multiple contacts over time may be necessary to develop relationships, familiarity, and trust before an individual is ready to participate in research^{3,13}. Accordingly, we argue that evaluating the effectiveness of outreach events requires a more holistic view of event attendance, moving beyond single-event immediate outcomes to exploring event attendance and research participation over time.

The purpose of this manuscript is to explore whether attendance at AA community events encourages research participation. Specifically, are individuals who attend more events more likely to participate in research? Does attendance at events designed specifically for AA encourage research participation more than events geared toward the general public? How does timing of research involvement relate to event attendance? Finally, what are the reasons event attendees do not participate in research?

To address these questions, we explored event attendance at one center's larger community outreach events between 2014 and 2018 in conjunction with records of research engagement. The research center has both an observational longitudinal program as well as an ever-

evolving option of clinical trial (i.e., interventional research) opportunities for older adults. Most of the research includes a minimum age of 65 years, with studies available for individuals with various levels of cognition (normal cognition, mild cognitive impairment, and dementia). While the geographic location of the center is predominantly Caucasian (only 6% minorities in the population > 65 years), the center makes ongoing efforts to engage diverse participants in research to ensure that research discoveries maximize their generalizability to disparate populations as much as possible.

Methods

Events

Between 2014 and 2018 the center held 14 large outreach efforts. These 14 events included ten focused on outreach to older adults in general, and four events designed specifically to engage AA older adults. The center has a long-standing commitment to community education, recognizing the important role community engagement can play in building trust, demonstrating respect, and supporting research participation^{14,15}.

The ten events with general outreach included five center health fairs (April or May, 2014-2018), four educational community symposiums (October or November, 2014-2017), and a Glen Campbell movie showing (March, 2015). The center health fairs, known locally as the 'Mind Matters Health Fair', focus on brain health and involve a combination of community exhibitors with interactive exhibits, speakers, opportunities for memory screenings, and a free lunch. The Community Symposium is an annual educational event that includes free breakfast, a keynote speaker, and a question and answer session. The Glen Campbell Movie showing was an opportunity to come to a local theater to view at no charge the movie "*I'll Be Me*," depicting his battle with AD.

The four events focused on AA outreach all took place at a local, well-known theater, with a history and mission of preserving and promoting AA cultural heritage through the arts. The events included two Garrett Davis plays (<https://www.gdavisproductions.net/gdavis>). Garrett Davis is an AA playwright who infuses humor and music with real-world issues. Davis is an Alzheimer's Association Ambassador and a long-time collaborator with US Against Alzheimer's^{16,17}. The two plays were *Forget Me Not* (August, 2014), focused on one family's experience with AD, and *Mama's Girls*, focused on the challenges of caregiving, followed by a musical blues concert (August, 2015). The third event was focused on Barbara 'B.' Smith, an AA restaurateur, model, author, businesswoman and television host and her husband Dan Gasby, as they navigate the challenges of her AD diagnosis (September, 2016)¹⁸. Smith, prior to her death in February 2020, and Gasby collaborated with the Global Alzheimer's Platform Network to increase AD awareness¹⁹. The fourth event was a musical production, *My War Wounds 2*, from local playwright Leslie Pryor, focused on awareness of health disparities in the AA community, in conjunction with a Jazz Concert from a local musician (October, 2018). Attendance at all events was completely free of charge.

Multiple advertisement strategies were used to promote these events. Typically, individuals in the center's existing mailing list who were within the group the event was designed for were invited. Local media opportunities, including TV and radio, were sought to promote

attendance. Flyers were shared in community locations, including churches, community and senior centers, and senior living communities; many of these efforts were paralleled through these groups' online efforts, including distribution of event information through Facebook groups of AA churches and other predominantly AA groups and e-newsletters. Information was also shared with various community contacts to help spread the word. For several of the AA focused events, we also invited AAs from an older adult voter's registration list who had indicated willingness to be contacted by the center for research opportunities.

Data

We compiled records of attendees from each of the outreach events, identifying each individual who attended at least one of the events and identifying whether unique individuals had attended multiple events. We limited our attention only to AAs who attended at least one event. We created three scores: count of total events attended (total events); count of AA-focused events attended (AA events); and count of general public events –specifically the center Health Fairs, symposia, and movie showing - attended (general events).

