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ORIGINAL ARTICLE

Updating and refining a study brochure for a cancer registry-based study of *BRCA* mutations among young African American breast cancer patients: lessons learned

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Abstract The aim of the present study was to update, refine, and evaluate a study brochure to promote participation in a population-based study of BRCA mutations among AA women with a personal history of early-onset breast cancer. A multi-step approach was used to develop this brochure and included: (1) feedback from community members (through a Community Advisory Panel (CAP)) to develop and refine the study brochure, (2) pilot testing of materials with the target audience, and (3) review of pilot testing results with the CAP. Based on the feedback received at each step, the study brochure was refined. In phase 1, the major changes included emphasizing the concept of leaving a legacy and family, using the terms Black and women of color, and use of patient vignettes and photos. In phase 2, attraction and cultural acceptability were identified as two areas for improvement in the study brochure. These results demonstrate that involvement of community members and target study population in the development of a study-specific brochure can provide invaluable feedback to optimize recruitment strategies. This approach can be readily adapted to develop study recruitment materials for individuals from a variety of cultural and ethnic backgrounds.

Keywords Genetics education · African American · BRCA · Study recruitment

Background

The prevalence and penetrance of *BRCA1* and *BRCA2* (*BRCA)* mutations in the African American (AA) community remains poorly defined. A number of small prevalence surveys in Black women have yielded varying results with respect to *BRCA* prevalence and penetrance specific to AA women (Fackenthal et al. 2005; Frank et al. 2002; Gao et al. 2000; Haffty et al. 2005; John et al. 2007; Kanaan et al. 2003; Malone et al. 2006; Mefford et al. 1999; Nanda et al. 2005; Olopade et al. 2003; Pal et al. 2004, 2008; Panguluri et al. 1999; Pegoraro et al. 2003; Shen et al. 2000). This lack of knowledge is perpetuated by low rates of participation by AA women in clinical and research *BRCA* genetic counseling and testing (Armstrong et al. 2005; Halbert et al. 2006). Previous studies have examined the various aspects which influence the uptake of genetic counseling and testing for inherited breast cancer in Black women. In a study of knowledge about genetic testing for breast cancer in African American women, Hughes et al. (1997) reported that Black women had lower levels of knowledge, potentially attributable to differences in exposure to genetic information and physician referral. Similarly, Kinney et al. (2001) reported high interest level in genetic testing despite limited knowledge among high-risk individuals in a study of a large *BRCA1* kindred. In a study of 76 African Americans at increased risk for breast cancer based on family history, results indicated that participants who declined counseling had significantly less knowledge about breast cancer genetics than those who followed through with counseling and testing (Thompson

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et al. 2002). More recently, Armstrong et al. (2005) showed that racial disparities in the use of *BRCA* counseling exist and are not explained by differences in risk factors for being a mutation carrier, socioeconomic factors, risk perception, attitudes, or recommendations from primary care physicians. Consequently, within the AA community, genetic services are underused, with previously cited barriers including lack of knowledge, negative attitudes regarding genetics and/or research, and concerns regarding racial discrimination (Simon and Petrucelli 2009). These barriers are likely to result in lack of informed decision making related to *BRCA* genetic counseling and testing among AA women. Information about the spectrum and frequency of *BRCA* mutations in the African American population continues to be limited as most studies have been performed in Caucasian populations (Pal et al. 2008). Without increased participation by AA women in both clinical and research-based *BRCA* genetic counseling and testing, it will be difficult to provide risk estimates and test results that are specific to AA populations.

