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Recruitment of Rural African Americans for Research Projects: Lessons Learned

Ishan C. Williams, PhD [Assistant Professor of Nursing],

School of Nursing, University of Virginia

Sharon W. Utz, PhD, RN [Associate Professor of Nursing],

University of Virginia

Randy Jones, PhD, RN [Assistant Professor of Nursing],

University of Virginia

Ivora Hinton, PhD [Coordinator of data analysis and Interpretation],

School of Nursing, University of Virginia

Richard Steeves, PhD, RN, FAAN [Madeline Higgenbotham Sly Professor of Nursing], and

University of Virginia

Gina Alexander, PhD, RN, MPH [Former Doctoral Student]

School of Nursing, University of Virginia

Ishan C. Williams: icw8t@eservices.virginia.edu

Abstract

Recruiting rural African Americans for research presents special problems because of cultural differences, the view of researchers as cultural “outsiders”, and transportation problems. This paper reports successful strategies in recruiting rural African American adults with type 2 diabetes for research studies. The researchers tested recruitment strategies commonly used in research, such as flyers, advertisements in local newspapers and radio stations. The researchers also encouraged referrals from medical professionals. When recruitment goals were not met, the researchers modified strategies. Twenty-two rural African American participants were recruited and randomly assigned to culturally-tailored Group or Individual Diabetes Self Management Education (DSME). The latter included storytelling and an interactive learning approach. The key recruitment strategies involved spending time in the community, visits to churches, and flyers to key leaders in the Black community. Enrolling rural African Americans required cultural competence, careful planning, and time in the community. Recruiting for clinical research is challenging and more difficult when targeting minority members in rural settings. Research in diabetes care is needed with rural African Americans because of high rates of diabetes, and limited health care access for this population. Effective recruitment and retention strategies are needed to test interventions to reduce health disparities.

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Keywords

recruitment; rural; African Americans; barriers

Introduction

Type 2 diabetes mellitus (T2DM) is a serious health problem that disproportionately affects African Americans who have a nation-wide prevalence of 14.7% compared to 8.4% among adults overall.¹ Most often studies with African Americans are conducted in urban areas where the largest populations reside. Although studies among rural residents are increasing, the majority have involved only female participants.²⁻⁴ It has been estimated that nearly one in four African American women over the age of 55 has diabetes -- twice the proportion of White women.¹ Among all African Americans over the age of 20, 11.8% of women and 8.4% of men have diabetes.⁵ Further, research has shown that African Americans, especially older African Americans who often have low health literacy, have worse glycemic control than members of other groups.⁶⁻⁸ Therefore, recruiting African Americans into research is essential to increase representation in research trials to understand why diabetes differentially affects one group over another.

Recruitment and retention of African Americans in research is challenging,⁹⁻¹¹ especially in rural areas.¹²⁻¹⁵ African Americans are more likely than White Americans to mistrust researchers, perceive a lack of relevance to the research, and lack transportation to the research site.^{12,14} Specifically, challenges that have been noted in research with rural African Americans also include lack of health care providers to refer community participants into research and a lack of infrastructure for research in rural communities—particularly in African American communities alike.¹⁴

As a result of these challenges, developing a relationship of trust with research participants and the overall community is critical for a study to succeed.^{16,17} Additionally, recruiting participants from a rural area has unique challenges that may be exacerbated when trying to recruit rural African Americans, given their underrepresentation in research studies.¹⁴ Rural culture is also unique in that often there is a lack of a formal infrastructure to conduct research. Research reports from studies conducted in rural areas often have a lack of detailed information about the recruitment of rural samples, which makes it difficult for other researchers when designing their studies.¹⁸ Bushy¹⁷ noted that gaining entry into a community and inviting members of another culture or a subgroup of a rural community to participate is both time-consuming and critical to successful recruitment. In rural areas, access, driving conditions, lack of resources, and the cultural outsider status of researchers make it especially difficult to recruit people into studies.¹⁵ Moreover, rural people have not been adequately represented in research studies to provide valid estimates of health outcomes, thus adding to the health disparity gap. Given these conditions, emphasis must be made on both recruiting and retaining rural residents--specifically rural African Americans--in all phases of the research process. The study reported here is a diabetes intervention study for African American men and women in rural Virginia. This paper describes the

recruitment strategies and methods used in the study to successfully recruit and retain rural African Americans with type 2 diabetes.

