Development of a Brochure for Increasing Awareness of Inherited Breast Cancer in Black Women

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Low levels of awareness about hereditary breast cancer and ovarian cancer and underutilization of genetic services combined with the high incidence of early onset breast cancer in the black community underscore the urgent need to provide information about hereditary breast and ovarian cancer to black women. The primary goal of the present study was to develop a culturally targeted brochure designed to increase awareness about inherited breast cancer among black women using the principles of Learner Verification. Three focus groups were conducted with black women, including those with or without a history of breast cancer ($n=46$), to evaluate the brochure. Data were analyzed through hand coding using a simple classification system placing participants' responses in the predetermined Learner Verification categories. On the basis of the feedback obtained, the brochure has been modified to improve cultural-targeting, relevance, and clarity and has been made available for dissemination. Our study illustrates the importance of obtaining feedback from the target audience when developing a culturally targeted informational brochure for black women. Further, the complexity of our subject matter (i.e., inherited breast and ovarian cancer) underscores the importance of using inviting visuals and personal vignettes, while maintaining a simple and clear message.

Introduction

THE INCIDENCE OF and mortality rates from early onset breast cancer in black women are higher than those observed in the Caucasian population (Newman, 2005). Given the younger age of onset, a proportion of cases may be due to mutations in the *BRCA* genes (Chen *et al.*, 2002; Armstrong *et al.*, 2005). However, black women with a family history of breast and/or ovarian cancer are much less likely to access genetic counseling and testing services compared to women from other racial and ethnic groups. A study investigating the characteristics of 646 women who received *BRCA* mutation testing in nonacademic settings between the years 1998 and 2000 found 94% were Caucasian, <1% were uninsured, and the median annual household income exceeded \$75,000 (Chen *et al.*, 2002). In a more recent case-control study of 408 women with a family history of breast or ovarian cancer, black women were significantly less likely to undergo *BRCA* genetic counseling than white women with a family history of breast or ovarian cancer (Armstrong *et al.*, 2005). In addition to the substantial evidence suggesting that there may be underutilization of cancer genetic counseling and testing services in the black community (Chen *et al.*, 2002; Armstrong *et al.*, 2005; Levy *et al.*, 2009), there have been a number of contributing factors identified including: low levels of awareness and

knowledge about hereditary cancer and genetic testing (Hughes *et al.*, 1997; Wideroff *et al.*, 2003b; Simon and Petrucci, 2009); inaccurate risk perception (Salant *et al.*, 2006; Spector *et al.*, 2009); communication of family history information (Matthews *et al.*, 2000; Underwood *et al.*, 2008); attitudes and cultural beliefs (Hughes *et al.*, 2003; Thompson *et al.*, 2003; Peters *et al.*, 2004; Edwards *et al.*, 2008; Simon and Petrucci, 2009); patient-initiated inquiry (Wideroff *et al.*, 2003a); and access to services (Hall and Olopade, 2006).

To date, few materials have been developed specifically to raise awareness and educate black women about hereditary breast cancer. Printed health education materials are an important and commonly used source of information for breast cancer patients and survivors from a variety of age groups, socioeconomic levels, and diverse racial/ethnic groups (Krueger, 1998; Talosig-Garcia and Davis, 2005; Ankem, 2006; Cowan and Hoskins, 2007; Masi *et al.*, 2007). Moreover, it is generally accepted that for black populations, culturally targeted materials may improve perceived relevance and acceptability compared to more generic materials (Kreuter and Haughton, 2006). To date, few materials have specifically been developed to improve awareness about hereditary breast cancer in black women. The most widely cited materials were developed with input from and use for a single high-risk black kindred from Louisiana (Baty *et al.*, 2003).

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However, these materials may not be relevant to black women in the general population as they were designed for a unique and specific population.

