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Recruitment of Three Generations of African American Women Into Genetics Research

Jacquelyn Y. Taylor, PhD, PNP-BC, RN
Yale University

Abstract

Successful outcomes for studies on health disparities depend on recruitment of research participants. Obtaining willing participants, protecting their rights, and acknowledging their contribution to research is as important as seeking answers to the study phenomena. Recruiting research participants can be an arduous process for investigators. Although literature has published participant recruitment methods, investigators sometimes underestimate the time and intensity required to attract eligible participants into research studies. This article reports on methods used to recruit 42 African American generational triads (grandmothers, mothers, and granddaughters) into a hypertension genetics study, the lessons learned, and suggestions for successful recruitment.

Keywords

recruitment; African American; genetics; multigenerational; health disparities

Recruiting participants into health disparities research can be challenging and time consuming. Various methodological articles (Keller, Gonzales, & Fleuriet, 2005; Gillis et al., 2001; Villarruel, Jemmott, Jemmott, & Eakin, 2006) on recruitment and retention of minorities in research have been disseminated to help investigators recruit ethnic samples efficiently and avoid mistakes. Some authors provide general overviews of “things to consider” when attempting to engage minority participants (Johnson & Arfken, 1992), whereas others provide in-depth explanations of the method that was most successful for their studies (Carter-Edwards, Fisher, Vaughn, & Svetkey, 2002).

Investigators agree that when conducting research with African Americans, the following aspects regarding recruitment should be considered: heterogeneity of the population (Taylor, Caldwell, Baser, Faison, & Jackson, 2007), use of recruiters (research assistants) of similar ethnicity or background (Brown, 2004), and knowledge of local cultural customs and expectations (Carter-Edwards, Fisher, Vaughn, & Svetkey, 2002; Johnson & Arfken, 1992). Personnel who come in direct contact with participants of different ethnic backgrounds often require cultural sensitivity training. For example, recruitment staff need to understand the importance of addressing African American participants by their respective titles (Sir, Mr., Mrs., Dr., Pastor, etc.), and consider and respect specific needs of each participant (work, privacy, childcare, time of interview, etc.; Brown, 2004). Gaining trust within the African American community could make substantial differences in recruitment efforts (Picot et al., 2002). Once trust is established, potential participants may assist in recruitment efforts by encouraging involvement of friends, family members, and neighbors who meet study criteria.

Deciding the best method to recruit participants for a particular type of study continues to be a topic of debate. Whether a researcher should use passive (advertisements) or active engagement (face-to-face) methods to recruit potential research participants depends largely on the comfort level and time constraints of the investigator, research team, and participants (Yancey, Ortega, & Kumanyika, 2006).

Engaging African American individuals in research studies can be difficult. Finding three generations of African American women from the same family who agree to take part in research is more problematic. In addition, agreeing on a common time when all three members of the triad can be together in the same place is an even greater challenge. All three members of the generational triad are required to sign consent forms, complete questionnaires, and provide personal health-related information in face-to-face structured interviews.

Research using multiple generations of family members (i.e., grandmothers, mothers, and granddaughters) is important to determine health risks, establish plans for health promotion, and provide appropriate care for families across life spans. Published literature on recruitment of African Americans into hypertension genetics studies was limited, although studies on recruitment for cancer genetics research (Halbert, et al., 2005; Hughes et al., 2004) and general recruitment of African Americans (Durant et al., 2007; Jackson et al., 2004) have been published. Although the nursing, medicine, public health, and psychological literature discuss recruitment of minority samples into research (Durant et al., 2007; Jackson et al., 2004; Johnson & Arfken, 1992; Villarruel, et al., 2006; Yancey et al., 2006), they lack strategies for successful recruitment of three generations of African Americans into research studies. This report adds to the literature regarding use of effective options to successfully recruit African American generational triads into genetics research.

Purpose

The purpose of this article is to evaluate the effectiveness of multiple techniques used to recruit three generational triads of urban African American women into a genetics study. In addition, the study provides suggestions that investigators planning to recruit multiple generation minority samples could use to increase participation in their research.

Methods

Sample

In the study, *Hypertension and Heredity: Hypertension Genetic Polymorphisms in Three Generations of African American Women*, three generations of maternally blood-related women were recruited to examine hypertension susceptibility genes. The investigator and research assistants who worked to recruit African American women into the three-generation genetic study were African Americans who lived in a large Midwestern urban area. They were knowledgeable about the local health and university systems as well as the social climate and historical treatment of Blacks in a large urban city located in the Midwest.

