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An Interdisciplinary Outreach Model of African American Recruitment for Alzheimer's Disease Research

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Purpose: The African American Outreach Satellite (Satellite) provides educational outreach to facilitate African American recruitment for longitudinal studies at the Washington University Alzheimer's Disease Research Center (ADRC). This descriptive article characterizes the Satellite's recruitment methods, plan for community engagement, results of recruitment efforts, and potential for replication. **Design and Methods:** The Satellite developed a comprehensive outreach and recruitment plan that identifies and addresses barriers to research participation. The Satellite conducts community outreach and recruitment programs and training for health care providers. **Results:** Enrollment of cognitively healthy and mildly demented African Americans for participation in all ADRC studies increased following

implementation of the recruitment plan. Current African American participation rates for ADRC studies include 39% for lumbar puncture, 43% for positron emission tomography with Pittsburgh Compound-B, 52% for magnetic resonance imaging, 95% for apolipoprotein E genotype testing, and 100% for clinical and cognitive assessment. **Implications:** The Satellite reduces barriers to research participation, encourages retention through sustained interactions with participants and their families, and develops lasting partnerships with community organizations and health professionals who care for African American elders.

Key Words: Dementia, Teams/interdisciplinary/multidisciplinary, Black, Education and training

Background

The National Institutes of Health mandates increased participation of racial and ethnic minorities in biomedical research (Department of Health and Human Services, National Institutes of Health, 1994). However, inequities in minority research participation persist (Levkoff & Sanchez, 2003). Although African Americans may experience a higher incidence and prevalence of Alzheimer's disease (AD; Demirovic et al., 2003; Gurland et al., 1999; Heyman et al., 1991), they remain underrepresented in AD research (Connell, Shaw, Holmes, & Foster, 2001; Dilworth-Anderson et al., 2008; Gauthier & Clarke, 1999). Limited enrollment of African Americans is problematic not only because inadequate research participation affects the generalizability of study findings but also because older adults represent the most rapidly growing segment of the population.

The National Institute on Aging (NIA) recently examined approaches to recruitment and retention of minority older adults in research and noted several factors that influence research participation. Past scientific misconduct, mistrust, limited clarity regarding informed consent, inequities in access to health care, researchers' lack of cultural sensitivity and limited understanding of community dynamics, and lack of access to institutions that conduct studies impede research participation. Minority elders may be disinclined to participate in research because investigators have not convinced them that research is conducted with an equitable balance of risks and benefits (Stahl & Vasquez, 2004).

Facilitators of minority participation in AD research include increasing awareness of AD among potential participants, their caregivers, health care providers, and community leaders; eliminating perceived barriers to access; developing a network of community collaborators; altruism, use of culturally congruent staff; and optimizing culturally responsive interactions between the research team and potential participants (UyBico, Pavel, & Gross, 2007; Ballard, Nash, Raiford, & Harrell, 1993; Welsh, Ballard, Nash, Raiford, & Harrell, 1994; Williams et al., 2010).

The African American Outreach Satellite and Minority Recruitment

The African American Outreach Satellite (Satellite) was funded by the NIA in 1992 as an administrative supplement to the Washington University Alzheimer's Disease Research Center (ADRC).

The Satellite's primary objective was to extend the ADRC's expertise to minority elders by providing home-based assessments, dementia diagnosis, and supportive services with a secondary goal of recruiting African Americans for ADRC studies (Edwards et al., 1999). A multidisciplinary team conducted home-based cognitive assessments and provided dementia diagnosis and case management. Interactions with this team resulted in sustained relationships with African American older adults and their families, community leaders, and health care providers. The Satellite's activities represent an established and highly successful collaboration between the ADRC and the St. Louis Area Agency on Aging.

African Americans are the largest minority group in St. Louis. Current demographic data indicate that African Americans compose 18.1% of the population in metropolitan St. Louis (Saint Louis Regional Chamber & Growth Association). The Satellite aims to achieve this level of representation in the ADRC cohort. The entire ADRC active participant pool is approximately 650 individuals, with 100–120 new participants enrolled annually.