Previous studies have shown that effective avenues and strategies for recruitment of AAs into research studies include religious institutions, community networks, senior centers, door-to-door canvassing (Curry and Jackson 2003), as well as physician referral (Royal et al. 2000). Methods shown to increase uptake of clinical and research-based genetic testing include referrals through the oncology care setting (Halbert et al. 2005). However, a limitation of these methods is their inability to define a study denominator, which is of critical importance in the estimation of disease prevalence in epidemiologic studies. In contrast, studies through population-based cancer registries, by which a study denominator can be readily determined, have the advantage of providing more generalizable data. In general, recruitment of population-based samples through cancer registries limits the ability to utilize methods with an element of personal communication at first contact. This limitation poses a unique challenge when recruiting AA women to participate in genetics research through a cancer registry. Several studies have documented lack of participation among AA women in research and clinical genetic testing for *BRCA*. Although face-to-face methods enhance recruitment, they often are not feasible in the context of population-based registry studies (e.g., a study that systematically samples an entire group of eligible patients defined by particular inclusion criteria such as disease status or geographic area). Thus, written materials play a greater role in the recruitment process. Developing a study-related brochure with the input of key stakeholders (e.g., community leaders, consumers) is more likely to appeal to the target audience (Parra-Medina et al. 2004). The purpose of this manuscript was to describe: (1) the updating and refining of a study-specific brochure for African American women to participate in a population-based study to investigate *BRCA* mutations among AA women diagnosed with invasive breast cancer at age 50 or younger, recruited through the Florida Cancer Data System (FCDS), and (2) the associated methods using a phased iterative approach in the development of a study brochure.

Materials and methods

The FCDS is the statewide cancer registry in Florida which mandates the following recruitment protocol for all studies involving primary data collection: (a) two mailings (which contain informational material about the study) 3 weeks apart, including a “telephone opt-out card” for patients who do not wish to be contacted by phone, and (b) if no patient response is received within 3 weeks of the second mailing, a member of the study team can then contact the potential participant by phone to explain the study and determine interest in study enrollment.

A three-phase approach was utilized in the updating and refining of the study brochure to be included in the informational material to potential participants. The first phase involved gathering input from a community advisory panel (CAP). This group was created for the purpose of providing input to optimize study recruitment strategies and creating a draft study brochure based on this input. The second phase involved pilot testing the draft study brochure with the target audience. The third phase involved reviewing the pilot test results with the CAP.

Phase 1: Initial CAP creation and input

In 2005, the study team considered applying for national grant funding to explore the role of *BRCA* mutations among AA breast cancer patients diagnosed ≤age 50 using FCDS in four counties within the state of Florida (i.e., Hillsborough, Pinellas, Polk, and Broward). Through our previous studies (Pal et al. 2008), we recognized the importance of the involvement of breast cancer survivors, community leaders, and community healthcare providers within the AA community and had formed relationships with many of these individuals. We formalized these existing relationships by creating a CAP during the initial phases of conceptualizing and preparing the grant application. The CAP consisted of 12 members representing a multicultural group of men and women. The majority of members were AAs involved in local, regional, and national organizations. These individuals included breast cancer survivors, members of breast cancer advocacy groups and support groups, patient advocates, community leaders, research partners, and healthcare providers, many of whom are members of the AA community. All CAP members provided a letter of support for the grant application that detailed their specific role on the project including: (1) meeting three times during the 2-year grant period, (2) helping the project team select appropriate participant incentives, (3) reviewing the study questionnaires/recruitment materials for participants, (4) assisting in the planning and conduct of a community forum regarding hereditary breast and ovarian cancer in the AA community, and (5) disseminating the findings of the study to the various organizations in the Tampa Bay area with which we are involved. In addition, all members acknowledged in their letter that they would receive a $25.00 honorarium for their participation during the annual face-to-face CAP meeting.

Notice of funding was received in April 2006. An in-person meeting with the CAP was held in December 2006 with the purpose of gathering input about recruitment approaches prior to the initiation of the population-based study. Seven of the 12 CAP members and all members of the study team attended. During the initial meeting, the study procedures were reviewed. In order to facilitate easy recall of suggestions by the CAP, the entire meeting was audio recorded and later transcribed; members of the study team also took handwritten notes.

