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ORIGINAL ARTICLE

Establishing a community partnership to optimize recruitment of African American pedigrees for a genetic epidemiology study

Heather M. Ochs-Balcom · Elisa M. Rodriguez · Deborah O. Erwin

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Abstract We developed a breast cancer genetic epidemiology study in collaboration with a community partnership to optimize recruitment and participation of African American women. We recognized that recruitment of relatives for a family-based study was a unique challenge in this minority group in the USA. Through an established partnership with The National Witness Project, we convened focus groups to identify potential recruitment challenges and issues related to decisions about study participation that may be unique to African Americans and family-based recruitment. Using the PEN-3 model, we analyzed qualitative data and applied the thematic findings to our recruitment protocol in order to mitigate potential recruitment challenges. The most relevant positive themes included a need for research and education and potential benefit to future generations. Negative themes included communication barriers in sharing disease status within a family and historical issues such as fatalistic attitudes and shamefulness of cancer. Collaboration with community partners allowed for development of culturally appropriate recruitment strategies for African American breast cancer survivors and their family members for a genetic epidemiology study. Understanding factors unique to family-based recruitment in the USA is a significant factor in enhancing participation of under-represented minorities in future genetic studies.

Keywords African American · Genetic epidemiology · Study design · Family study · Community-based research

H. M. Ochs-Balcom (✉)
Department of Social and Preventive Medicine,
School of Public Health and Health Professions,
University at Buffalo,
270 Farber Hall,
Buffalo, NY 14214-8001, USA
e-mail: hmochs2@buffalo.edu

E. M. Rodriguez
Department of Behavioral Science and Community Health,
College of Public Health and Health Professions,
University of Florida,
Gainesville, FL, USA

D. O. Erwin
Office of Cancer Health Disparities Research,
Department of Cancer Prevention and Population Sciences,
Roswell Park Cancer Institute,
Buffalo, NY, USA

Introduction

In the USA, women of African ancestry have higher incidence of pre-menopausal breast cancer and higher mortality compared to women primarily of European ancestry (Ries et al. 1975). Studies show that for women diagnosed at the same stage, African American women have higher mortality (Eley et al. 1994; Elledge et al. 1994). The lack of engagement with the African American community in ongoing research and resulting lower participation rates in research studies is recognized as a crucial factor in the overall effectiveness and progress in the study of disparities in breast cancer mortality as well as overall health disparities in the USA.

African Americans are historically under-represented in medical research due to legacies from slavery and discrimination in the USA, resulting in distrust and fear of exploitation by the medical and scientific community (Corbie-Smith et al. 1999; Gamble 1993; Kass et al. 1996). It is known that studies of a genetic nature are plagued by even more minority under-representation (Hughes et al. 2004; Lerman et al. 1999). A resurgence in the appreciation of families for the study of rare genetic variants (Clerget-Darpoux and Elston

2007) coupled with the growing interest in cancer health disparities research led to our development of a community partnership with the National Witness Project (WP) in efforts to study African American pedigrees with breast cancer to search for novel genes segregating in these pedigrees. Although family linkage studies resulting in the discovery of *BRCA1* and *BRCA2* were conducted 20 years ago for US women of European origin (Hall et al. 1990), there are no comparable studies for women of African descent. A major reason this level of genetic research has not been initiated in the USA is due to the complications of recruitment within the African American population. Due to the unique nature of a family-based genetic study, we recognized that special attention and consideration would be required to address these barriers to minority research participation.

Unlike more frequently used minority recruitment methods such as tumor registries, physician referrals, and hospital and high-risk clinic-based recruitment, a great deal less is known about how to enhance recruitment that is tailored to community-based outreach (Hughes et al. 2004). We determined that this approach would be most applicable for informing our recruitment strategies to appeal to the greatest range of potential African American participants. We utilized a partnership with the National WP, a culturally competent, community-based breast and cervical cancer education program designed to meet the specific cultural, spiritual, and learning style levels of underserved African American women (Erwin et al. 1992; Hurd et al. 2003) to help design our recruitment strategies. We invited the National WP network of 25 program sites in 22 states and their regionally represented Steering Committee to facilitate collection of information about different aspects of individual and family recruitment that may influence recruitment and participation for our family-based genetic epidemiology study.