The recruitment policy adopted by the ADRC in 2004 states that all new enrollees must be eligible for and willing to complete the entire longitudinal ADRC protocol, including comprehensive clinical and cognitive assessments, blood collection for genotyping, structural neuroimaging with magnetic resonance imaging (MRI), amyloid imaging with positron emission tomography (PET) using Pittsburgh Compound-B (PIB), and lumbar puncture (LP) for collection of cerebrospinal fluid. However, in 2005 and 2006, African American enrollment declined by greater than 50% concomitant with initiation of the requirement that all newly enrolled participants be willing to have LP.

In 2004, the Satellite modified its primary goal to focus on enhancing minority recruitment to optimize enrollment of African American participants with normal cognition and mild dementia of the Alzheimer type in longitudinal ADRC studies due to concerns that the concurrent shift in the ADRC research portfolio to emphasize AD biomarker studies would disproportionately discourage African Americans from participating. In response to diminishing African American enrollment, the requirement for willingness to have LP was waived for African Americans, and we formulated a systemic plan to enhance minority recruitment and retention for longitudinal studies at the ADRC.

Table 1. African American Enrollment in All Alzheimer's Disease Research Center Studies (1999–2008)

	Total participants enrolled	Number of African Americans	% African American
1999	140	12	8.6
2000	115	13	11
2001 ^a	137	14	10
2002	134	28	21
2003	130	30	23
2004 ^b	147	31	21
2005	92	10	10
2006 ^c	134	19	14
2007	139	31	22
2008	105	20	19

^aFormation of African American Advisory Board.

^bImplementation of lumbar puncture (LP) requirement August 1, 2004.

^cElimination of LP requirement for African American participants and implementation of new systemic plan for African American recruitment August 1, 2006.

Informed by the findings of extant literature regarding minority research recruitment, we outlined a recruitment plan designed to address these barriers and facilitators of research participation. With increased recruitment activities following the creation of the ADRC African American Advisory Board (AAAB) and the Satellite's greater emphasis on minority recruitment, African American enrollment doubled from prior levels and generally has exceeded the target of African Americans representing 18% of newly recruited ADRC participants each year (Table 1). The AAAB was established by the ADRC Director in 2001 to provide guidance in development of novel approaches to address issues of African American recruitment and retention for ADRC studies and to facilitate new collaborations with community groups.

Some research studies conduct recruitment without the benefit of a systemic plan intended to organize outreach and recruitment efforts, map out necessary steps, and plan for allocation of staff time and resources. As research programs become more complex, invasive, and costly, the importance of a comprehensive recruitment plan becomes more compelling.

Community outreach and education programs were selected empirically as the primary foundation of our Satellite recruitment initiatives. We hypothesized that a comprehensive recruitment program with appropriate infrastructure and culturally responsive outreach programming, informed by data from pertinent recruitment meth-

ods research, would result in increased African American enrollment in our ADRC's studies. This descriptive article outlines the recruitment plan and the results of the minority recruitment methodology that we implemented.

Strategic Plan for African American Outreach and Recruitment

Social marketing is an effective person-centered research recruitment method that borrows from business models, and it was the primary recruitment approach that we employed. It involves the application of commercial marketing techniques to the analysis, planning, execution, and evaluation of programs to influence the behavior of target audiences to improve their welfare and that of society (Andreasen, 1995; Nichols et al., 2004). In a recent systematic review, social marketing alone or in conjunction with community outreach yielded the highest percentage of participants for many of the studies reviewed (UyBico et al., 2007). Although highly effective for recruitment of racial and ethnic minority participants, social marketing is a recruitment method that is applicable to all target populations.

Social marketing in clinical research involves six principles: product, price, place, promotion, participants, and partners. Product refers to the study or intervention. Price is the cost of participating in the study and encompasses time commitment, effort, financial costs, and the cost of changing behavior. Place is the venue where potential participants receive information about the study or where research is conducted. Promotion refers to the marketing techniques used to recruit participants. Partners are community collaborators who contribute to our recruitment efforts (Nichols et al., 2004). Recruitment and retention activities are evaluated and modified in response to feedback from active and potential participants.

Social marketing requires a dynamic research process, including formative, pretest, and monitoring and evaluation research. Formative research is intended to examine the needs and wants of potential participants prior to implementing programs. Pretest research is used to test strategy elements before being used in the field. Monitoring and evaluation research is employed to examine the status of projects so that they can be refined to optimize efficiency and effectiveness. The success of social marketing relates to a focus on the needs and wants of participants and modification of the

recruitment process to address these concerns. The social marketing model is highly effective for research recruitment because of the emphasis on participants, the most vital element in the success of patient-oriented research (Andreasen, 1995).