A convenience sample of 126 (42 triads) urban African American women agreed to participate in the study. To meet the inclusion criteria for the study, participants were required to self-identify as African American and have a living family of at least three generations to constitute the triad of grandmother–mother–granddaughter. All African American women who were recruited for the study resided in urban and suburban neighborhoods in a large Midwestern urban area. Although participants self-identified as African American, the recruiters were aware of the heterogeneity of Blacks in America that include, but is not limited to, Blacks of mixed heritage, African immigrants, Caribbean Blacks, and Blacks of various other origins (Brown, 2004). For purposes of this article, all participants are referred to as African American.

Recruitment Procedures

Multiple procedures were used to recruit African American women for the multigenerational genetic study. Participants in this study were recruited from a large urban metropolitan area in the Midwest because cardiovascular disease, associated with hypertension, is the most prevalent cause of death among African American residents (American Heart Association, 2007; Community Health Institutes, 1998). Demographic statistics for the area indicated a majority African American population, with nearly half of the households living at or below the poverty level (United States Department of Health and Human Services, 2005). The study was approved by the University of Michigan and Wayne State University Institutional Review Boards.

Participants were recruited by the investigator and research assistants using four different methods.

1. *Use of advertisements:* Project flyers were posted in university campus eateries, bus stops, student center, halls, dorms, and gym facilities. Flyers also were posted in neighborhood areas including local stores, markets, and community centers. Advertisements indicating “research participants wanted” were posted in local and university newspapers. The flyers provided a general description of the study and provided contact information for potential participation in the study.
2. *Churches:* Leaders of local churches were contacted by the investigator. She met separately with pastors or church representatives of 15 urban churches to discuss the project. She asked for permission to have either the researcher or the pastor/church representative make an announcement at scheduled church service times about the importance of the study and to encourage participation by women congregants. Flyers also were placed on church bulletin boards or placed in church bulletins. Previous research has reported that churches in ethnic communities can be a positive portal for successful recruitment of potential participants in research (Carter-Edwards et al., 2002; Hatch & Voorhorst, 1992, Taylor & Holtrop, 2007). However, when using church members in a research project, eliminating reporting of church names involved can help maintain the confidentiality of the participants.
3. *Historically Black sororities and other social networks:* An announcement was made at monthly meetings of a local chapter of an international sorority. Monthly meetings of the local chapters can result in gatherings of women, ranging from a few members to more than 100 women. The principal investigator met with the president of the local chapter to discuss the proposed project prior to mailing blind solicitations to the chapter. When permission to proceed was granted, flyers were given to the chapter president or her designee for distribution and announcement at the meetings. A brief description of the study, purpose, and inclusion criteria were provided during the announcement. Information on contacting the principal investigator was distributed to women attending the monthly meetings. To comply with the principles of anonymous participation and confidentiality in human studies, the name and location of the historically Black sorority that participated in this study will not be disclosed in this report. Social networks also were used to increase sample size by asking women in the sorority to refer friends, neighbors, colleagues, and community affiliates as possible participants in the study.
4. *Participant resource pools:* The University of Michigan Women’s Health Registry (WHR) and Wayne State University, Institute of Gerontology Participant Resource Pool (PRP) provided lists of individuals who had indicated previously that they would like to be contacted to participate in research. The University of Michigan has compiled a list of women who expressed interest in participating in health-related

research studies. The women on this health registry were pre-screened through short interviews. Potential participants provided their contact information and granted permission to release that information to health-related research studies being conducted at the university. Investigators interested in using this registry met with the WHR personnel and submitted a short description of the research project and inclusion criteria. After receiving approval in writing from the group to use the list, the internal review board at the university/research center granted approval to begin data collection. A specialty registry of older women interested in participating in research projects also is maintained by the Wayne State University Institute of Gerontology PRP. Obtaining use of this registry required a formal application, submission of project protocol for external review, and copies of key personnel biosketches.

When requests for use of the WHR and PRP were approved, electronic files containing names, addresses, and phone numbers of African Americans who expressed interest in participating in research was provided to the investigator from each group. Each potential candidate was contacted by phone and the inclusion criteria for the study were discussed to determine interest and eligibility. If participants met the study criteria, they were invited to participate. Separate monthly reports were submitted to the WHR and PRP directors on the status of potential participants contacted from each list.