Our group developed a study-specific culturally targeted brochure (for directed patient recruitment) while conducting a cancer registry-based study of *BRCA* mutation prevalence in black women, in partnership with a Community Advisory Panel (Vadaparampil and Pal, 2010). The Community Advisory Panel members represented various stakeholders in the local black community, including breast cancer survivors, religious leaders, healthcare professionals, and patient advocates. The purpose of the partnership was to obtain feedback about study-related procedures, including recruitment strategies and information dissemination within the black community about inherited breast cancer. This academic partnership resulted in the development of a study-specific brochure, refined following pilot testing through individual interviews using the principles of Learner Verification (LV) (Doak *et al.*, 1996), for use during initial participant contact for the registry-based study. During the development and dissemination of the study-specific brochure, the need for a general informational brochure to promote awareness about inherited breast cancer in black women was identified by the Community Advisory Panel. Because the original study brochure was developed for direct patient recruitment, it was not suitable for the purpose of dissemination to a general audience.

LV provides an excellent framework for the health communication challenge of developing materials with effective messaging. LV, which is rooted in information processing theory, focuses on the persuasiveness of a health message and provides a systematic process for assessing this with unique audiences. Specific components of LV that are typically assessed with the target audience include attractiveness, comprehension, cultural acceptability, self-efficacy, and persuasion (Doak *et al.*, 1996). Given that the primary purpose of our brochure was limited to raising awareness (as opposed to promoting uptake of a particular behavior such as genetic counseling and/or testing), we focused on evaluating attractiveness, comprehension, and cultural acceptability of a culturally targeted informational brochure about hereditary breast and ovarian cancer (HBOC).

Materials and Methods

Draft brochure development

After identifying the need for a culturally targeted brochure to increase the awareness of HBOC, a study brochure was drafted. The study brochure was used as a template for drafting this informational brochure. The study investigators (which comprised a clinical geneticist and a behavioral scientist, both with specific expertise about HBOC) drafted this culturally targeted informational brochure, and reviewed the brochure with the Community Advisory Panel. This brochure was subsequently evaluated through focus groups as outlined below.

Participant recruitment

The study was approved by the institutional review board at the University of South Florida and written informed consent was obtained from all study participants. Study eligibility criteria included female gender, self-identification as

black or African American, and membership in one of the three preselected local organizations.

To ensure that women represented varying age groups, educational levels, and personal cancer histories, preselected local community-based organizations included (1) Black Student Union, comprised of undergraduate college students from the local university; (2) Sistahs Surviving Breast Cancer Support Group, comprised of breast cancer survivors, along with their support system members (i.e., family and friends); (3) Local Chapter of the American Cancer Society Reach to Recovery Support Group, comprised primarily of breast cancer survivors.

Leaders of the community organizations first approached and informed their members about the study using a letter that described the study and provided a toll-free number for any women who did not wish to be contacted about the study. Leaders then shared contact information with the researchers. For those who did not opt-out within 2 weeks, a study team member directly contacted the women in the organization and provided them a brief description of the study. Those who expressed interest were mailed a package of information that included a copy of the informed consent document, a copy of the brochure (Fig. 1), and a letter from our study team formally describing the study, as well as the date and location of the interview and contact information for any additional questions. Participants were asked to review both the consent document and the brochure before attending the focus group. Given that the participants were members of intact groups, a separate focus group was conducted for each of the three organizations. On the day of the focus group, study personnel reviewed the informed consent document. During the focus groups, participants were provided with a meal, and at the end of the focus group, participants were given an African American breast cancer awareness pin and bookmark from the Susan G. Komen for the Cure Foundation and a \$10 Target gift card, in recognition of their time.

Conduct of focus groups

Each of the three focus groups was conducted by race-concordant moderators. Moderators used a structured interview guide developed to evaluate the brochure based on the three specific components of LV: cultural acceptability, attractiveness, and comprehension (see Table 1). The interview guide asked participants about specific features of the brochure (title, cover, photos, and testimonials) as well their overall assessment of the understanding of the intent and specific items of comprehension. Women were asked to offer suggestions for improvement if there was a general negative or inconclusive response to any of the LV questions. The brochure was distributed to all women in the focus group to review. In addition, each of the panels of the tri-fold brochure was enlarged to poster size so that it could be viewed by the whole group at the same time and specific features on each page could be viewed simultaneously by the entire group.