Implementation

Our formative research included meeting with community leaders and the clergy to discuss their goals and objectives for AD education and recruitment. Our pretest research involved piloting presentations with our longstanding community partners. Attendees of these pilot programs provided feedback regarding the presentations. Content was modified based on their input. Monitoring and evaluation research involves continued assessment of our programs and recruitment approaches. Participants who enroll and the number of additional community organizations contacted as a result of each recruitment activity are tracked. In addition, we review the type of program, for example, lecture, panel discussion, or health fair, to ascertain which modes of interaction with the community are most effective to achieve recruitment goals. Both formative and monitoring and evaluation research data indicated that a similar format for education and recruitment activities would be effective for recruitment of cognitively normal and demented participants. The most commonly requested outreach and recruitment formats were educational programs discussing normal cognitive aging, dementia, and the relevance of AD research. The success of content and venue for these outreach activities was evaluated to plan future programming.

Alvarez, Vasquez, Mayorga, Feaster, and Mitrani (2006) describe a comprehensive algorithm for establishing relationships with community organizations. The authors developed a “recruitment process model” for interactions with community organizations. The goals of the model were to increase the recruitment of minority participants and to cultivate relationships with community organizations. The recruitment process model involves identification of a community organization, ascertainment that the community organization would have potential participants, contact with the organization leadership, determination of the community organization’s interest, visits to the community organization, and interaction with potential participants and community organization staff. They characterize three components of

community organizations to be targeted for outreach: administrators and supervisors, service providers, and service recipients (Alvarez et al., 2006). Outcomes from interactions with the organization are examined to determine if an appropriate yield of potential participants continues. This continued critical appraisal of recruitment success determines the need for and frequency of revisits and interactions with the community organization. The model emphasizes the relevance of determining referral modes, which were classified as provider referral, self-referral, flyer-referral, and participant–participant referral (Alvarez et al., 2006).

Our recruitment plan integrated the infrastructure of the social marketing model, as described by Andreasen (1995), and an algorithm for interactions with community organizations as outlined by Alvarez and colleagues (2006). The recruitment process model described by Alvarez provided a standard protocol for contacting community organizations and an effective method for tracking the outcomes of these interactions using a recruitment process log form. Review of the information provided by the logs informed future interactions with community groups and helped to refine our minority recruitment program.

A key goal of our strategic plan was to increase awareness of AD among clergy and their congregations and community organizations in the African American community. Interaction with the local clergy and their congregations and community organizations to develop recruitment and outreach programs and initiate new collaborations were a key component of our recruitment plan. We contacted community leaders at senior congregate housing, churches, adult day programs, and relevant community organizations to arrange outreach and recruitment programs. Our initial contacts with new community organizations involved identification of appropriate individuals who make decisions about health education programming for the specific community organization. Based on the plan outlined in initial and subsequent meetings with the leadership from community organizations, recruitment and educational activities were customized to the needs, interests, and time constraints of the community organizations. For example, if recent programs conducted for a community organization featured an introductory AD overview, subsequent programs may feature a multidisciplinary panel discussion on dementia care or a presentation on pharmacologic and nonpharmacologic interventions for dementia management. Figure 1