Methods

The study was conducted in 2006 at community center in a rural county in central Virginia. The purpose of the study was to test a culturally-tailored tailored intervention for teaching diabetes self-management education (DSME), and to compare individual and group approaches. The selected setting fit the definition of rural using the Rural Area Commuting Area (RUCA) codes developed by the United States Office of Management and Budget. The Institutional Review Board at the affiliated university approved the study. In order to enroll in the study, participants had to self-identify as African American, be age 18 years old or older, be diagnosed with type 2 diabetes, be a resident of the rural county, and be able to give informed consent. All participants signed an informed consent form and agreed to be randomized to a series of diabetes self-management training sessions either with a small Group intervention or an Individual meeting with a diabetes educator to improve self-management of diabetes. Where applicable, all materials used in the intervention were designed for persons with low literacy (e.g., 6–8th grade level), with the exception of materials from the American Diabetes Association.

Demographics of the Sample

A convenience sample of 22 volunteers (16 women, 6 men) was screened at a local community center then randomly assigned (using a table of random numbers) to the culturally-tailored Group or Individual Diabetes Self-Management Education (DSME). Because more men were randomly assigned to one group, a second random drawing was done to assure a similar proportion of men in both of the groups.

Table 1 presents a summary of key demographic characteristics of the analytic sample. Participants were on average 60 years of age and mostly female (76%). Only about one-third of participants completed high school. Medicare and Medicaid were the most commonly reported health insurance. Participants generally had been diagnosed with diabetes for 9 years, and 90% also reported having high blood pressure (hypertension). For additional details about the intervention and findings, the reader is referred to another report of the results.¹⁵

The Intervention

The culturally tailored intervention was based on focus group research collected with rural African Americans in the same region. Based on the focus group findings, the research team developed a culturally tailored intervention specifically for rural African Americans. The general intervention approach used was Afro-centric, emphasizing positive approaches and community involvement and using diabetes education materials developed specifically for African Americans. The framework for setting goals and problem-solving one's diabetes management was based on the 7 areas of self-management behaviors identified by American Association of Diabetes Educators¹ which are: healthy eating, being active, monitoring (blood glucose), taking medication, problem solving, reducing risks, and healthy coping. All

participants in the study were taught by experienced certified diabetes educators either individually or in small groups. All participants set an individual goal with the diabetes educator, based on his/her priority for diabetes self-management. The progress participants made toward their goal was reviewed at each session, either within the Group or by participant's Individual discussion with educators. Participants in both the Group and Individual DSME received the same materials, incentive gifts and payments.

Individual intervention—Participants assigned to individual DSME met with the diabetes educator on three occasions over the 8-week period at the same time as the group sessions; however they met in a separate room. Individual sessions were on average 10–15 minutes and focused on reviewing the goal originally set, obstacles and progress on meeting the goal, and help facilitating problem-solving or goal revision. The diabetic educator provided information and/or resources as needed to participants throughout the study.

Group intervention—Group sessions for the culturally tailored DSME intervention were held weekly for two hours each over an 8-week period. The Group intervention incorporated additional cultural elements suggested in previous research with a similar rural African American community¹⁶ including: (a) the tradition of storytelling and use of figurative language; (b) a desire for learning through activities (e.g., cooking, label reading); (c) a desire to hear from people with diabetes who are like them (e.g., African American, living in a rural region); (d) pervasive concerns about costs of care; (e) preference for sharing experiences in a supportive group (e.g., learning together “like we do at Wednesday night bible study”); and (f) discussions about the use of complementary and alternative therapies such as teas/herbs/supplements. The culturally tailored Group intervention thus reflected the values, beliefs, food preferences, language, and health care practices of rural African American men and women. Specifically, during the cooking demonstrations, meals of typical ethnic food preferences were prepared by an African American dietician familiar with regional preferences. Participation of family members or friends was encouraged to capitalize on the value of family and supportive friends,^{14,21} African American role models were invited to attend sessions and share success stories, and the intervention included information about the use of complementary and alternative therapies. The use of an African American storyteller also facilitated cultural translation of the educational materials and culturally competent learning methods.⁴

Data Analysis

Although this article does not report on the findings of the diabetes study, it is important to note that there were several outcomes measured in the parent study, found in detail in another report.¹⁹ Participants completed the outcome measures at baseline and immediately post intervention (10 weeks after baseline). Data were analyzed by pre/post measure comparisons of mean scores from the Group versus Individual DSME intervention participants. It was hypothesized that participants in the Group intervention would achieve statistically significant improvements on all outcome measures compared to the participants receiving Individual education.