Our specific study objective was to determine how perceptions, beliefs, and knowledge in the African American community potentially impact one's willingness to participate in a family-based genetic study. The use of focus groups and application of the PEN-3 model helped us to identify critical themes that informed reinforcement and revision of the study protocol for a family-based genetic epidemiology study. In addition, we describe several of the challenges that have been encountered in recruitment of participants along the way.

Methods

Community partnerships

Our initial partnership for this study began with the National WP, starting through their regionally represented steering committee. Created in Arkansas in 1991, the WP is replicated in more than 25 sites nationally to include over 400 volunteers that reach approximately 10,000 women per year. Each WP site includes four or more survivors who serve as "role models" and four or more lay health advocates. Some sites have as many as 20 volunteers, of which 15 may be breast cancer survivors. The recruitment plan for the family-based genetic study was designed to focus exclusively on the partnership with the National WP network, as they were able to identify approximately 106 such families through their network.

In addition to our partnership with the National WP, we were able to partner with a breast cancer survivor who has served as a key informant for the project and further consults on study-related activities. The key informant and her relatives instigated the development of the genetic study as a result of their family history of breast cancer that is unexplained by the BRCA mutations as they do not carry the gene.

Data collection

Two focus groups were convened, each of which were designed to solicit general information and response to the genetic study protocol (see description below about the proposed recruitment for the genetic study), and another group was used to vet the materials and program plans. WP staff from the Western New York site helped to identify and invite families who have more than two breast cancer survivors who are blood relatives from their list of WP volunteers and advocates, including invitations for the survivors and any unaffected female family members. Informed consent was obtained for all women. The study was approved by the University at Buffalo Health Sciences Institutional Review Board. We provided dinner for the participants during the meeting.

Each focus group began with a brief scripted explanation of the study provided by a race-concordant group facilitator and included the overarching goal of the genetic study and requirements for participation. We then elicited attitudes about participation in a family-based genetic study, including demographics and broad areas of focus such as sharing disease information with relatives, contacting family members to participate, and the use and choice of incentives.

A segment of the questions with categorical responses was answered via a community-friendly audience response system (ARS) that uses electronic keypads (Gamito et al. 2005), while open-ended questions were designed to stimulate discussion in the group. Anonymity of participants and all responses was maintained and no personal identifying information was elicited.

ARS-based questions included age, race, breast cancer diagnosis, family history of breast cancer, comfort in sharing disease status with family members, feelings about participating in a study with relatives, comfort in sharing relevant

study information with relatives for recruitment purposes, whether additional information may be helpful for recruitment of their relatives, and how willing they thought their relatives would be to participate in a family-based genetic study.

With regard to open-ended questions, we elicited an overall first response to the study and the protocol as designed and described, factors that might cause the participant to enroll or refuse participation in the study, including questions about whether certain words or phrases should be avoided in study materials. Current knowledge of the use of DNA in medical research was another focus; we probed the knowledge of the participants about DNA collection procedures and attitudes regarding contributing their DNA for genetic research. All open-ended responses were recorded and transcribed for further analysis.

An additional focus on sharing disease information with relatives was also included, since the first survivor to enroll in the study (typically referred to as the proband or index case) would be asked to tell her relatives about the study and encourage them to participate. In this regard, we questioned how comfortable women were sharing information about their own breast cancer diagnosis with both younger and older female relatives. We elicited a response to what feelings women might have about discussing a genetic study with their family and what methods of communication might be preferred for talking with relatives about the study. In addition, another question asked whether they would like additional educational information to accompany their discussion with relatives about the study, such as a brochure, DVD, and/or study website. For our own study purposes, we elicited responses about incentives for participating in the study, given the study participation requirements of time and information, as well as input on development of a title and logo for the study.