Phase 2: Pilot testing of materials with target audience

The existing brochure was previously developed for a community-based study of *BRCA* in AA women (Pal et al. 2008) and is referred to hereafter as the "community study brochure." The community-based study included AA breast cancer patients with a personal or family history suggestive of hereditary predisposition to breast cancer. Recruitment strategies included physicians at the Moffitt Cancer Center Breast Program, community-based oncologists, primary care physicians, newspaper advertisements and brochures, community or support groups, and the Florida State Cancer Registry. Due to low recruitment rates, the team developed a study brochure that was distributed at various events that may be attended by our target population (e.g., health fairs, community events). All participants underwent genetic counseling and *BRCA* mutation analysis. Of the 51 women tested for *BRCA* mutations, three were identified as mutation carriers (5.9%), including one in *BRCA1* and two in *BRCA2*. Results provided evidence that *BRCA* mutations are seen in high-risk African American women and also provided the opportunity to develop a template upon which the "new study brochure" is based.

The study team revised the study protocol to pilot test the brochure in the target population. All study procedures and materials were approved through the Institutional Review Boards at both the University of South Florida and the Florida Department of Health. A 12-item interview guide based on the principles of Learner Verification was developed (Table 1; Doak et al. 1996). Learner Verification is a useful framework for formative research that utilizes individual interviews to establish the appropriateness of the communications such as written materials (i.e., the study brochure) for the target population (i.e., AA breast cancer patients). Learner Verification focuses on the following five key elements, including: (1) attraction, (2) comprehension, (3) self-efficacy, (4) cultural acceptability, and (5) persuasion. Because a sample size of ten individuals generally is considered sufficient to conduct Learner Verification (Doak et al. 1996), 14 patients were approached to account for non-participation. The study team had access to participants from a previous community-based study (Pal et al. 2008), through which 42 individuals provided written permission to be recontacted for future studies.

The study research assistant was instructed to contact women in groups of four to five on a daily basis until the list was exhausted or 14 women agreed to participate. During the first week of phase 2, at least one phone call was placed to 22 individuals. From this group, the team was able to speak directly with 16 patients, of whom 14 agreed to participation and two declined. Further contact with the remaining six subjects was not pursued, as our target was 14 participants.

A draft brochure and informed consent documents were mailed for review prior to the scheduled phone interview, with the requirement that a signed copy of the informed consent document was received by the study team prior to conducting the interview. The study coordinator took handwritten notes and summarized participant responses to each question from the interview guide. Upon completion of the phone interview, all participants were mailed a $25.00 gift card. Once all interviews were complete, members of the study team reviewed the notes from each of the interviews to assess which elements of Learner Verification were addressed and which could be improved upon based on the participants' responses. After completing all interviews, the data were analyzed using methods for small sample sizes suggested by Doak et al. (1996). A member of the study team reviewed the interview notes and displayed responses to each question by participant using a simple tabular format. Responses were evaluated to examine the number of individuals who provided incorrect or negative responses to all Learner Verification questions (Doak et al. 1996).

Phase 3: Review of the pilot test results with the CAP

The final step of this three-phase process was to re-review the results of pilot testing with the CAP to finalize changes to the "new study brochure" (referred to hereafter as the "Final Version of New Study Brochure"), which incorporated feedback obtained through the pilot testing. A conference call