Results

Recruitment and Retention Strategies

Our primary goal was to recruit sufficient participants to test the feasibility of the intervention and provide beginning data about its effectiveness. Previous successful recruitment for focus group research in similar rural communities led us to expect sufficient participants for the study. Based on the focus group results and experience of the research team, the recruitment strategies put into place were: advertisement flyers put into barber shops, salons, grocery stores, and a toll-free number was used to encourage potential participants to call for additional information and preliminary screening. In addition, meetings were held with key leaders in the Alliance of Black Churches. Initially, however, using these strategies, our recruitment goals were not met. We therefore re-examined the strategies we had in place and developed a new plan that included more face time in the community and more use of local media. For example, visiting a rural church on Sunday mornings and participating in local town events while not collecting data more often than previously noted. There was also an article in the local paper describing the study with a photo of a local resident. With these strategies our recruitment increased by 6 participants in one data collection period to a total of 22 participants, which represented 70% of the targeted number (Target N=30). The participants were obtained over two enrollment periods lasting approximately 3 months before beginning the intervention (See flow diagram). Only one participant dropped out after enrolling, noting lack of unavailability and time, although the person indicated she was very much interested in the study. Other reasons noted for not starting the intervention were problems with scheduling and or not showing up when the intervention started. Thus retention of participants was also very high (21 of 22 completed the study). Participants in the Group DSME intervention started the educational sessions within 2 weeks of screening, which had been previously shown to reduce attrition.¹⁴

Specific recruitment strategies used by the research team included having minority research team members, which has been shown to increase the likelihood that reporting and referring, as well as other ethical issues, will be handled appropriately.^{22,23} Both passive and active recruitment strategies²⁴ were used to increase participation. Passive strategies included disseminating information about the study through flyers, advertisements, public service announcements, and local newspaper articles, each of which prompted potential participants to contact the research staff. Active strategies included hiring research staff to directly contact prospective participants and people with influence in the African American community (e.g., pastors, the local National Association for the Advancement of Colored People [NAACP] organization, church groups, medical providers) to convey to the community the importance of the study. As suggested by Banks-Wallace and colleagues,²⁵ interaction with the research team members (including the principal investigator and telephone screeners) provided support for the African American participants in the study to become engaged in the intervention.

In rural areas, researchers are often seen as cultural “outsiders;”²⁶ thus the researchers attempted to spend time in the community, making key contacts and conducting the research at an appropriate time for community members, which may have helped build trust. For

instance, the researchers held the intervention sessions after 4pm, when most of the major employers in the area ended their shifts. Additionally, there was an exercise program held at the same community center earlier in the morning, and several of the participants took part in that program. The high rate of satisfaction with their interactions may have influenced participants to encourage others to come or keep coming to the Group or Individual DSME sessions.

Strategies to overcome barriers to participation included conducting the research out in the community, which was convenient for participants, reminding participants of appointments (phone calls and postcards), and reaching out to community organizations. During the screening process, the researchers also asked participants who agreed to be in the study how they thought we could get the word out to other people who might be interested. The researchers felt it was important to develop this partnership with participants in order to determine which recruitment strategies were successful and which were not useful. Incorporating participants' input into recruitment strategies added momentum to the recruitment process and may have helped minimize the "outsider" perception of the researchers.

The researchers maintained a delicate balance between keeping good relationships with key community advocates while offering the intervention only to a subgroup (i.e., African Americans). A few people who were not African American called the study's toll-free phone number and wanted to participate (n=5). The limitation to African Americans was seen as controversial to some community members, yet apparently because of positive relationships, the researchers were able to handle the situation by offering referrals to other diabetes education resources. Our staff and the community partners were able to explain to people who did not meet the study criteria that if the results of the present study improved outcomes for the subgroup with the highest rates of diabetes, then the program could be offered to all persons in the community, with the same expected results. Additionally, researchers continued to reiterate that we were not offering a "health care service" but were conducting research. These clarifications helped community members to support the cause of the study in hopes that the program would be successful enough to implement it broadly in this rural community.

Strategies to encourage participants to remain in the study included reminders and incentives. Participants in the Group DSME intervention came weekly to group sessions and were routinely reminded what each week's session would include. As an incentive, pedometers, light refreshments, diabetic cookbooks, and foot care products were provided, and door prizes were awarded, including foot care kits, exercise videotapes, and/or books with recipes for African Americans with diabetes. All participants were awarded a certificate of completion at the end of the intervention. Participants in the Individual DSME intervention group were sent letters 2 weeks prior to each data-collection session, and all were telephoned 1 day prior to each session to remind them to attend. To encourage continued participation of both groups, at each data collection session (3 times during the study), \$25.00 compensation was given to each participant and door prizes were offered. Contact information was also gathered to avoid losing participants in follow-up sessions and for emergency contact information.