We reviewed research records and the contact database and cross-referenced with the list of AAs who attended any events. Typically, individuals are included in the contact database if at any time they express an interest in research involvement, through event registration forms, follow-up contact requests, or center contact at another time. For each individual, we recorded if they were or had been a participant in an interventional study or the observational longitudinal study and noted date of first enrollment, as appropriate. If they lacked any research involvement, we reviewed notes to glean insight into specific reasons for non-participation. Gender was not routinely collected and so was omitted from analysis to avoid making inaccurate attributions. Age was frequently collected at the event, and for those who expressed interest in research engagement, age was confirmed during follow-up contact.

Data Analysis

We used descriptive statistics to explore the relationship between event attendance and research participation. We used independent samples t-tests to explore if there were differences based on age or event attendance between those who ultimately became involved in research and those that did not.

Results

Event Attendance

Across the events evaluated, 773 AAs attended one or more event. On average, individuals attended 1.32 events (range 1-8). Evaluating only the AA-focused events, 721 (93.27%) AAs attended one or more event. On average, individuals attended 1.11 AA-focused events (range 0-4). When querying events for the general public, 114 (14.62%) AAs attended one or more event. On average, individuals attended 0.21 of these events (range 0 to 5). Across events, AA attendance at events geared toward the public was fairly low, whereas attendance at AA focused events was higher (See Table 1).

Research Engagement

Among the 773 AAs who attended one or more of these events, 495 (64.04%) of these individuals were not listed in the recruitment database, suggesting that they had never requested contact to discuss research opportunities. Of the 773 unique AA attendees, 278 (35.96%) were present in the recruitment database, suggesting some expression of research interest. Of these 278 individuals, 88 were engaged with research (11.34% of all attendees, 31.65% of those expressing research interest): 66 (8.54% of all attendees, 23.74% of those expressing research interest) were engaged with the longitudinal program only, 8 (1.03% of all attendees, 2.88% of those expressing research interest) with clinical trials only, and an additional 14 (1.81% of all attendees, 5.04% of those expressing research interest) with both the longitudinal observation program and clinical trials. Due to the small numbers, for this manuscript, we consider research engagement to be participation in the longitudinal study or any of the clinical trials offered during the period of study.

For the 88 research-engaged individuals, 63.6% (n=56) were already involved in research prior to their first event attendance. For the remaining 32 individuals, time from first event attendance to first research participation ranged from 2 days to 1,424 days, roughly 3 years 11 months (average = 539.16 days, SD = 420.70). For these 32 individuals, they attended an average of 1.28 events before their research involvement (range of 1-3).

For the remaining 190 individuals who were listed in the database but did not become involved in research, the most commonly identified barrier for lack of participation was the individual was too young for available opportunities (n=64, 33.68%, mean age 58.89 years). Other common reasons for non-participation included competing life demands such as work schedules or caring for a family member (n=23, 12.11%), uncontrolled or exclusionary health conditions (n=13, 6.84%), or a general lack of interest (n=16, 8.42%). Less frequently mentioned reasons for non-participation included the absence of a study partner (n=1, 0.52%), disinterest in interventional medication studies (n=3, 4.21%), and disinterest in blood draws (n=3, 1.58%). While multiple reasons could be cited, frequently, once one barrier was identified, additional barriers were not explored. For over a third of these 190 individuals (n=74, 38.95%), efforts to reach the individual regarding possible research engagement were not successful and therefore specific reasons for non-participation remain unknown. Typically, these efforts involved two phone attempts when a phone number was available or one mail attempt when a phone number was not provided.

Research Engagement and Demographic Factors

To explore potential differences in those who engaged in research versus those who expressed some interest but did not get involved, we focused on individuals listed in the recruitment database. In order to focus on those who had expressed interest and had the potential for involvement, we removed those who were age-ineligible (younger than 65) for current opportunities. We found that individuals who were engaged in research studies tended to be older (mean age = 78.88, SD=6.98) than those who did not get involved (mean age=75.79, SD=7.49; $t(205) = -3.01, p=.003$).

Relationship between Event Attendance and Research Engagement

Of the 88 individuals with research involvement, 66 (75%) attended an AA-focused event (range 1-4 events). In contrast, 43 (49%) of these individuals attended one of the general audience events (range 1-4 events) (See Figure 1). The data show that while the highest numbers of attendees and subsequent research enrollees are derived from AA-focused events, the relative research engagement of AA attendees is more than four times as great if they engaged in a general audience event.

Of the 88 individuals with research involvement, 56 (63.63%) of them were already involved in research prior to their first event attendance. There were 32 individuals (36.36%), who were new to research after their first event attendance. For these 32 individuals who were new to research, 24 (72%) of them attended at least one AA-focused event and 14 (44%) of these individuals attended at least one of the general audience events. When looked at in combination, 8 (25%) only attended general audience events, 6 (19%) attended both general audience and AA-focused events, while 18 (56%) attended only AA-focused events.