Table 1 Elements of learner verification assessed in study brochure

Elements of Learner Verification assessed	Questions from interview guide	Sample summary statements of participant responses (n=14)
Attraction (Does the material appeal to the target audience?)	What about the appearance of this brochure intrigued you?	Colors were attention getting, related to the stories, the topics discussed were explained and to the point, everyone could read (participant K) Personal stories, inviting (participant C) Face of woman on front makes you curious (participant I)
	If you were sent this brochure in the mail, would you want to read it to find out more about breast cancer?	No, she looks sad, not happy, need to show the whole face of a survivor, thriving and has spirit (participant L) No, she is sitting there looking and not doing anything, does relates to other pictures (participant H)
Comprehension (Does the target audience understand the material?)	Tell me in your own words what you think the purpose of this brochure is?	Alert women to availability of *BRCA1/2* testing and family history (participant D)
	Did this brochure help you to understand the purpose of genetic testing? Are there any risks in your family that would make you want to have genetic testing?	To inform general overview of the statistics with African American women with breast cancer, what's available to them, what they can do about it. Also to inform of the impact that this disease is having on women of color and informational bout a study that is uncovering why this happens and why the incidence is so high (participant I)
Self-efficacy (Does the target audience feel the message is doable for them?)	After reading this brochure, would you want to participate in this study? (probes: If you wanted to participate would you be able to?)	Show and educate that there is a possibility of genetic testing, where limited education is available (participant F)
	Did this brochure help you to understand why genetic testing is important to African American women with breast cancer?	To get AA women to be proactive in their breast care and know if they have risk factors (participant L)
Cultural acceptability (Does the target audience perceive the message to be salient and acceptable?)	How do feel about the phrase “Women of Color”? (probes: Do you think most African American women would feel the same way?; Do you think there is another term that African American women identify with?)	Women of Color is ok but prefer Black. Politically correct would be African American (participant G)
	Is there anything in this brochure that makes you feel uncomfortable about genetic testing?	[The term women of color] Pertains to more than just AA women, not offended by it, believe Women of Color is better than AA (participant J)
	Do you relate to any of the women in this brochure?	Phrase encompasses too many people, pictures help identify African American women, keep women of color it is not offensive (participant H)
Persuasion (does the message convince the target audience to take action?)	If you received this brochure in the mail, would you want to have a genetic test for *BRCA*?	Call to action for women specified, possibility of genetic testing and breast cancer link (participant G)
	Do you think your family and friends might have genetic counseling/testing if they received this brochure?	To encourage breast cancer patients to participant in studies for Women of Color (participant M) Get people to sign up for genetic testing and to get additional information about the results (participant H)

was organized with CAP members, during which time we highlighted key issues based on phase 2 findings. We followed this summary with a series of general questions to assess whether the revised brochure was improved with respect to key concepts of Learner Verification (e.g., purpose, cultural acceptability; Doak et al. 1996). Six of the seven CAP members who attended the initial CAP meetings and all members of the study team were present on the call.

Results

Phase 1: Initial CAP Input

During the review of study procedures, the CAP recommended developing a study brochure that could be included in the initial mailing to potential participants identified through FCDS. The CAP made several key suggestions related to the content and layout of a brochure for the current study (described in Table 2). Following the CAP meeting, members of the study team reviewed the "community study brochure." In general, any suggestions made by the CAP related to scientific/clinical information presented in the study brochure were discussed with the CAP. However, given the extensive clinical expertise on our team (i.e., a clinical geneticist and a genetics counselor), those issues generally were addressed with the CAP, but the ultimate decision about content related to scientific/clinical information was made by the study team. For example, one CAP member suggested downplaying the clinical importance of *BRCA* testing. In her opinion, she felt testing did not provide any clinical advantage to women already diagnosed with breast cancer. However, given available data regarding the increased risk for a contralateral breast cancer and ovarian cancer breast cancer patients with a *BRCA* mutation (Hartmann et al. 1999, 2001; Metcalfe et al. 2004) combined with available screening and surgical risk reduction measures (Daly et al. 2006), the team felt that this suggestion could not be implemented. With respect to suggestions about non-clinical issues, the team implemented the suggestion given by the majority of CAP members. For example, there were conflicting suggestions about non-clinical issues (e.g., some women suggested using the term Women of Color rather than African American in the title of the study brochure). In that situation, the majority of women indicated that Women of Color was the term they preferred, and that is what was included in the study brochure.

The title of the original brochure was "African American Women with Breast Cancer: A study to explore hereditary and hormonal factors." The community study brochure was in a tri-fold format and printed on an 8 1/2×11 sheet of paper. There were seven brief sections listed in Table 3. Key suggestions by the CAP for a study brochure for the present cancer registry-based study and the method by which they were implemented in the revision of the original study brochure are outlined in Table 2.