Data collection

Once a signed informed consent document was obtained, participants were asked to complete a brief anonymous questionnaire to collect basic sociodemographic characteristics before beginning the focus group discussion. During each

FIG. 1. Study brochure.

focus group session, handwritten notes of the respondents' answers to the questions were taken by three members of the study team for each session, which were subsequently transcribed and summarized following the session.

Data analysis

Basic descriptive data related to demographic and clinical characteristics were summarized using descriptive statistics. The transcripts and summaries were reviewed by all members of the study team. Data were analyzed using hand coding and a simple classification system that categorized participant responses into the predetermined categories, based on the

principles of LV. The transcripts were independently evaluated and coded independently by at least three members of the study team (S.V., A.G., and T.P.) and an inter-rater reliability rate of 90% agreement on all codes was achieved after reviewing all transcripts.

Results

Demographic characteristics of participants

For the Black Student Union, the group leader provided contact information for 11 female members, 9 of who attended the focus group. For the Reach to Recovery organization,

TABLE 1. FOCUS GROUP GUIDE FOR BROCHURE

	Question	Principle of learner verification
1	First of all, are there any general comments?	A, C, CA
2	Tell me in your own words what these educational materials are all about?	C
3	What did you especially like about the visual aid? About the educational materials?	A, C, CA
4	Did you find the information useful?	C, CA
5	How could these visual aids be improved?	A, C, CA
6	How did you find the length of the visual aids was it too long or too short?	A
7	Was the information presented easy to understand (probe: what are some examples of things that were not clear or hard to understand)?	C
8	Did you like the flow of the information?	C
9	Were there any words that were hard to understand?	C
10	Was the visual aid visually pleasing? Did they catch your attention?	A
11	Do you think African American women would consider the visual aids would be culturally relevant?	CA
12	Did you think the visual aids addressed the following issues? If not, should it have been addressed? PROBES: Importance of religion and faith Concepts of honor and respect Trust or lack of trust Survival Health concerns as family issues Individual and community responsibility	CA
13	Did the visual aids help you understand who may be at an increased risk for developing breast cancer and/or ovarian cancer?	C
14	Would you need to know anything else about <i>BRCA1/2</i> before making a decision about whether or not to have testing?	C
15	Do you think that if your friends or neighbors would be willing to consider genetic testing if they were provided with this information?	C
16	Do you think you could discuss the pros and cons of genetic testing with friends and family after reviewing the visual aid?	C
17	Do you think you could make a decision about whether genetic testing is right for you based on the visual aid?	C
18	American women who have been diagnosed with breast cancer?	CA

G, general question; CA, cultural acceptability; C, comprehension; A, attractiveness.

contact information was provided for 15 members, 9 of who attended the focus group. For the Sistahs Surviving Breast Cancer organization, the leader provided contact information for 23 women and 28 attended. These additional women did not receive the initial contact letter by the group leader. Because this focus group was held during a regularly scheduled meeting time, these women were expecting a regular group meeting. However, once they arrived and learned of the study, they expressed interest in participation. Given that they were part of the target audience, these additional participants were also consented and included in the focus group. Characteristics of study participants ($n=46$) are summarized by organization in Table 2. In total, there were 46 participants, with varying demographic and socioeconomic backgrounds. The majority of participants were over age 41 (67%) and married (43%). Thirty-seven percent were college graduates or beyond and 72% had children.

Results of focus group data

Cultural acceptability. When participants were asked about perceived cultural aspects to the brochure, all who gave their input indicated that the brochure was representative of black culture and the majority noticed the attempt to help black women understand why hereditary cancer may be rel-

evant to them. When asked about the photos and personal stories, participants agreed that these elements made the brochure culturally relevant.

"The pictures make it believable—it looks like my neighbor."

"Stories along with pictures make the brochure believable."

However, an area for improvement was identified with respect to cultural acceptability. The phrase "women of color" was not well accepted across all three groups. In response to questions about this phrase, the majority of respondents used the term "black" to refer to the target audience for the brochure.

"Women of color brings up thoughts of Spanish and Asian women, but the subtitle breaks down that it is really for black women."