Individuals who ultimately participated in research attended a greater number of overall events (mean=1.77, SD = 1.04) compared to those who did not enroll in research (mean = 1.27, SD =0.72; $t(771) = -5.847$, $p < .001$). This relationship also held when looking at attendance at events focused on the general public. Research-engaged individuals attended more events for the general public (mean=0.72, SD=0.92) compared to those who did not get involved in research (mean = 0.15, SD=0.51; $t(771) = 8.71$, $p < .001$). Despite the finding above that the majority of those who were involved with research attended at least one AA event, total attendance at AA focused events was not related to research engagement. Those who ultimately became involved in research attended slightly fewer AA focused events (mean=1.06, SD=.89) than those who did not get involved in research (mean = 1.12, SD=0.54; $t(771) = 0.92$, $p = 0.36$) (See Figure 2).

To explore whether *any* attendance rather than a count of attendance explained research engagement, we examined whether those who had ever attended general audience events differed from those who had not. Having ever attended a general audience event ($n=114$) was associated with a greater likelihood of research engagement, $X^2(1, 773) = 91.29$, $p < .001$. Of the 114 individuals who attended general audience events, 43 (37.7%) had some research involvement. In contrast, among those who did not attend any general events, 45 (6.8%) had some research involvement. On the other hand, having ever attended an AA-focused event was associated with a decreased likelihood of research engagement, $X^2(1, 773) = 52.85$, $p < .001$. Of the 721 who attended any AA events, 66 (9.2%) had some research involvement. In contrast, of the 52 individuals with no AA event attendance, 22 were involved with research (42.3%). Findings regarding first event type (general audience vs. AA) reflect this same pattern of greater likelihood of research engagement among those who first attend a general audience event (findings not reported, but available by request from the authors).

Discussion

These findings suggest that community outreach events appear to be an effective strategy for encouraging research engagement^{14,20}. In terms of absolute reach, AA focused-events had a broad reach and ultimately touched 75% of the research-engaged individuals. However, attendance at AA focused events was not statistically related to research engagement. While initially these contrasting results seemed puzzling, upon further reflection a clearer picture emerged. AA focused events reached a large number of AA individuals; however, this reach was broad and therefore less focused on individuals who ultimately became involved in research. In contrast, the events focused on the general public, while accounting for a smaller absolute number of individuals engaged in research, were more clearly related to research participation. Ever attending, and attending a greater number of such events, were both associated with a greater likelihood of research involvement.

These findings can be interpreted in multiple ways. Large AA events may play a valuable role in raising awareness about research opportunities; while many who hear this message do not engage in research, large events focused on AA individuals are likely to reach some AA individuals who otherwise may not learn about opportunities for research involvement. Such efforts, however, may be more effective if paralleled by strengthening event promotion efforts within the AA community to encourage greater AA attendance at community events. The increased frequency of engagement seen among individuals who attended general community events may reflect such individuals' background and experiences; attendance at general audience events may indicate having already overcome an initial layer of engagement barriers that may then extend to an increased likelihood of engaging in research activities as well²¹. Thus, tackling one barrier - engagement in general audience outreach events - facilitated overcoming barriers to overt research engagement. This reduction in research-related barriers after general audience event attendance may relate to the opportunity to engage in activities such as brief memory screens that help to demystify the research process²².

The nature of the events themselves may also play a role in the likelihood of research involvement. Events for the general community were typically research and brain health specific, whereas those focused on the AA community had dementia themes, but had a stronger entertainment aspect. Events more focused on brain health and dementia may help overcome avoidance and communicate the need and value of research involvement, encouraging participation in dementia prevention and treatment research²³. Future research will need to tease apart how event foci (e.g. brain health, research, and/or dementia), approach (education, entertainment), and engagement group goal (general public or AA specific) play a role in research engagement. Ongoing efforts to explore these factors will require careful and comprehensive collection of event attendance data, as well as exploration of multiple outreach approaches. Developing a minimum dataset of event characteristics and attendee demographics, including gender to avoid inferences, for consistent collection would support these efforts. Multi-site collaborations to evaluate community outreach efforts may be needed to produce a large enough number of events and sufficient number of research-engaged individuals to enable conclusions regarding event attributes that support research involvement. Attention to timing and sequence of events may also be important. It is

possible that by scheduling AA focused events immediately preceding community events may help encourage greater attendance at the latter through the draw of the former. New approaches to encourage research participation may also be warranted. Incorporating step-by-step information regarding the research process into AA focused events may provide an opportunity to ask questions, voice concerns, and receive research-education in a comfortable setting, hopefully reducing barriers to participation.