No fee was charged for use of either the PRP or WHR. Once approved, the registries were easy to use and helpful in recruiting multigenerational families into this genetic study. The method of using health registries yielded the second largest number of multigenerational participants into the genetics study. Researchers who are interested in accessing research pools should consider checking Web sites of research universities (University of Michigan Women's Health Registry, Wayne State University Institute of Gerontology, etc.).

Barriers and Strategies to Overcome Recruitment Barriers

Participants in the hypertension genetics study voiced several concerns with genetics studies and reviewing these concerns was essential prior to embarking on the interviews. Participants wanted to know if blood samples were needed for the DNA sample. Many participants were unwilling to provide blood samples, but once informed that noninvasive buccal swab saliva samples would be used, participants were more at ease about being in the study. Information was provided to all participants regarding who would have access to their DNA, what DNA biomarkers would be explored (only hypertension polymorphisms), how long the DNA would be stored before it is destroyed (one year), and who would have access to their DNA status reports (only the principal investigator of the hypertension genetics study, laboratory technician, and research assistants).

Several other barriers were found in recruiting three generations of African Americans into the hypertension genetics study. Investigators had difficulty scheduling interviews at the onset of participant recruitment. Initially, interviews were scheduled separately when each individual member of the triad was available. Although all three members verbally agreed to participate, some members of the triad never set a date and time for the interview or did not participate if disputes arose within the triad. This method of individual interviews was replaced with the method of requiring each member of the triad to interview at the same time and place. Changing the interview appointment method to a "family interview" saved time for both the families and the interviewer. Instead of each individual interview requiring 1 to 2 hours per person, the total time for interviewing the family lasted 1 to 2 hours.

Interviewers for the hypertension genetics study also changed their work schedules to accommodate the family triad interview time frames. Interviewers were flexible, scheduling appointments for evenings, weekends, and holidays. Many interviews were conducted on

holidays (e.g., Thanksgiving, Christmas Eve, and Martin Luther King Day) when all three members of the family were planning to be together. Holiday interviews were very successful because interviewers met other family members who also agreed to participate in the study. In some cases, participants would call close friends immediately to request their participation in the study. Prior to starting the interview, each member of the triad had to sign an informed consent form. If the youngest member of the triad was a minor, her mother signed the consent form. On completion of the interviews, each research participant received a \$20 gift card (\$60 per family) as an honorarium for their participation.

Results

Demographics

Each participant completed a demographic survey to provide a profile of participants' social contextual status. The demographic survey was intended to obtain information regarding age, highest level of education attained, marital status, and income. The purpose of presenting this information was to provide a context for the female triads who agreed to participate in the study.

The participants ranged in age from 1 year to 93 years of age. The mean age of the grandmothers was 66.76 years ($SD = 12.56$), with their ages ranging from 42 to 93 years. The mothers ranged in age from 20 to 69 years, with a mean of 42.12 ($SD = 11.71$) years. The average age of the granddaughters was 17.76 ($SD = 13.25$) years, with their ages ranging from 1 year to 50 years (see Table 1).

The grandmothers' educational levels were generally high school ($n = 10$; 23.8%) or some college ($n = 11$; 26.2%). In contrast, the largest group of mothers ($n = 15$; 35.7%) had completed some college, with 11 (26.2%) indicating they had attained bachelor degrees. Because of the granddaughters' ages, most had not yet completed high school ($n = 18$; 42.9%). One (2.4%) grandmother and one (2.4%) granddaughter had obtained doctorate degrees (see Table 2).

Grandmothers were more likely to be widowed ($n = 15$; 35.7%) or married ($n = 12$; 28.6%), whereas mothers tended to be either married ($n = 18$; 42.9%) or single ($n = 13$; 31.0%). Most granddaughters were single ($n = 35$; 83.3%). The largest group of grandmothers had incomes between \$10,000 and \$40,000 ($n = 23$; 54.8%). The largest group of mothers had incomes between \$40,000 and \$60,000 ($n = 10$; 23.8%). The largest group of granddaughters who were working had income levels that ranged from \$10,000 to \$20,000 ($n = 10$; 23.8%; see Table 2).

Participants Recruited

The largest group of participants were recruited from a historically Black sorority chapter (17 triads, $n = 51$; 40.5%). Participant resource lists (14 triads, $n = 42$; 33.3%) provided by WHR and PRP provided the second largest group of participants. The smallest number of participants were from either local churches (6 triads, $n = 18$; 14.3%) or posting of study flyers and newspaper advertisements (5 triads, $n = 15$; 11.9%).