Data analysis

We categorized focus group responses using the PEN-3 model, a theoretical framework for evaluating qualitative data within three dimensions of health beliefs and behavior (Airhinenbuwa 1992, 1995; Erwin et al. 2005). These methods and how the PEN-3 model is applied to qualitative findings are fully described in another paper by one of our authors (Erwin et al. 2010). Basically, the thematic responses are analyzed as to whether they are "Perceptions," "Enablers," or "Nurturers" according to how they impact the individual's behaviors. Secondly, they are analyzed as to their "Positive," "Existential," or "Negative" impact on the screening behaviors. This provides a 3×3 table of categorized responses and themes that can then serve as a guide for addressing programmatic factors to address the negative factors, encourage the positive ones, and become aware of those factors which may indirectly impact the desired behaviors.

Our qualitative results provided pilot indicators for stimulating research participation, and we used the thematic output to design a tailored study protocol for the genetic epidemiology study, where positive aspects are reinforced and negative aspects are controlled to the fullest extent possible. We have applied this model to develop programs to fit within a community's existing beliefs and practices in other studies to date (Erwin et al. 2005). Once the findings were analyzed by the study team, the recruitment plans, logo, name, culturally tailored messages, and brochure were vetted by a larger group of African American women through the National WP Steering Committee members. This process allowed the materials and recruitment plans to be assessed and informed by African American women from all regions of the USA.

Tailoring the recruitment process for genetic study

Focus group participants were introduced to the protocol for the genetic study as a first step. They were then asked to respond to this planned protocol, in addition to a number of more specific questions as detailed above.

African American breast cancer survivors who identify themselves as having a living first (sibling, mother), second (grandmother, aunt, or niece), and/or third degree (cousin) blood relative who is also a breast cancer survivor are invited to participate. Once a survivor is identified and contacts the study center, she is screened for eligibility criteria (Table 1). If eligible, a study packet is sent via US mail, which contains the consent form, HIPAA form, study questionnaire, medical records release, saliva collection kit, and a self-addressed stamped envelope with paid return postage. Once returned to the study center, this proband is then asked to contact their eligible family member (or members) and encourage them to participate.

Results

We invited 27 African American women from Buffalo through their connections with the local WP to participate

Table 1 Eligibility criteria for genetic epidemiology study

- Self-identifies as African American
- Breast cancer survivor
- Has at least one living blood relative with breast cancer (sister, mother, daughter, grandmother, aunt, niece, cousin)
- Willing to provide a saliva sample
- Willing to allow for medical records release to confirm breast cancer diagnosis
- *BRCA1/2* negative, if tested

in two focus groups. A total of 14 women participated. The women were either breast cancer survivors (n=9) (from nine different families) or unaffected family members of a breast cancer survivor (n=5). A majority of participants (n=12) were older than 50 years of age, and as expected based on recruitment, 12 women reported having a family history of breast cancer.

All of the breast cancer survivors were "comfortable" or "very comfortable" sharing information about their breast cancer diagnosis with their relatives and felt equally comfortable discussing their breast cancer diagnosis with older and younger female relatives. All of the women were willing to pass along the study material to their relatives to help with recruitment efforts, with telephone communication as the most preferred method of contact. All women agreed that a short DVD about the study and a study website would also be helpful in explaining the research study to their relatives. Only eight or 57% of women said they believe that their relatives would be "willing" or "very willing" to participate in this family-based genetic study.

Table 2 details our PEN-3 classification of themes as positive (things that improve one's participation in a genetic study), existential (unfamiliar things that have no harmful consequences on participation), and negative (things that compromise one's participation in a family-based genetic study). Positive themes that we identified include a familiarity with DNA and exposure to DNA terminology and the fact that DNA is something that is shared between

Table 2 Categorizing themes by cultural empowerment—perceptions, enablers, and nurturers