The new study brochure was kept in a format and layout similar to the community study brochure (i.e., question and answer format, tri-fold, printed on 8 1/2×11 sheet of paper). In addition to changes described in Table 2, some of the major modifications included changing the title of the new brochure to "The Causes of Breast Cancer in Women of Color: A Study to Explore Breast Cancer Risk Factors among Young Black Women." Sections were also added about the benefits of genetic testing and benefits of study participation. Lastly, an additional testimonial from a previous study participant was also included. The final suggestion from the CAP was to pilot test the study brochure with high-risk individuals within the target population. Based on these suggestions, a draft brochure was developed and served as the basis for Phase 2.

Table 2 CAP suggestions for study brochure

Suggestion	Implementation
Emphasizing the concept of "leaving a legacy" when discussing genetic testing	Leaving a legacy was included as a potential benefit to participating in genetic testing
Acknowledging the role of the impact of genetic testing on the family	Addressed as part of the benefits of testing as well as through personal stories and that described the impact of genetic testing on their family members. Also included photos of individual who when through genetic testing as well as their family members.
Using Black instead of African American	The term Black was used consistently throughout the study brochure
Using phrase Women of Color	The term used on the front cover
Using of warm colors to enhance visual appeal	Vibrant colors (red and yellow) were selected
Including actual patient stories	Two participants from the previous community-based study women agreed to share their story for the study brochure
Using of actual patient photos	Two participants from the previous community-based study were photographed with the family members of their choosing in their own home by a professional photographer

Table 3 Study brochure related changes

	Community study brochure	New study brochure	Final Version of New Study Brochure
Study description	Developed by study team for community-based study of AA women	Developed by study team for population-based study with input from CAP (phase 1)	Developed by study team for population-based study with input from patients and CAP (phases 2 and 3)
Colors	Primarily white with few pink accents	Red and yellow	Red and yellow
Presentation	Tri-fold; 81/2×11 paper	Tri-fold; 81/2×11 paper	Tri-fold; 81/2×11 paper
Cover photo	Photo of Cancer Survivor	Used stock clip art of African American woman in early 40s	Photo of local prominent business women and breast cancer survivor
Logos	Moffitt Cancer Center	Susan G. Komen	Susan G. Komen and Moffitt Cancer Center
Number of sections	7	8	10
Titles of sections			
Breast Cancer and African American women	Here is why studying breast cancer in African American women is important	Why are we interested in breast cancer among Black women?	Why are we interested in breast cancer among Black women?
Current Study Information	Current Study Information	Not included as a specific section	Not included as a specific section
Previous Study Results	Previous Study Results	Not included	Not included
Testimonials and photos	Benita's Story (photo of Benita survivor alone)	Benita's story Evora's story (photo of Benita alone; stock photo AA mother, father, and two children)	Benita's story Evora's story (photo of Benita and her son; photo of Evora and her two sisters)
Benefits to Study Participation	What will I receive if I join the study?	How could genetic counseling and testing for BRCA1 and BRCA2 help you? Why is genetic testing important? What will I receive if I join?	How could genetic counseling and testing for BRCA1 and BRCA2 help you? Why is your participation in this study important? What will I receive if I join?
Eligibility Criteria	Who can join?	Who is eligible for the study?	Who is eligible for the study?
Study Team Contact Information	Who do I call?	Who do I call?	How do I reach the study team? How do I reach you?
Steps to Participation	Not included	What will I be asked to do?	What will I be asked to do?
Information about who is conducting the study	Not included	Not included	Who are we?
Other	Not included	How did we get your information?	How did we get your information?