"Women of color is too general and not specific to black women"

Comprehension. Participants were asked if there were aspects of the brochure they did not understand, and specifically asked to comment on their understanding of the terms "genetic counseling" and "genetic testing." The majority found the brochure easy to understand and read.

"Readings flow easily and organizes different topics."

TABLE 2. DEMOGRAPHIC CHARACTERISTICS OF FOCUS GROUP PARTICIPANTS (N = 46)

Variable	Black student union (n = 9), n (%)	Reach to recovery (n = 9), n (%)	Sistahs surviving breast cancer (n = 28), n (%)
Age			
18–29	9 (100)	0 (0.0)	0 (0.0)
30–41	0 (0.0)	1 (11.1)	5 (17.9)
41 and older	0 (0.0)	8 (88.9)	23 (82.1)
Hispanic	1 (11.1)	1 (12.5)	0 (0.0)
Black/African American	7 (77.8)	9 (100.0)	25 (89.3)
Marital status			
Single or never married	9 (100.0)	1 (11.1)	3 (10.7)
Married/living as married	0 (0.0)	6 (66.7)	13 (46.5)
Divorced or separated or widowed	0 (0.0)	2 (22.2)	7 (25.0)
Educational level			
<High school	0 (0.0)	0 (0.0)	3 (10.7)
High school/GED	0 (0.0)	1 (11.1)	4 (14.3)
≥Some college	8 (88.9)	8 (88.9)	21 (75.0)
Health insurance	6 (66.7)	9 (100.0)	23 (85.2)
Have particular clinic you visit	5 (55.6)	9 (100.0)	27 (96.4)
Have children	0 (0.0)	9 (100.0)	23 (82.1)

Percentages are based on responses to question. Missing data are not included.

“Gives basic information, not too much, which is good.”

However, respondents noted that there were some areas with respect to comprehension that could be improved. Some women expressed confusion about the meaning of the title “The Causes of Hereditary Breast and Ovarian cancer.”

“This is too wordy—is there a different word that can be used?”

“If you use this word, explain what it means.”

When asked if they understood the term genetic counseling, many commented that the brochure focused on why a woman should get counseling and not what it entailed.

“It isn’t defined, just listed.”

“The brochure doesn’t specifically explain what genetic counseling is. . . . I won’t be able explain to anyone else what it means.”

When participants were asked about their understanding of genetic testing, the majority indicated that they did understand, although some felt the focus was on who should be concerned about getting a testing versus explaining the testing process.

“No, the brochure doesn’t even explain what the test is.”

“Include how long genetic testing would take.”

“I still don’t know much about the test itself, what it is, where to get it, and how much it costs.”

Finally, while women from the older groups generally found the cover both appealing and relevant for women their age, the majority of college students did not appear to understand why this information was relevant to them. Interestingly, women from the groups comprised of older women

were concerned that younger women may not understand the importance of this information.

“. . . when I first looked at the pamphlet it seems like genetic testing is for older women”

“I probably would not read it because it does not appeal to my age”

“Genetic testing applies to the younger generation when the older generation is affected, [it] benefits the offspring.”

Attractiveness. When asked about the colors and photos in the brochure, in general, participants had favorable comments:

“The colors are beautiful and afro-centric.”

“I can definitely see a real person. . . . an aunt or family member in the pictures.”

“I would look at it because you don’t see too many black women on the cover of anything and because the Susan G. Komen logo is on the brochure.”

However, a few indicated that incorporation of African American flag colors may make the brochure more readily identifiable as targeting black women.

“Use the colors in bookmark [red, green, black].”

“[Should be] afro-centric, attention-grabbing.”

Brochure revisions

After the completion and analysis of the data emerging from conduct of the focus groups, the study team revised the brochure based on respondent’s feedback (Fig. 2), as summarized in Table 3. In particular, the cover photo of a single breast cancer survivor in her 50s was replaced by boxes in a checkered design; some of these boxes, in a random manner, contained pictures of black women of different ages. The African American flag colors were incorporated within this checkered design, and they were also added as borders to the photos of breast cancer survivors included within the brochure. Information that early onset aggressive breast cancer is more common in young black women was included in the top left panel. The information about genetic counseling and testing was greatly simplified, as the study team recognized that a tri-fold brochure could introduce these concepts, but would likely not be sufficient to fully explain the purpose and process of these clinical services. However, additional details were included about how genetic testing was conducted through a blood sample and addressed the logistics of the test procedure.