	Themes	Positive (things that improve one's participation in a genetic study)	Existential (unfamiliar things that have no harmful consequences on participation)	Negative (things that compromise one's participation)
Perceptions	Low knowledge about research and breast cancer		X	X
	Some knowledge about DNA	X		
	Lack of sharing disease status with family members		X	X
	Security of data/confidentiality concerns			X
	What I don't know won't hurt me			X
Enablers	Genetics on TV	X		X
	Lack of research in African Americans	X		X
	Guinea pig/Tuskegee			X
	Disparity in the amount of information about breast cancer in African Americans	X		X
	Shamefulness of cancer; wrongdoing or punishment			X
	Fatalism			X
	Communication barriers			X
	Celebrity spokesperson	X		
Nurturers	Extensive time commitment			X
	Personal experience with studies/ genetic testing	X		
	Secrecy/family business		X	X
	Need for research	X		
	Fear of knowing			X
	Asking for saliva sample only (not blood)	X		
	Study on breast cancer only (not any disease)	X		
	Becoming aware of genetic risk	X		X
	Need for education	X		
	Don't know family history		X	
	Benefit for future generations	X		
	First breast cancer family study in African Americans	X	X	

relatives. Some women reported having positive and personal experience with genetic testing. Other positive themes include the lack of information about breast cancer specific to African Americans, the overall need for inclusion in research opportunities, and awareness. Also, women were excited about the possibility to improve knowledge about breast cancer to benefit their young female relatives and the possibility of preventing them from having similar outcomes. Once women were told that our study is the first study explicitly designed to study African American families only, they responded positively to the fact that this study is exclusively for them. With regard to enticing women to participate, these women felt strongly that enlisting a celebrity spokesperson or someone influential in their communities to the study to endorse its goals would increase the number of women and families willing to participate in the study.

We identified several negative themes that might be expected to have an adverse effect on one's decision to participate in a family-based genetic study. Barriers to study participation included lack of knowledge regarding research participation and breast cancer research in general, as well as secrecy within families about disease status that is related to shame, wrongdoing, and a more general fear of knowing surrounding a breast cancer diagnosis. These factors are major components of the overall communication barrier we identified as a negative theme. Women had a great deal of concern about confidentiality of data and being used as guinea pigs. Extensive time commitments for completing study requirements as well as a possible need to provide a blood sample were additional negative themes.

Table 3 describes how we tailored our approach to the planned genetic study in terms of both general recruitment and overall study protocol based on PEN-3 classification of our focus group results. We made plans to reinforce positive aspects and revise negative aspects that were identified from the focus groups in a variety of different ways which included both verbal communication and printed study materials.

We emphasized positive themes such as improving knowledge about breast cancer in African American women and the need and awareness of research opportunities for African Americans as positive aspects of the current genetic study, one designed exclusively for African American women. We especially highlighted our attention to maintaining confidentiality of study data, potential benefit to future generations, ease of study participation regarding time commitment, and saliva only (not blood) for DNA sample. We emphasized that we are using their medical records for the sole purpose of confirming details about their breast cancer diagnosis and will not have access to any other part of their medical record.

Another outcome of our focus groups was the study logo (Fig. 1) and name for the study—"The Jewels in Our Genes Study." The name and logo were developed in order to portray an image that women could identify that also signified the study goals, in that the "Jewels," once found via the genetic linkage study will allow for positive outcomes with regard to addressing health disparities of breast cancer in African American women.

Although the recruitment and family linkage study is still in process and will be fully reported at a later time, we are making positive, if slow progress toward our recruitment goal of 150 families and an estimated 400 women. As of this time, we have successfully recruited 37 families and 77 women, with 23 more families in process.

Discussion

This formative research phase of the study, informed by the focus group results and the specific themes identified and classified using the PEN-3 model, provided guidance for culturally tailored recruitment of African American women for a family-based genetic research study. We developed a recruitment protocol and materials that were designed to be culturally sensitive and personally responsive to many of the factors that we discovered in this formative research.

To our knowledge, this is the first study to investigate and implement a recruitment strategy that utilizes a community network-based approach to recruit families for a genetic study. Because of the lack of existing literature regarding how best to optimize recruitment in the community, we studied relative factors important to women who are eligible to be recruited to a genetic study. Our study differs from those using hospital or clinic-based recruitment methods that are most frequently used to identify potential study participants. While hospital-based methods are more efficient in identifying potential participants, the results are not generalizable to the larger population since not all individuals have access to care in the USA. While community-based recruitment is more representative, it is inherently more time consuming in that members of the community are essential to assist with recruitment.

