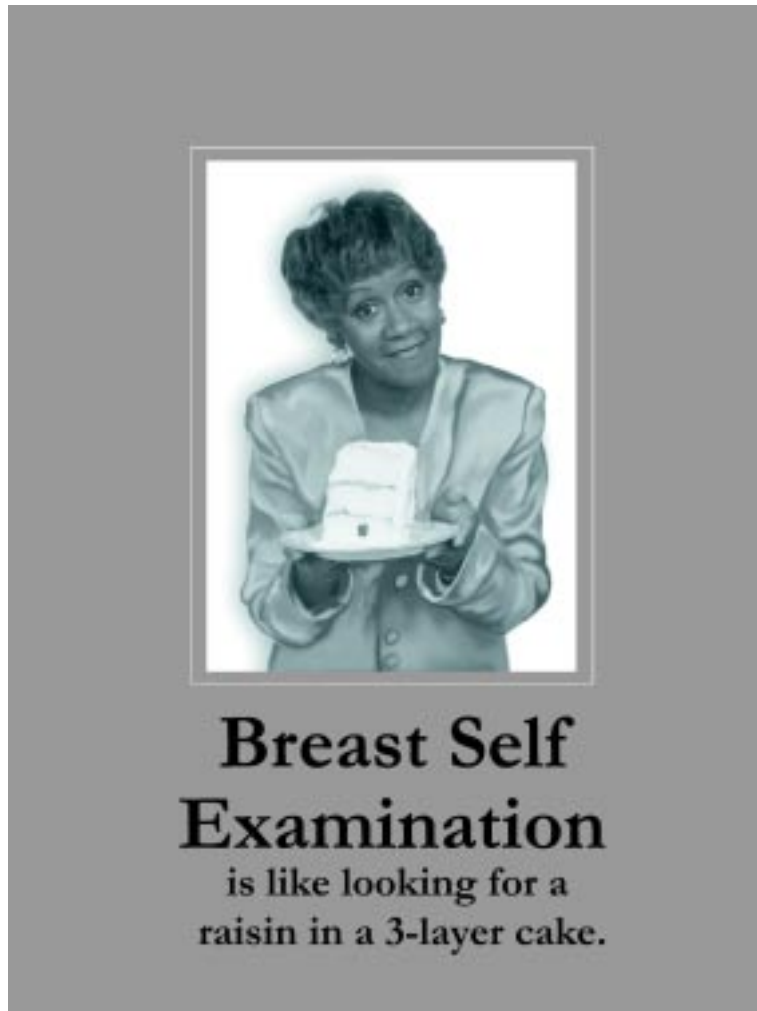


# Pull-Out Patient Education Booklet Included for Healthcare Providers



Attached is a complementary copy of the breast self-examination booklet discussed in “Developing and Testing Lay Literature About Breast Cancer Screening for African American Women” (see next page) by Elizabeth Ann Coleman, PhD, RN, AOCN®, Sharon Coon, PhD(c), MNsc, RN, AOCN®, Carolyn Mohrmann, MBA, Susan Hardin, RN, BSN, OCN®, Beth Stewart, BS, Regina Shoate Gibson, RN, Mary Cantrell, MA, Janet Lord, PhD, RN, and Jeanne Heard, PhD, MD.

“Breast Self Examination Is Like Looking for a Raisin in a 3-Layer Cake” was developed by The Delta Project Team as a result of research funded by the National Cancer Institute, National Institutes of Health (extramural grant project R25 CA66888). Generous support was provided by The Susan G. Komen Breast Cancer Foundation. Other contributors included The Earl Knudsen Charitable Foundation in Pittsburgh, PA, Pfizer Inc., and Bristol-Myers Squibb.