Discussion

As in previous studies, our team found that focus groups are an effective means of gathering information during the process of developing cancer genetic education materials for black populations (Baty *et al.*, 2003; Thompson *et al.*, 2004; Lubitz *et al.*, 2007). Using this approach, guided by key principles of LV, our team was able to identify areas in need of improvement for the educational brochure. Although the brochure was largely viewed positively by participants, areas of improvement in the areas of LV assessed including cultural acceptability, comprehension, and attractiveness.

With respect to cultural acceptability, several issues emerged. First, women in our study preferred terms other than “women of color” to describe their community. Specifically, most women appeared to prefer the term “black” over

"women of color". A previous study of ~3000 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 to explain why the women in our study preferred the term black as our sample consisted only of women from the South. Additionally, some

women in our sample wanted more specific information about why hereditary breast cancer was relevant to their community. A recent review of social determinants of breast cancer disparities in mortality between black and white women suggest for black women usually consider themselves to be at lower risk for developing breast cancer than do white women (Gerend and Pai, 2008). However, this pattern is observed even among black women with established risk factors such as a personal or family history of breast cancer suggestive of HBOC (Hughes *et al.*, 1996; Brewster *et al.*, 2007; Gerend

TABLE 3. SUMMARY OF BROCHURE CHANGES BASED ON FOCUS GROUP DATA

<i>Learner verification topic</i>	<i>Draft brochure</i>	<i>Final brochure</i>
Cultural acceptability	African American or women of color Limited amount of breast cancer specific information at back of brochure	Black Moved content to more prominent location on inside left panel, and expanded information
Comprehension	Used the term "Hereditary" in title Extensive information included about genetic counseling and testing, however, due to limited space, unable to effectively explain the concept Little mention of importance of hereditary cancer for younger black women	Used the term "Family Link" in title Reduced amount of information about genetic counseling and testing, and rather described the availability of genetic services and basic facts about Included information pertinent to young black women in expanded section of why this topic is of relevance to black women
Attractiveness	Used vibrant colors (red and yellow) Single photo of breast cancer survivor in her 50s No reference to or pictures of young women	Changed to more afro-centric colors (green, red, black) Several pictures included, comprising younger women, families and couples

and Pai, 2008). Thus, including elements such as terms and information unique to black women may help to enhance both the cultural acceptability and personal relevance of the information about HBOC.

Another issue identified from our focus groups was associated with comprehension of concepts and terms, including hereditary, genetic counseling, and genetic testing, that were used throughout the brochure, but not well understood or clear to participants. This issue of comprehension of genetic terminology was previously identified as a source of concern in a study evaluating educational materials describing genetic risk for cancer conducted by Thompson and colleagues (Thompson *et al.*, 2004). In their study, although definitions and a glossary were included as part of the educational materials, when the African American adult learners who participated in the study were asked to evaluate how well they understood the meaning of the words used in the booklet all participants selected "a little" or "not at all," suggesting that keeping highly technical terms and using supporting definitions may not be an optimal approach. Thus, our team opted to substitute the term hereditary with the phrase of "runs in the family." Another area where participants expressed low levels of comprehension was related to the terms genetic counseling and testing. Participants felt that the terms were introduced but lacked substantive operational explanation of the process or procedures. Upon discussion with the study team, there was consensus that providing detailed information about genetic counseling in addition to introducing HBOC was beyond the scope of a brief educational brochure. Therefore, we revised the information focusing on purpose of brochure as a means to introduce and increase awareness of these topics with the idea that individuals who wanted additional information would either use one of the resources for additional information provided or discuss the topic with a healthcare professional.

A final area of comprehension that was identified was that many of the women who were part of the focus group that included college age students felt that the brochure was for older women like their mother or aunt. Given the increased incidence of and mortality rates from early onset breast cancer (which may be associated with mutations in the *BRCA* genes)

compared to the Caucasian population (Aziz *et al.*, 1999; Newman, 2005), it is particularly important to inform younger black women about HBOC. Thus, modifying certain elements related to information about early onset breast cancer among black women and including photos of younger women may help them better understand that the younger black women are also at risk for HBOC.