We suggest the main strength of our study is the partnership with the National WP and their assistance in the study design, promotion, and execution of the study. This collaboration between our study staff and the WP steering committee has provided some successes, but the recruitment is still slower than planned within the study timeline. In the original grant proposal, we did an informal survey to find out whether there were sufficient families with multiple breast cancer survivors that exists within the WP network, and indeed we found out that there are

Table 3 Translation and application of PEN-3 analysis to recruitment protocol

Socio-cultural/behavioral processes	Negative/positive/neutral	Reinforce (+) through program intervention	Revise (−) through program intervention
Some knowledge about DNA	+	• Include elements like DNA sharing with relatives, this can help us to study breast cancer	
Genetics on TV	+/−	• Biological samples are part of DNA collection	• Genetic information remains de-identified and confidential
Lack of research in African Americans	+/−	• Reinforce that without research our lack of knowledge will remain	• Acknowledge this as the first family-based study
Lack of knowledge about breast cancer	+/−	• Include more informational material	• Include links to resources for more information about breast cancer
Celebrity spokesperson	+	• Endorsement	• Attempt to make contact
Personal experience with studies/genetic testing	+	• Similar DNA collection	• Ensure confidentiality
Need for research	+	• Reinforce that without research our lack of knowledge will remain; benefit to future generation	
Asking for saliva sample only (not blood)	+	• Reiterate in brochure	
Study on breast cancer only	+	• Asking for breast cancer and other cancer-related information only	• Will only ask for medical records relating to breast cancer diagnosis
Becoming aware of genetic risk	+/−	• Emphasize the outcomes of linkage study, genetic test is down the road	• Include the outcomes of the study and exactly what will be shared with study participants
Need for education	+	• Links with trusted sources of information	
Low knowledge about research	+/−	• Emphasize differences in clinical trials and observational studies	
Confidentiality concerns	−	• Address specifically in brochure	
What I don't know won't hurt me/fear of knowing	−	• Benefits to future generations	
Guinea pig/Tuskegee	−	• Emphasize that the genetic study is not a clinical trial; will not be asked to take any medications	• Detail process and, consequences of participating, • Provide newsletters and study updates
Shamefulness/wrongdoing or punishment	−	• Provide educational materials that include known risk factors	• Explain that better education and research will result in better outcomes for future generations
Fatalism	−		• Survivor's narrative
Lack of sharing disease status with family members/family business/ communication barriers	−	• Emphasize communication as positive	• Add in elements about family coming together
		• Family participates together	• Family pictures
Extensive time commitment	−	• Include a precise estimate of how much time is required for participation	• Shorten whenever possible • Allow participants to complete over the phone

approximately 106 potential families. In spite of this high number of potentially eligible families identified within the WP community network, and the application of our formative findings to our recruitment process, we continue to experience challenges getting the families to enroll. These challenges were clearly identified and predicted in the findings from our focus groups that demonstrated that just over half of the participants reported their family

Fig. 1 The Jewels in Our Genes study logo, developed in partnership with The National Witness Project

members would be willing to participate in a genetic study. These qualitative data are being supported by our recruitment results.

From the formative findings, along with our experiences so far, we believe the continued reluctance to participate is partially attributed to the lack of knowledge about research in general and, more specifically, the complexities of genetic epidemiology that are difficult to explain to lay volunteers and recruiters at the WP sites. It is also attributed to the level of time and involvement required by women who are not likely to prioritize our study over the many day-to-day challenges and responsibilities they have in their lives. We believe there continues to be potential issues of distrust and fear related to sharing DNA and/or personal health information with scientists the women may not know. Moreover, although the printed materials, recruitment process, and forms themselves have been crafted to address as many culturally sensitive issues and concerns as possible, and to enhance the positive findings from our formative research, the actual processes from contacting the participants, having participants contact their family members, and obtaining all of the biospecimens and required survey forms are carefully controlled through the prescribed Institutional Review Board protocol requirements and allow little involvement of our community partners or women within the WP. This is something we would like to address in the future.