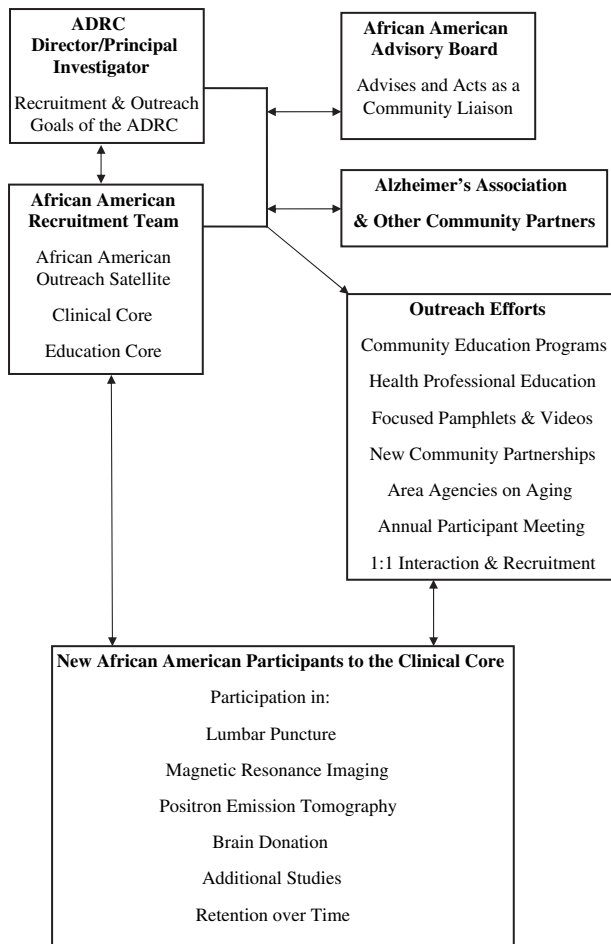


Figure 1. Alzheimer's Disease Research Center (ADRC) recruitment and outreach chart.

shows the organizational structure involved in our minority recruitment efforts. Our African American recruitment program was supported by a network of sustained community collaborators, especially the local chapter of the Alzheimer's Association, an African American nurse sorority, and a church-based AD support group.

Health care Provider Outreach and Training

The Satellite administered a training program entitled the Urban Clinician Partners Program (UCPP) targeted toward health care professionals who care for African American patients. Each UCPP training program lasted 2.5 days and included a mix of didactic, observational, and skill-based teaching techniques. Clinicians received a daily stipend and 20 hr of continuing medical education credit for participating in the program. Health care providers who attended the UCPP were predominately based in the St. Louis area.

UCPP attendees who participated in the first year of training completed surveys evaluating their

experiences with the training program. One of the authors (M. M. Williams) reviewed responses to the quantitative and open-ended questions. The curriculum received high marks. Clinicians conveyed that their confidence in diagnosing and treating dementia was enhanced, and they appreciated the value and relevance of the training and AD information. The clinicians requested shorter training sessions and opportunities for training at their clinical practices. Our health care provider activities were modified to reflect these suggested changes. In 2007, a series of shorter training modules were developed and designed to be customized to the needs, preferred training site, and time constraints of the health care providers and their staff.

Collaborations With the Clergy and Religious Organizations

With the support of an AAAB board member, who is the health advocate for a clergy organization, we developed brief presentations regarding the relevance of AD research that one of our authors (M. M. Williams) presented to the clergy during their administrative meetings. Typical attendance was 50 clergy; the presentations resulted in numerous invitations to speak during or immediately following services at their churches. Presentations at these initial churches led to referrals to speak at other area churches. The pastors' endorsement of the ADRC was integral to success in African American research recruitment.

Use of Media

With the assistance of an AAAB member, we conducted radio interviews discussing AD, the importance of AD diagnosis, and the relevance of research participation. The Education Core staff developed a radio advertisement that discussed the importance of research participation. The radio segment ran for several weeks before and after radio interviews and resulted in a number of telephone calls regarding research. The Satellite contacted radio stations with a predominately African American audience and met with radio show staff to discuss potential content. The format of AD discussions was customized to accommodate the needs, times constraints, and preferences of the program staff. Several of these radio programs were conducted in partnership with the St. Louis chapter of the Alzheimer's Association.

Table 2. Percentage of Participants Enrolled in Additional Studies by African American Race Versus non-African American Race, 2005–2009

Study	African American	Non-African American
Lumbar puncture	39%	66%
Pittsburgh Compound-B	43%	55%
Genetics	95%	99.8%
Magnetic resonance imaging	52%	73%

Outreach Literature

Satellite literature and presentations for the African American community were modified to have a coordinated color scheme and style to develop a consistent format for our outreach materials. In 2006, the Education Core developed a 5-min presentation on AD and research that was used to initiate dialogues with community leaders, clergy, and other gatekeepers. The Satellite employed this template to develop presentations of various lengths, with the content modified to the preferences of the intended audience. Additionally, the Satellite utilized AD literature available from the NIA Alzheimer’s Disease Education and Referral Center, which was very popular in the local African American community.

Results

Outcomes of Recruitment Efforts

In the first 6 months following implementation of the recruitment strategic plan, a total of 19 African American participants enrolled in ADRC studies. Table 1 shows the results of recruitment efforts in the years prior to and since implementation of the plan. In 2007, as a consequence of the comprehensive recruitment plan, a total of 29 African American participants enrolled in ADRC studies and a total of 3,451 African Americans attended outreach and recruitment activities. In subsequent years, the number of community-dwelling African Americans who attended our programs continues to increase.