Phase 2: Pilot testing of materials with the target audience

Participants' statements addressing issues related to each of the aspects of Learner Verification are summarized in Table 3. Overall, it appeared that the purpose, comprehension, self-efficacy, and persuasion elements of Learner Verification were met based on study participants' responses. The two areas in need of further improvement included attraction and cultural acceptability. With respect to attraction, although most women liked the red and yellow colors used in the brochure, several participants suggested that the woman in the cover photo looked sad and out of place compared to the more vibrant photos inside the brochure. The main area of cultural acceptability where there still appeared to be a lack of consensus was in the use of the term "Women of Color." Several women made comments indicating that the term was very general and includes women other than those who are AA. Yet, those same women suggested keeping this term in the brochure.

Phase 3: Review of the pilot test results with the CAP

The final results of phase 2 were summarized and discussed with the CAP. With regard to the photo on the cover, one CAP member suggested using a prominent community leader and breast cancer survivor from the local community. She was contacted and agreed to provide her photo on the cover. When the issue of the term "Women of Color" was revisited with the CAP, the panel also suggested keeping this term. One new issue not previously raised in phase 1 or

2 was that the current title "Breast Cancer in Women of Color" was too general and could lead to expectations about a brochure that is more about all aspects of breast cancer (e.g., prevention, treatment, etc.) rather than a brochure focused on specific risk factors. The suggestion by a CAP member to change the title to "The *Causes of* Breast Cancer in Women of Color" was implemented. Additional suggestions from CAP members included: (1) highlighting why the study is important to the potential participant, thus the heading of the section entitled "Why is genetic testing important?" was changed to "Why is your participation in this study important?"; (2) including information about the study team and the institution at which the study was based, thus a section titled "Who are we?" was added; and (3) emphasizing the contact information was implemented by including it in two sections titled "How do I reach the study team?" and "How do I reach you?" Table 3 summarizes the major changes implemented in the final version of our study brochure.

Recruitment to the population based study through the cancer registry using the final version of the study brochure began in February 2008 and is ongoing. As of January 2009, of those with whom contact has been established, 83% (n=77) have indicated interest in study participation. Of these individuals, 11 called the study team after receiving the mailing, 23 sent in the response card, and 43 were actively called, of which 11 (100%), 21 (91%), and 31 (72%) agreed to participate, respectively. However, because receipt of the brochure was not an experimental condition, we cannot with certainty determine to what extent the brochure influenced recruitment.

Discussion

These results demonstrate that involvement of community members and target study population in the development of a study-specific brochure can provide invaluable feedback to optimize recruitment strategies. One important finding that was present early on and consistent throughout various phases of the study was that women in our study preferred terms other than African American to describe their community. Specifically, most women appeared to prefer the term Black over African American. A previous study of approximately 3,000 African Americans selected using a race-targeted random digit dial technique found that overall, there was a nearly equal preference for the term Black and African American; this preference did not vary based on gender or level of education. However, those residing in the South were 25% less likely to prefer the term African American ($p<0.01$; Sigelman et al. 2005). These regional preferences may help explain why the women in our study preferred the term Black as our sample consisted only of women from the South. However, there was more ambiguity with regard to preference for the term "Women of Color." The inclusive nature of the term beyond AA women was appealing to some, although others pointed out that the study and the associated brochure were really targeted only toward AA women. Thus, the preference of this term is worthy of further exploration among larger groups of AA women.

The concept of family was an issue that was emphasized in various ways (e.g., photos, personal stories, concept of a legacy) throughout our study brochure. The importance of family with respect to genetic testing is a concept that has been emphasized as important by individuals from the general population, as well as those from the AA community. Previous studies have found that providing information to family members, particularly children, is one of the most important predictors of interest in and/or intention to obtain genetic testing for a variety of hereditary cancers (Kinney et al. 2000, 2001; Lerman et al. 1995; Peters et al. 2006; Ulrich et al. 1998; Vadaparampil et al. 2007).