There are several limitations to the study. First and foremost is the fact that this is a limited sampling and the women who attended focus groups may not be representative of the population of African American women throughout the USA. Moreover, many of the women who declined to participate in the focus groups (52% response rate) may have chosen not to participate because of negative perceptions or experiences related to research or genetic studies that could not be captured in our findings and, therefore, not fully addressed in our tailoring process. The focus group findings were amplified and verified by the vetting process with the National WP Steering Committee members in an attempt to counter local bias. Another limitation is the fact that until women actually participate in the study and recruitment processes, all of the barriers and problems are not revealed. The focus group questions and discovery process are designed to effectively solicit in-depth personal experiences and perceptions, but are limited by the questions asked and the life experiences of participants. Therefore, some of the methodological challenges experienced by the study team once recruitment began were not able to be determined in this formative process.

Based on our collective experience to date working with community groups, we have made a few other informal observations that may benefit others conducting similar research in community-based outreach-type settings in the USA as well as in other international settings. While the WP volunteers at the sites across the USA are well-trained and literate in terms of outreach methods and speaking to the importance of cancer screening per the design of ongoing WP programs, educating and motivating women to participate in genetic research is not a comfortable transition. Recruitment to this type of studies by lay volunteers is expected to be problematic in other countries as well. Further research internationally is needed to test the similarities and differences with our results. We believe that more successful recruitment via this network requires more extensive training with lay women at each site, specifically regarding education about research and the research process. Although the genetic epidemiologist was new to the WP organization and has had only limited exposure to the WP and the women in the organization, in those cases where a WP staff member was qualified and available to help women inform their family members about the study, support the consent process, obtain the DNA sample, and complete forms, the outcomes have been more timely and satisfactory for participants and scientists. In addition, the WP program is unique in its use of survivor testimonies as part of the health promotion/disease prevention process which further reinforces study participation and provides a component of observational learning that can also increase credibility of the research project in the eyes of the participants. Adaptation and implementation of an observational learning component that is relevant and meaningful with regard to genetic research participation has yet to be translated with respect to this study. It may be that participants' feedback regarding a celebrity spokesperson or community advocate for the project provides evidence of

a credible communication channel that would help to diffuse information on genetic research specific to African Americans and further increase study participation and credibility.

We are recognizing that, like all community-based participatory research projects, this is an iterative process. It requires considerable time and energy to gain acceptance by potential participants and cannot be easily done with just one brochure, one electronic-blast message, or one telephone call. We examine our findings with our community partners, apply changes to our process, examine recruitment results, and then go through this process again and again. There is no "magic bullet" for recruitment of African American women in the USA for studies requiring this level of commitment (i.e., time, DNA, medical records). As intended, it is truly a "co-learning" experience (Israel et al. 2005) for the academic scientists as well as the community partners on the team. We continue to develop a better understanding of the factors related to participation in genetic epidemiology research in the USA and continue to reform our recruitment protocol based on information directly obtained from focus group participants, WP community members, and other collaborating partners along the way.

The findings of this qualitative study presented herein will improve awareness about the challenges of family-based recruitment in the African American community, especially with regard to working with established community partners. We anticipate that greater understanding of the factors related to participation will enhance the cultural competency of investigators, relationship with the community, and the overall success of recruitment. In spite of the challenges that we have encountered, we believe our findings may provide opportunities for others wishing to conduct family-based studies of research addressing cancer health disparities in the USA and elsewhere. Based upon our work to develop a culturally sensitive recruitment protocol, we can more efficiently recruit African Americans to research and suggest that this process may serve as a model for others wishing to conduct research within minority communities. Some encouraging new findings suggest that a major reason for lower participation rates of African Americans in genetic studies is in fact difficulty in making initial contact with potential participants due to incorrect contact information (Hartz et al. 2011). The same study purports that once contact was made, African Americans were actually more likely to participate in a genetic study than European Americans (Hartz et al. 2011).

In summary, the PEN-3 qualitative findings provided pilot indicators for stimulating research participation, and we used the thematic output to design a tailored recruitment protocol for the family-based genetic study, where positive aspects are reinforced and negative aspects are controlled to the extent possible.

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Conflicts of interest The authors declare that they have no conflict of interest.

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