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# Developing and Testing Lay Literature About Breast Cancer Screening for African American Women

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In a three-year study funded by the National Cancer Institute, the authors tested a multimethod approach to increase breast cancer screening in primary care clinics in the Mississippi River Delta region of eastern Arkansas, an extremely rural area with a high concentration of African Americans, a high percentage of elderly citizens, and a low per-capita income. Standardized patients taught healthcare providers in their office settings. Prompts, such as posters and easy-to-read newsletters, were supplied to the clinics. The researchers reviewed available lay literature to select appropriate materials to place in the clinics for women with low literacy skills. A review of the lay literature on breast cancer screening published during the past decade did not meet all of the researchers' criteria: low literacy level (at or below third grade), accurate in illustrating correct breast self-examination (BSE) techniques, and culturally sensitive (Mohrmann et al., 2000). The researchers found a need for culturally sensitive lay literature for women with low literacy.

More than 23 million women living in the United States described themselves as African American in the 2000 census (U.S. Cen-

Written materials about breast cancer screening for African American women with low literacy skills are needed. Available materials were not at or below third-grade reading levels, were not culturally sensitive, and were not accurate in illustrating correct breast self-examination (BSE) techniques. Focus groups representing the target population helped the authors design a pamphlet describing how to perform BSE and a motivational picture book to help women overcome barriers to screening. The authors chose a food theme for the cover of the pamphlet written at a third-grade level and suggested a photographic version. In the motivational book, two women address barriers to screening and replace myths and fears with facts and actions. Data from 162 women showed that they learned from both the photographic and illustrated versions. Women in the photographic group found significantly more lumps in the silicone models, so the authors chose that version to use in final testing. Finally, nurses pretested a group of patients before they reviewed the materials and post-tested another group after they reviewed them. The group who had reviewed the materials had greater knowledge of and intent to follow the guidelines and received higher scores on BSE techniques.

**Key Words:** breast self-examination, mammography, preventive health services

sus Bureau, 1999b). Socioeconomic status coupled with related factors, such as education and poverty, are strongly associated

with race and ethnicity. The percentage of the U.S. population lacking high school education included 23% of African Americans (U.S. Census Bureau, 1999a). Almost 23% (2.51 million) of all African American women had not completed high school (U.S. Census Bureau, 1999a). This study targeted undereducated African American women.

In 2002, 203,500 women were diagnosed with and 40,000 women died from breast cancer (American Cancer Society, 2002). African American women have a higher lifetime risk of dying from breast cancer when compared with Caucasian women (3.39% versus 3.12%) even though they have a lower lifetime risk of being diagnosed with the disease than Caucasian women (10.21% versus 13.95%) (Surveillance, Epidemiology, and End Results, 2002). In an

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analysis of female patients with breast cancer, the single most important factor leading to low survival rates among African American women was late diagnosis at an incurable stage of the disease (Eley et al., 1994). Fatalistic attitudes, lack of insurance and preventive care, lack of awareness, and lack of knowledge are common, significant barriers to early detection methods such as mammography, clinical breast examination (CBE), and BSE (Davis et al., 1996; Greenwald & Sonick, 1986; Husaini et al., 2002; Paul, Barratt, Redman, Cockburn, & Lowe, 1999; Phillips, Cohen, & Tarzian, 2001; Seidman, Gelb, Silverberg, LaVerda, & Lubera, 1987; Shapiro, Venet, Strax, & Venet, 1988; Tabar et al., 1985; Tanne, 1999).

Almost 90 million American adults (47% of the U.S. population) demonstrated low levels of functional literacy in the 1992 National Adult Literacy Survey (NALS) (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993). The NALS sample represented the noninstitutionalized population ages 16 and older living in households in the United States (National Center for Education Statistics, U.S. Department of Education, 2002). Survey results revealed a significant positive correlation among literacy, education, and income levels (U.S. Department of Health and Human Services, 1994). The U.S. Census Bureau (1999c) showed that, among African Americans in the United States, 8% had less than a ninth-grade education, another 23% had less than a high school diploma, and 26.1% lived below the poverty level as of March 1999.

## Discovering the Need for Low-Literacy Materials

Research shows that, even with easy-to-read material, people with low literacy skills learn less, partly because they do not expect to learn much from printed materials. They may be able to read each word but are less likely to comprehend what they read. If the reading is difficult or if materials do not address information they believe to be beneficial or relevant, they will not be motivated to read it (Doak, Doak, & Meade, 1996). The researchers planned to review available materials on breast cancer screening, check them for reading levels and accuracy, select a group of appropriate materials, and distribute them as a packet to primary care clinics in the Mississippi River Delta region for healthcare providers to give to their patients to break down barriers to screening.