The research procedures also were designed to increase retention. In the Group DSME intervention, participants were given flexibility to adapt the topics so that they had some control over the information they felt was needed. This promoted discussion, problem-solving and ownership by the participants. For those receiving the DSME through individual meetings with the diabetes educator, individual tailoring continued throughout the intervention, with a focus on each person's goals with problem-solving to improve diabetes management.

The multiple strategies used for diabetes self-management education demonstrated the appreciation researchers had for rural participants and the community. It was important to bring the study to the community, and to develop collaborative relationships and establish trust to enhance recruitment and retention. At the conclusion of the study (in 6 months), all participants and other community members were sent a summary describing the results of the study and providing information on how to contact the researchers if further information was needed. It was also important to disseminate the research findings in a timely manner, because this was essential to conducting future research in this rural community. Follow up meetings to present results were also held in the community with groups such as the Alliance of Black Churches and NAACP.

Discussion

In this study, the nature and timing of contacts with potential participants were integral to success in recruiting and retaining African American participants. Because some African Americans may have difficulty in trusting researchers,¹² it is essential to meet with key contact persons to learn more about the population and to include members of the community in planning and designing research.²⁷ Word of mouth strategies require more time but generate more responses than media based strategies.²⁴ Additionally, incentives may influence the return of participants in both intervention and control groups, but the timing of the incentives may not matter.

In this research, cultural adaptations may have positively influenced recruitment and retention. The unique challenges of recruiting rural participants were recognized and considered in the recruitment plan. Previous studies have shown that it is helpful to include researchers from the racial group of interest.^{9,11,22} as was done in this study. In addition, the researchers for this study found that if the entire research team is respectful and demonstrates awareness of the importance of culture, community members appear to feel more comfortable participating. Similarly, other researchers have shown that establishing trust and spending time in the community are essential to recruitment success.^{12,24,28}

Results of this study suggest that in order to engage minority populations in research, a strategic plan is necessary using a variety of recruitment strategies. Additionally, researchers should not assume that successful methods for recruitment and retention in one community will work in all other communities.²⁹ Failure to understand the unique culture of a population may distance researchers from the community they are interested in investigating.

Although many factors cannot be predicted or controlled when recruiting rural African American participants, key principles that are consistent with previous studies and the current project are: investing time in developing relationships with the community, understanding the needs of the population being served, and being sensitive to the culture.³⁰ Initiating a research project without fully understanding these factors violates the trust of the African American community.³¹

Implications for Practice

Several implications are suggested. There is a need to adapt a culturally-sensitive approach to recruiting that combines multiple methods and trusting relationships among all ethnic or cultural populations, which should be adopted when dealing with rural African Americans in research studies. This can be achieved by providing culturally-sensitive and relevant research opportunities to rural African Americans, which can increase the number of participants into research studies. In addition, recruitment methods should relate to the ways of integrating the participants' personal needs with the professional needs of the research team. For example, this could be achieved by providing incentives that directly relate to the reason participants are being asked to participate (i.e., culturally relevant cookbooks for diabetics). With all the insights learned, the goal is to further provide guidance to clinicians about approaches to caring for the large numbers of rural African American adults with T2DM who are at high risk for complications. If approached correctly, more African Americans will enter research studies about diabetes and help to address an important health disparity.