The overall attractiveness of the brochure was uniformly reviewed favorably by participants. Similar to previous studies evaluating the development of cancer genetic education materials (Thompson *et al.*, 2004; Lubitz *et al.*, 2007), our participants rated areas of attractiveness like font size, appeal of the images, and photos accompanied by testimonials favorably. However, the participants in the Thompson study (Thompson *et al.*, 2004) indicated that they did not like the way the booklet looked overall. While the authors did not specifically probe for additional information related to this issue, they speculated that this may be due to the fact that the materials were not provided to the participants in color and did not look like a typical health brochure. In our study, all participants were provided a high-quality color 8.5×11 tri-fold brochure, which may explain possible differences with regard to overall ratings of attractiveness.

However, within the context of attractiveness, there were two key areas identified for improvement. The first relates to the color scheme used. Several women expressed an inclination for colors that represented the African American flag (red black and green) over the colors of the original brochure (bright red and yellow). The second area related to the perceived attractiveness of the brochure for younger women. The younger women felt the brochure would appeal to older family members such as their mothers or aunts, but did not feel it was meant for them. Thus, modifying certain elements related to attractiveness, including the color scheme and photographs, in order that individuals from the entire target audience, including younger black women, may better identify with the educational material may ultimately serve to increase the perceived attractiveness of our educational materials.

To our knowledge, this is among the largest focus group-based study to evaluate a breast cancer genetic education

brochure for black women. Previous studies using focus groups to evaluate genetic education materials for minority populations have had limited diversity with respect to risk, cancer status, educational level, and age (Baty *et al.*, 2003; Thompson *et al.*, 2004; Lubitz *et al.*, 2007). As with any study, however, the results should be considered in light of certain limitations. First, our focus groups consisted of three intact groups. It is possible that responses may have differed if the groups had been comprised of participants with no previously existing relationships. However, given that recruiting to focus groups to ensure an adequate number of participants represents an ongoing challenge in health research especially in minority populations (Webb, 2002; Howatson-Jones, 2007), there were several advantages to using intact groups, including mutually convenient time and meeting locations, which resulted in excellent participation rates. Our sample was recruited from the Tampa Bay area and may not be representative of blacks from other regions of the United States. However, there were similarities between key findings from our study and those conducted with other groups of black populations from other parts of the country (Baty *et al.*, 2003; Thompson *et al.*, 2004; Lubitz *et al.*, 2007). Additionally, as with all qualitative research, these results may not be transferable to other populations.

In a recent study by John and colleagues, the prevalence of *BRCA1* mutations was particularly high in black women found to have breast cancer before age 35, when compared to whites as well as all other racial ethnic groups (John *et al.*, 2007). Yet, previous studies systematically document underutilization of risk-appropriate *BRCA* genetic counseling and testing services among the black community (Chen *et al.*, 2002; Armstrong *et al.*, 2005). One possible explanation lies in lower levels of awareness and knowledge related to HBOC risk and availability of genetic testing services (Hughes *et al.*, 1997; Wideroff *et al.*, 2003b; Simon and Petrucelli, 2009). Thus, there is an urgent need for outreach and intervention efforts to increase awareness about HBOC in the black community (Thompson *et al.*, 2002). Our study discusses the process by which we developed an educational brochure about HBOC targeted at black women. Since this work has been completed, we have made our educational brochure available to members of our Community Advisory Panel and others who have requested this information. To date we received 17 requests and distributed 3,395 brochures for use in various educational venues such as community health fairs and other events held by black organizations in the Tampa Bay area and beyond. This work has the potential to be particularly timely and relevant given national attention related to breast cancer among young women due to legislative efforts such as Early Act (H.R. 1740), <http://wassermanschultz.house.gov/earlyact/summary.shtml>. This bill is designed to "... develop and implement a national education campaign about the threat breast cancer poses to young women of all ethnic and cultural backgrounds, and the particular heightened risks of certain groups."

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