Unfortunately, the researchers found a scarcity of materials that fit their criteria for African American women with low literacy

skills. They reviewed cancer-related publications from 19 organizations that developed materials intended for African American audiences. Sixty-one documents were examined for cultural sensitivity and readability. The mean Flesch Reading Ease Score of 65 yielded a Flesch-Kincaid mean grade level of 7.5, but the desired level was 3.5 (third- to fourth-grade level). The review suggested that educational materials on breast cancer do not provide information to undereducated, economically disadvantaged African American women.

## Developing Low-Literacy Materials

The researchers received additional funding in 1997 to develop and evaluate appropriate lay literature for African American women with low literacy skills. Focus groups representing the target population helped design a pamphlet describing how to perform BSE and a motivational picture book to help women overcome barriers to breast cancer screening.

Initially, the researchers developed materials only in an illustrated version. The drawings were instructional but not lifelike, and many women in the focus groups indicated that they would like to see real, step-by-step photographs of a woman performing BSE. BSE materials had not included actual pictures of bare breasts for general distribution. The researchers hired a professional photographer to take pictures of a breast teaching associate professional (BTAP) doing each step of BSE, showing posture, form, technique, fingers used, patterns, and pressures to be used in an actual BSE. Using the photographs, a professional artist drew each step of BSE. Although the drawings were very similar to the photographs, they were not actual pictures of bare breasts. The researchers' plan was to test the drawings against the photographs to determine which was more effective.

For the pamphlet cover, the focus groups had a choice of three different themes: a food theme and two that represented designs and patterns from African art and artifacts. The majority preferred the food theme; therefore, the cover features the theme "Breast Self Examination is Like Looking for a Raisin in a 3-Layer Cake." The pamphlet's large print is easy to read and has accompanying illustrations to guide women through each step of BSE. Outlining techniques recommended by the American Cancer Society, it is written at a third-grade level. The pamphlet has been reproduced and included in this journal issue (see page 65).

The motivational picture book, titled *Ruby and Pearl: Two Jewels on a Journey*, is aimed at improving breast cancer screening behaviors among African American women, especially the undereducated and economically disadvantaged. The characters Ruby and Pearl address barriers to breast cancer screening using a light, conversational, vernacular approach touched with humor. Their journey of discovery replaces myths and fears with facts and actions. Excerpts from the picture book are shown in Figure 1.

## Testing Photographs Versus Drawings

Volunteers from the Witness Project® not only helped develop the materials but also recruited women from the community to assess the effectiveness of the materials. The Witness Project is a culturally competent, community-based cancer education program through which cancer survivors and lay health advisors increase awareness, knowledge, screening, and early detection behaviors in rural and low-income African American populations to reduce mortality and morbidity from cancer. The project's Web site is [www.acrc.uams.edu/Outreach/Witness/Project/index.html](http://www.acrc.uams.edu/Outreach/Witness/Project/index.html).

Women from work sites, churches, and civic organizations in Little Rock, AR, and surrounding areas that included higher numbers of African Americans with a high school education or less participated in the evaluation of the materials. They met with the researchers in small groups of as many as 10 during their lunch breaks at their work sites or at meeting places. After introductions, consent forms were distributed, read aloud, and then signed by each participant.

The Rapid Estimate of Adult Literacy in Medicine test, used to assess reading skills based on recognition of health-related or medical words, was given to each participant. To determine their current knowledge about breast cancer, detection, and beliefs about and understandings of the disease, each participant completed a written pretest, then showed researchers how they do BSE by performing a breast examination on silicone breast models. These "self-examinations" were scored on the percentage of area covered, duration, number and types of motions, part of fingers used, number and types of pressures used, types of examination pattern used, and number of lumps found.