Discussion

Multiple methods of recruitment of African American participants have been reported in the literature, but few have discussed methods involving the use of historically Black sororities or participant resource pools (Ford, Havstad, & Tilley, 2003; Satia, Galanko, & Rimer, 2005; Vesey, 2002). Historically Black sororities should be considered as fruitful recruitment options for studies on African Americans. Working with sororities can require a certain degree of procedural follow-through, but results can be worth the effort, particularly for investigators interested in multigenerational studies. Black sororities have long proud histories of legacy,

with multiple generations of the same family joining the same organization. Two, three, or even four generations of women from the same family often attend regularly scheduled meetings together. In such instances, researchers met with a captive audience and all members of the potential family generational sample were available to review, discuss, and decide if they would participate in the study.

Investigators who are members in good standing of historically Black sororities may have an easier time gaining entry into these organizations because of their previously established recognition and trust from the membership. Researchers who are not members of these organizations should develop strategies to engage members of these groups in the same way as they would approach other service organizations to obtain research participants. Examples of historically Black sororities include but are not limited to Alpha Kappa Alpha Sorority, Incorporated; Delta Sigma Theta; Zeta Phi Beta; and Sigma Gamma Rho.

The use of health registries was more effective in enrolling three generation families than recruitment via churches and use of advertisements. Although the process used to meet all the requirements established by the two universities to use their registries was rigorous, the registries provided potential participants who were interested in research. In addition, the registry maintained by the Institute of Gerontology at Wayne State University gave the researcher access to older African American women. These women were the grandmothers who could influence their daughters and granddaughters to agree to participate in the multigenerational research.

Recruitment of research participants via religious organizations in the hypertension genetics study required direct contact with church representatives (pastor, deacon, etc.) to discuss the project and its importance, along with risks and benefits associated with participation. Each church used different methods to disseminate information regarding the study and recruitment procedures. Some churches invited researchers to make personal appeals to the congregation, whereas only the pastor made announcements on behalf of the research team in other churches. Some churches took a more active role in recruitment, whereas others preferred passive methods (i.e., posting flyers or study inserts in church bulletins). Regardless of the method of recruitment allowed by the church, researchers in the three generation hypertension study were aware that they were guests in the church and understood that church leaders knew the best method for recruitment in their particular congregation.

The use of flyers posted in public areas was the least effective method of participant recruitment in this study. Either the flyers were placed in areas not frequented by people who were interested in research or potential participants were skeptical of the offer and did not contact the research office. Perhaps the use of other forms of advertising (e.g., television or radio) could provide additional participants who met the inclusion criteria for the study.

Limitations

A limitation of this study was the educational level of the participants who were recruited for the study. The educational level of participants recruited using the methods in the present study was not of concern because the primary focus of the study was genetics research. However, researchers conducting social science and behavioral research should be aware that the use of Black sororities and resource pools may result in skewed samples with higher socioeconomic levels (weighted combination of education and occupation). The second limitation of the study was that all participants were African American women and other recruitment procedures may be more applicable for members of other ethnic and gender groups.

Recommendations and Lessons Learned

Understanding of, and sensitivity to, African American culture is an important starting point for recruiting Blacks into research programs. Familiarity with the surrounding environment, political atmosphere, and social issues that influence participation in research is helpful when conducting field work with African American families. Participants allow investigators to share their lives by completing questionnaires that provide personal and health related information. In return, investigators need to be respectful and appreciate African Americans' skepticism about participating in research.

Levkoff and Sanchez (2003) suggested examining the target populations' history with the associated academic and/or hospital entities prior to embarking on the study. Having a knowledge base of major negative and positive experiences from the past can provide a foundation for intelligent conversation when seeking to gain the trust of community leaders and willing participants. Levkoff and Sanchez (2003) explained that research on African Americans required a more "hands-on" approach, with investigators becoming known and respected by local church leaders, elders, and other respected community representatives. Commitment from the local community is necessary for success in recruiting African American research participants. Without support from community leaders, difficulties can arise in finding willing participants because of reminders of tragedies associated with research trials of the past (i.e., the Tuskegee experiments; Brown & Topcu, 2003).