Our results identified substantial delays between event attendance and new research involvement; accordingly, analysis of event impact should include a significant follow-up period. These delays could be due to various factors including: becoming age appropriate for available opportunities, developing new concerns that heighten research interest, retiring or experiencing other life changes that may reduce competing demands, and identifying opportunities that are a better fit for their research interests, procedure willingness, and availability ²⁴. Regardless of the reasons, these delays highlight that research willingness and engagement are fluid concepts; there appears to be value (in terms of ultimate research engagement) to maintaining contact and ongoing follow-up, rather than a one-time check-in for research interest.

This research has several limitations related to comprehensiveness of attendance data and racial data of attendees. Racial data was not consistently collected, so some AA who attended the events may not have been counted. For AA focused events, we assumed attendees were AA, unless we had records indicating otherwise. Individuals at other events were identified as AA if they completed an evaluation that provided racial information, if we had information linking their name to their racial data, or if study staff indicated AA race on registration forms. For these reasons, the numbers presented here are likely underestimates of actual AA event attendance. Regarding comprehensiveness of attendance data, for several of the events evaluated, true attendance is known to be higher than recorded. A known cause of this discrepancy is that some events allowed individuals to register for multiple individuals –meaning unique names of attendees were not always available. This is especially the case with the B. Smith event where registration was handled by the theater venue rather than center staff. As a result, despite attendance closer to 300 we received only 68 unique names. Further, attendance data was not collected in a consistent manner across events. For instance, the Health Fair events had a more complete listing of attendees as registration was required upon entry, but the community symposium events collected attendance data through evaluation forms, which are not always turned in. These limitations suggest the need for consistent and comprehensive collection of attendance data to enable ongoing analysis of event effectiveness. In addition, due to the retrospective nature of this research, additional variables such as education and income were not collected. Expanding the data collected at events would enable further insight into factors related to research participation. To avoid the collection of additional variables negatively impacting attitudes regarding the event, additions in collected attendee data would need to be weighed with the potential for such items to be viewed as being unnecessarily invasive or personal. Despite these limitations, however, this study provides valuable insights into real-world outcomes related to community outreach for ultimate research participation.

The present study explored the center's largest outreach efforts. However, numerous smaller events are held throughout the year, many focused on outreach to the AA community, in community settings and through church-based efforts ²⁵. We are currently developing better tracking mechanisms to enable exploration of smaller events' impact. Exploring outcomes such as research trust and attitudes toward engagement, which could be measured on a continuum, may enable more nuanced insight into event impact ²⁶. As numbers of engaged individuals grow, exploring aspects of research engagement, such as agreement to brain donation or willingness to try experimental medications, would be valuable areas for future exploration.

Given that the majority of individuals who were engaged in research had their initial research visits prior to their initial event attendance, future research should explore the role event attendance plays in retention. If event attendance is related to retention, does this reflect higher levels of baseline engagement and commitment leading to event attendance, or do the events themselves provide feedback and encouragement that promote retention? Further, since the largest reason for research non-participation was being too young for available opportunities, it may be worthwhile to explore strategies for continuing to engage middle-aged adults to enable a research-ready cohort when opportunities match their age. This would also be consistent with the push for preclinical interventions during the asymptomatic phase of the AD, often beginning before the 6th decade of life. Since health decisions are often made in consultation with other family members, increasing and sustaining research interest in middle-aged and younger AA adults may also have positive influences on older adult research engagement ²⁷.

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Figure 1.
African American Event Attendance and Research Engagement

Figure 2.
Relationship between African American Attendance at Events and Research Involvement

Table 1.

African American Event Attendance

Event	Date	Known AA attendance
<i>General Public</i>		
2014 Health Fair	April 2014	14
2014 Symposium	November 2014	1
Glenn Campbell	March 2015	5
2015 Health Fair	May 2015	24
2015 Symposium	November 2015	3
2016 Health Fair	May 2016	46
2016 Symposium	November 2016	0
2017 Health Fair	April 2017	42
2017 Symposium	November 2017	3
2018 Health Fair	May 2018	28
<i>AA Targeted Events</i>		
2014 Garrett Davis	August 2014	101
2015 Garrett Davis	August 2015	285
2016 B. Smith	September 2016	68
2018 Leslie Pryor	October 2018	404