After completing the pretest, the women were given the materials to read and review while eating lunch. They received either



**FIGURE 1. EXCERPTS FROM THE PICTURE BOOK *RUBY AND PEARL: TWO JEWELS ON A JOURNEY* (CONTINUED ON NEXT PAGE)**

*Note.* From the College of Nursing at the University of Arkansas for Medical Sciences. Reprinted with permission.

the photographic or illustrated version of the materials based on random assignment by group. After lunch, the participants completed a written post-test to determine

what they had learned from reviewing the materials. They then performed a second examination on the silicone breast models. After the post-test, a participant from the

Witness Project demonstrated how to perform BSE, which was followed by a question-and-answer period about breast cancer screening.



FIGURE 1. EXCERPTS FROM THE PICTURE BOOK *RUBY AND PEARL: TWO JEWELS ON A JOURNEY* (CONTINUED FROM PREVIOUS PAGE)

Note. From the College of Nursing at the University of Arkansas for Medical Sciences. Reprinted with permission.

## Results

The sample consisted of 162 women, 80% African American, 15% Caucasian, and 5% other races. They ranged in age from 17–72 years, with a mean age of 43. Results from data analysis for the 162 women who completed the pre- and post-tests (82 who received the drawings of the educational material and 80 who received the photographic versions) showed that the women learned from both versions. Both groups made significant improvements in their knowledge related to breast cancer screening, BSE confidence, and performance scores when examining the silicone breast models. The average post-test performance score was 56 of 100, indicating that the women needed to learn more and needed to take information, such as the pamphlet, with them to continue to improve their BSE techniques.

The women's ability to find lumps when examining the silicone breast models did vary

significantly by group even though no significant difference was found in their examining techniques. The positive predictive value equals the number of lumps found divided by the sum of the number of lumps present and the number of false detections. A significant improvement was found in the positive predictive value on the post-test when compared to the positive predictive value on the pretest for the women who received the photographic versions of the materials but not for the women who received the illustrated versions. On the post-test, the performance scores showed a positive correlation with the positive predictive value of finding lumps in the silicone breast models.

Of the 93 women 40 or older who did not have a mammogram within the past year, six indicated on the pretest that they did not plan to get a mammogram within the year. All six were in the group that received the photographic versions of the educational materials. All but one of these women said on

the post-test that they planned to get a mammogram within the year.

The women's comments showed their enthusiasm for the materials. They said, "I got your attention with the vibrant colors; we're all drawn to colors," "The people look normal, they don't look like models," and, "A lot of times when you see pamphlets, they have a cover of the person, then when you start turning, they just have diagrams." Because women said that seeing bare breasts did not bother them and the positive predictive value improved with the use of the photographic versions, the researchers chose the photographic versions of the materials for the dissemination phase of the project.

## Methods to Test Dissemination of Materials

Concurrent with the study to develop the educational materials, advanced practice

nurses and nurse practitioners from across the state attended a Breast Cancer Intensive Training workshop led by the College of Nursing faculty at the University of Arkansas for Medical Sciences in Little Rock. During the workshop, part of a continuing education series funded through an Arkansas Department of Health contract, one to three nurses were taught at a time. The program required the attendees to learn to evaluate BSE techniques using a checklist developed and validated by the principal investigator. Inter-rater reliability was more than or equal to 95% (Coleman & Pennypacker, 1991a, 1991b).

Through the Arkansas Department of Health, the researchers enlisted the help of 26 nurse practitioners who attended the workshop. They represented 37 counties in Arkansas. From November 2000–February 2001, the nurses administered a pretest, which consisted of a brief evaluation of knowledge of and intent to follow breast cancer screening guidelines and a performance check of actual BSE techniques, to 258 women seen in their clinics. The performance test included an evaluation of the components of BSE performance. The BSE techniques were scored using the same checklist the nurses used in the workshop. Four items were added to assess intent, and these were pretested for clarity in focus groups of African American women.

During the fourth month of the project, the participating facilities received one copy of the motivational picture book to display in waiting rooms and copies of the pamphlet to distribute to women during the next three months. From April–June 2001, the nurses gave a post-test, which was identical to the pretest, to 116 women after they had reviewed the motivational picture book and pamphlet.