This manuscript represents an initial effort to develop a structured approach to updating and refining a study brochure to recruit AA women for a study about genetic testing for hereditary breast and ovarian cancer. There are, however, limitations that should be considered. First, those women who participated in phase 2 of this process were women who previously had genetic counseling and testing; therefore, they may have been more familiar with the concepts related to genetics and may not represent the truly naïve participant which we were trying to recruit. However, the purpose of our brochure was less about educating women about genetics and genetic testing (which would be done for participants via a genetic counseling session after enrollment in the study) and more about recruiting women. Second, our results were based on relatively small samples of women at each phase. However, available literature suggests that small samples of both advisors and pilot participants are sufficient to develop and review study materials (Doak et al. 1996; Parra-Medina et al. 2004). Additionally, the majority of our pilot testing in phase 2 took place via the telephone rather than in-person (only one participant in the pilot test opted for a face-to-face interview). Each interview method has advantages and disadvantages. When compared to telephone-based qualitative interviews, face-to-face interviews are more likely to have limited geographic reach, be more resource-intensive (e.g., time, cost), and yield slower data collection. Phone interviews also have disadvantages. For example, it is more difficult to build rapport with participants or observe nonverbal cues such as body language. However, between the two methods, in-person interviews carry the highest extent of interview bias due to the tendency for participants to provide what they perceive as more socially acceptable answers (Sawaya 2004). Finally, we did not systematically evaluate the impact of the study brochure in recruiting women to the study. While we have some evidence of both face and content validity, future studies should focus on evaluating the efficacy of the study brochure in recruiting women using a randomized design.

Practice implications

In the updating and refining of the current study brochure, several lessons were learned by the team that may also inform the future replication of such a process for other research studies. First, based on the team's opinion, involving the stakeholders in the process as early as possible and on a continuous basis enhanced the quality of the materials produced. Furthermore, providing members of a CAP or focus group with appropriate incentives to acknowledge their time and efforts is critical. Additionally, sharing the credit for materials developed may also enhance how vested individuals may feel in a particular project. In the current study, the efforts for the study brochure solidified a community–academic partnership between the study team and CAP members. This partnership is named B-GREAT (Breast Cancer Genetics Research, Education, and Advocacy Team) and is acknowledged in all materials developed by this joint collaboration. Another valuable lesson was that developing, testing, and finalizing study materials require allocation of both time and resources. Generally, conducting CAP conference calls or face-to-face meetings, as well as participant interviews, require extensive coordination and organization. Additionally, this process must be incorporated in the study timeline. For the current study, recruitment was delayed by approximately 4 months to update, refine, and finalize a study brochure that met the approval of the study team and the CAP. These costs and time frame are not traditionally written into a funding application; thus, limited time, attention, and personnel are devoted to using a comprehensive approach to developing study materials. Finally, all materials benefit from review and re-review of individuals who work with, live in, and/or are part of the target study population. It is important not only to elicit opinions and suggestions from the community but also to implement their suggestions and have them re-review the changes to ensure that what they suggested is adequately reflected in the study materials.

In addition to providing important insight and guidance in the development of the study brochure, the relationship between the CAP and the study team has continued to evolve and focus on educating the AA community about hereditary breast cancer. Upon completion of the study brochure, many CAP members requested copies to use as a health education tool for AA women. Given that the study brochure was targeted toward women who met clinical criteria for *BRCA* testing and was designed to encourage women to participate in a study, the team felt that revisions should be made prior to general dissemination. Thus, the team has partnered with the CAP to pilot test a lay audience brochure with the communities that CAP members serve (Rivers et al. 2007; Vadaparampil et al. 2008). Once these materials have been finalized, this brochure will be available for various outreach/education efforts to improve awareness of genetic counseling and testing within the AA community. Our team also continues to work with the CAP to develop a more detailed booklet about hereditary breast cancer that can be used as a culturally tailored companion piece for face-to-face or phone-based genetic counseling (Permuth-Wey et al. 2010). Finally, the CAP continues to play an active role in new research efforts by the team and has been involved in two additional research applications submitted to national organizations since the initial grant was awarded.

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