Although research has shown that the Black church can be an effective avenue for recruitment of research participants, other options should be explored to increase African American participation, particularly multigenerational families into research. The use of historically Black sororities should be considered as recruitment sites. Another recommended option for recruitment is participant resource lists. These lists are compiled by groups or agencies interested in conducting research with particular populations who have voiced interest in being research participants. Both sororities and participant resource lists were shown to be the most effective methods used with recruiting African American maternal generational triads into the hypertension and genetics study.

Working with three generation family participants requires skill in coordinating work, school, and babysitting schedules. Recruiters for multiple generation studies must be flexible with day, evening, and weekend availability to accommodate needs of multigenerational families. Holiday availability was welcome by families and recruiters. Recruiters were able to interview family members on holidays when the family was scheduled to be together. Generational triads were helpful in recruiting other family members and close friends who met the criteria for the study. This snowball sample selection process among family and friends on holidays saved time for the recruiters and resulted in greater numbers of participants in the study.

Typically, in the African American family, the grandmother is the matriarch and head of the family. The matriarch is looked upon as the "rock" in the family and younger members of family look to her for advice and guidance. Recruiters, in many cases, contacted the grandmother first to review the study and ascertain her thoughts on participation prior to contacting other members of the generational triad. Once the grandmother agreed to participate then the second and third generations usually agreed to participate as well. Gaining the trust and acceptance of the grandmother in the generational triad is essential when recruiting three generations of African American women into research studies.

Investigating new and innovative methods of participant recruitment among African American populations is important when conducting research studies on multiple generations of African Americans. These methods could provide researchers and participants with potential benefits for health-care prevention and treatment of high blood pressure as well as other chronic

conditions. This report indicated that it is feasible to gain the trust of three generations of African American women and successfully recruit them into health disparities research. DNA analyses and follow-up studies with this sample of three generations are currently underway.

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Table 1

Age (in Years) of Participants by Triad Membership

Triad Membership	Number	Mean	SD	Median	Range	
					Minimum	Maximum
Grandmother	42	65.76	12.56	65.50	42	93
Mother	42	42.12	11.71	41.50	20	69
Granddaughter	42	17.76	13.25	15.50	1	50
Total	126	41.88	23.27	42.50	1	93

Table 2

Demographic Characteristics by Triad Membership

Personal Characteristics	Triad Membership							
	Grandmother		Mother		Granddaughter		Total	
	N	Percentage	N	Percentage	N	Percentage	N	Percentage
Educational level								
Less than high school	4	9.5	1	2.4	18	42.9	23	18.3
High school/GED	10	23.8	6	14.3	5	11.9	21	16.7
Some college	11	26.2	15	35.7	6	14.3	32	25.4
Associate degree	7	16.7	2	4.8	1	2.4	10	7.9
Bachelor's degree	4	9.5	11	26.2	9	21.4	24	19.0
Master's degree	4	9.5	7	16.7	1	2.4	12	9.5
Doctorate	1	2.4	0	0	1	2.4	2	1.6
Missing	1	2.4	0	0	1	2.4	2	1.6
Total	42	100.0	42	100.0	42	100.0	126	100.0
Marital status								
Married	12	28.6	18	42.9	4	9.5	34	27.0
Single	4	9.5	13	31.0	35	83.3	52	41.3
Divorced	10	23.8	10	23.8	3	7.1	23	18.3
Separated	1	2.4	1	2.4	0	0	2	1.6
Widowed	15	35.7	0	0	0	0	15	11.9
Total	42	100.0	42	100.0	42	100.0	126	100.0
Household income (\$)								
Less than 10,000	6	14.3	5	11.9	10	23.8	21	16.7
10,000–20,000	9	21.4	5	11.9	5	11.9	19	15.1
20,000–30,000	7	16.7	3	7.1	3	7.1	13	10.3
30,000–40,000	7	16.7	7	16.7	3	7.1	17	13.5
40,000–60,000	5	11.9	10	23.8	8	19.0	23	18.3
60,000–80,000	3	7.1	6	14.3	5	11.9	14	11.1
80,000 and higher	3	7.1	6	14.3	6	14.3	15	11.9
Missing	2	4.8	0	0	2	4.8	4	3.2

Triad Membership									
Personal Characteristics		Grandmother		Mother		Granddaughter		Total	
		N	Percentage	N	Percentage	N	Percentage	N	Percentage
Total		42	100.0	42	100.0	42	100.0	126	100.0