Following implementation of the new recruitment initiative, the number of African American participants in ADRC supported activities has increased considerably (Table 2). For example, presently, 95% of African American participants contribute blood for genotyping, 52% of eligible African Americans participate in structural MRI, and 43% participate in PIB PET studies. The number of African American participants completing LP studies

Table 3. Satellite Outreach and Recruitment Activities May 1, 2005 to February 28, 2009

Recruitment events (May 1, 2005 to February 28, 2009)	Number of events	Total number of attendees ^a
Alzheimer’s disease presentations	81	3,240
Health fairs	44	3,300
African American participant meeting	1	120
Health provider training	36	421
Total	162	7,081

^aThe numbers represent the total number of attendees at Satellite activities held in the metropolitan St. Louis area from May 1, 2005 to February 28, 2009.

annually has more than doubled, with 5 African Americans completing LP from May 1, 2005 to July 31, 2006 and 29 African Americans completing LP from August 1, 2006 to February 28, 2009.

The number of health care providers who participated in our training sessions increased considerably. Less than 10 health care professionals who provide care for African Americans were trained annually through the original program. Following curriculum modifications, including shorter format and training conducted at the health care providers’ practices, there was a marked increase in participation in the UCPP. A total of 79 health care providers who served predominately African American patients attended the revised health care provider training in 2007. A total of 110 providers were trained in 2008, and 115 providers were trained in 2009. The curriculum continues to be modified in response to health care provider feedback. The next intended step is to develop additional appropriate metrics to assess the impact of training.

The Satellite forged sustained collaborative relationships with the state chapter of the National Medical Association, home health agencies, and an African American nursing sorority. These collaborations provided the Satellite the opportunity to conduct research updates and develop opportunities for dialogues with African American physicians and nurses to discuss research results and future directions. The Satellite worked in partnership with health care providers to conduct community outreach programs and develop new education programs specifically targeted to health care providers.

The recruitment plan generated a considerable number of community outreach and education activities (Table 3). Many of the Satellite’s interactions resulted in lasting collaborations with community

groups. The members of these groups are strong advocates for AD research participation, and leaders from these organizations have assisted us in establishing relationships with new community groups. We conduct AD outreach programs with several organizations that request our annual participation. These include events held in honor of AD caregivers and individuals with AD at local African American churches, participation in the annual Missouri Black Expo, and AD educational programs at senior centers, senior congregate housing, and public libraries. Several of these programs involved state-level community events.

Discussion

Successful recruitment is persistently one of the most difficult aspects of patient-oriented research. Recruitment of racial and ethnic minority participants presents additional challenges due to mistrust, lack of access to and awareness of research studies, and limited interactions between researchers and diverse communities (Stahl & Vasquez, 2004). Studies involving older minority cohorts confront greater complexities, as recruitment is compounded by the aggregate of barriers confronted by older adults and minority populations. Establishment and maintenance of successful community-academic partnerships is an essential component of effective African American outreach and recruitment efforts.

The social marketing model facilitates development of an active dynamic program of African American recruitment for AD research. With the use of formative, pretest, and monitoring and evaluation research, the Satellite recruitment program continues to evolve to meet the changing demands of the study and the needs and concerns of our pool of potential and active participants. In addition, the systemic research plan described would be effective for both general recruitment and recruitment of any racial or ethnic minority group.

The primary limitation of the outreach activities was venues that were low yield for recruitment or not relevant to our target cohorts of participation. This limitation was resolved through our complex assessment of outreach programs and feedback from the organizations we targeted, potential participants, and our recruitment staff. There were few unsuccessful recruitment activities, as venues that were anticipated to have limited numbers of potential participants were targeted via passive recruitment methods rather than expenditure of recruitment team time and effort.

The urgency of diverse representation in patient-oriented research is increasingly compelling due to changing demographics in the United States and must be given a high priority. Sufficiently diverse samples permit greater generalizability of study findings and permit equitable access to the benefits of research participation. As health disparities persist and inequities in research participation mirror inequities in health status and health care, increasing minority participation in patient-oriented research is an integral step in the address of disparities.

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