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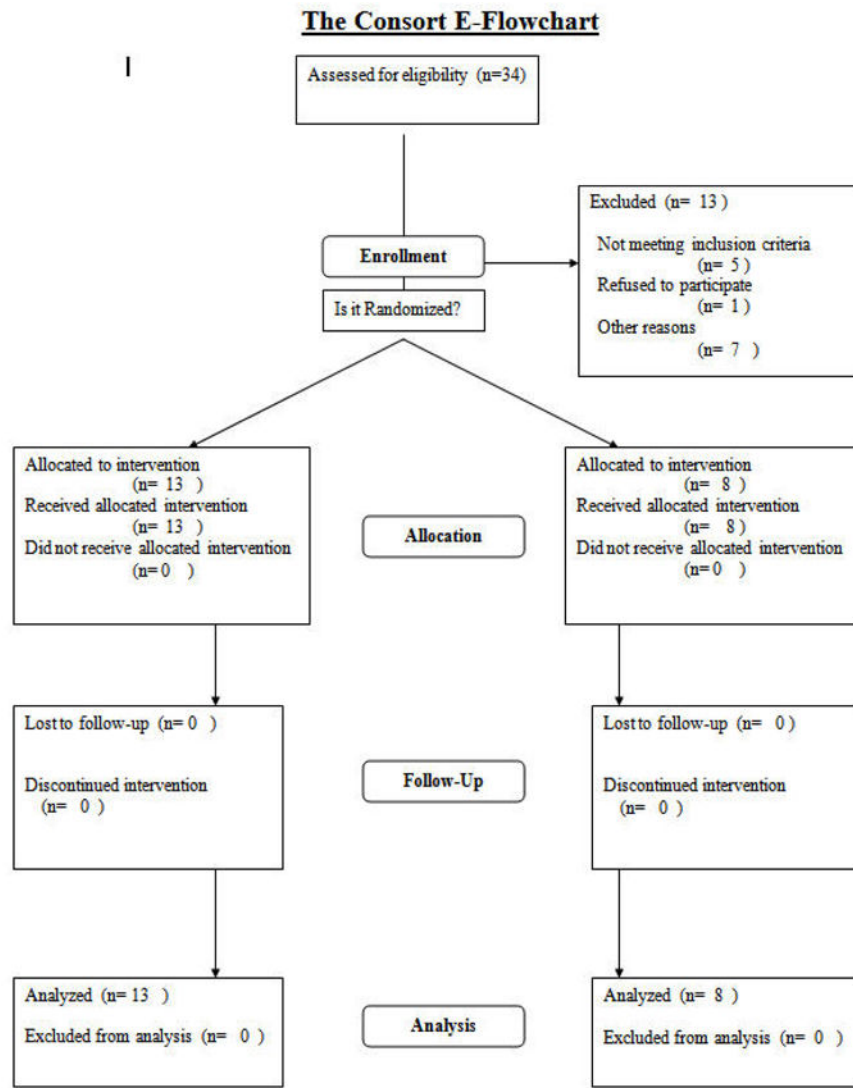


Figure 1.
The Consort E-Flowchart of Participants

Table 1

Demographic Characteristics of the Sample

	All Participants (n=21)	Group DSME (n=13)	Individual DSME (n=8)
Age			
Mean Age, years (SD)	60.2 (14.6)	62.4 (14.7)	56.6 (14.7)
Gender			
% Female	76.2% (16)	76.9% (10)	75% (6)
% Male	28.5% (6)	23.1% (3)	37.5% (3)
Education (highest grade or year completed)			
Less than high school completion	47.7% (10)	53.9 (10)	37.5% (3)
High school graduate	33.3% (7)	23.1% (3)	50% (4)
College Education		15.4% (2)	12.5% (1)
Type of Insurance (% covered)			
Public insurance	66.7% (14)	69.2% (9)	62.5% (5)
Private insurance	47.6% (10)	46.2% (6)	50% (4)
Residence (%)			
In a rural area (not a farm)	47.6% (10)	53.8% (7)	37.5% (3)
In a small rural town	33.3% (7)	23.1% (3)	50% (4)
In a small town	19% (4)	23.1% (3)	12.5% (1)
Diabetes History			
Years with diagnosed diabetes (Mean, SD)	9.2 (6.9)	10.4 (7.1)	7.1 (6.3)
Has ever attended diabetes education (%yes)	57.1% (12)	61.5% (8)	50% (4)
Health History (% present)			
Cardiovascular disease *	33.3% (7)	30.8% (4)	37.5% (3)
High blood pressure	90.5% (19)	92.3% (12)	87.5% (7)
Eye disease	19% (4)	23.1% (3)	12.5% (1)
Kidney disease	9.5% (2)	15.4% (2)	0
Numbness/tingling in the legs or feet	23.8% (5)	15.4% (2)	37.5% (3)
Diabetes Treatment and Management (%yes)			

	All Participants (n=21)	Group DSME (n=13)	Individual DSME (n=8)
Takes oral medication	71.4% (15)	69.2% (9)	75% (6)
Takes insulin shots	38.1% (8)	46.2% (6)	25% (2)
Regular exercise	66.7% (14)	61.5% (8)	75% (6)
Special diet	52.4% (11)	53.8% (7)	50% (4)
Losing weight	47.6% (10)	53.8% (7)	37.5% (3)

* Indicates self-reported history of heart problems and/or stroke