## Results of the Dissemination Evaluation

The researchers used descriptive statistics (i.e., chi-square test and t test) to check for equivalence of groups, the chi-square test and one-way analysis of variance to test for group differences, and Pearson's correlation to look for relationships among outcome variables. The pretest group consisted of 121 African Americans, 34 Hispanics, 101 Caucasians, and 2 women of another race. Their ages ranged from 14–69 years, with a mean age of 33.7 (SD = 14.2). The post-test group was comprised of 61 African Americans, 3 Hispanics, and 52 Caucasians. Their ages ranged from 15–64 years, with a mean age of 41.2 (SD = 14.7). No significant differ-

ences in race were found between the groups, but the pretest group was younger ( $p < 0.001$ ).

The group of women who had reviewed the materials had a greater knowledge of and intention to follow guidelines for CBE and BSE ( $p < 0.001$ ). Considering only the women who were 40 or older, no significant difference was found between the groups' intentions to have a yearly mammogram. However, all but 22 of those women (15 from the pretest group and 7 from the post-test group) said they planned to have a yearly mammogram. The group of women who were 40 or older who reviewed the materials had greater knowledge of their need for mammography on a yearly basis than the women in that age group who had not reviewed the materials ( $p < 0.01$ ).

The women who reviewed the materials had higher scores on the performance of BSE techniques than the women who had not reviewed the materials (mean score of 10.2 versus 4.3, with 19 being a perfect score). This was a statistically significant difference ( $F = 58.7$ ,  $p < 0.001$ ). When the analysis was done with only the African Americans who were 40 or older, the statistically significant results remained true ( $p = 0.001$ ). BSE score was positively correlated with age ( $r = 0.334$ ), screening knowledge ( $r = 0.424$ ), and screening intent ( $r = 0.349$ ).

## Conclusion

These findings indicate that the materials were effective in increasing women's knowledge of and intent to follow breast cancer screening guidelines and in teaching them BSE techniques. In July and August 2001, additional copies of the pamphlet were mailed to the participating clinics in appreciation of their assistance with the project.

The Susan G. Komen Breast Cancer Foundation, Pfizer's Health Literacy Grants, and the Earl Knudsen Charitable Foundation funded the development and evaluation of the materials. Bristol-Myers Squibb provided a grant to print additional copies of the pamphlet for distribution nationwide to healthcare providers for use with their patients. A sponsor is needed to publish and distribute the motivational picture book to primary care offices.

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**Healthcare providers may contact the author to obtain copies of the pamphlet.**

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**For more information on this topic, visit the following Web sites.**

**National Women's Health Network**

[www.womenshealthnetwork.org/advocacy/wocbreastca/african.htm](http://www.womenshealthnetwork.org/advocacy/wocbreastca/african.htm)

**BlackWomensHealth.com**

[www.blackwomenshealth.com](http://www.blackwomenshealth.com)

**Colorado HealthSite**

[www.coloradohealthsite.org/CHNReports/raceandbrcancer.html](http://www.coloradohealthsite.org/CHNReports/raceandbrcancer.html)

Links can be found using ONS Online at [www.ons.org](http://www.ons.org).

## Rapid Recap

### Developing and Testing Lay Literature About Breast Cancer Screening for African American Women

- Lay literature on breast cancer screening for African American women with low literacy needs to be written at a third-grade or lower reading level, contain accurate information, and be culturally sensitive.
- Focus groups representing the target population can provide helpful information when developing educational materials.
- African American women participating in this project preferred to learn about breast self-examination (BSE) via photographs illustrating BSE rather than drawings of BSE techniques.
- An evidence-based approach to testing educational materials helps ensure that the materials developed will be readable, contain accurate information, and be relevant to the target population.



## Clinical Practice Guidelines & Outcomes Data in Oncology

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## Conference Agenda

**March 12, 6 p.m.—9 p.m.**

Conference Welcome Reception

**March 13, 8 a.m.—3 p.m.**

NCCN Guidelines Development Process

Update: Cervical Cancer Screening Guidelines

Update: Acute Myeloid Leukemia Guidelines

NCCN Oncology Outcomes Database

**March 14, 8 a.m.—3 p.m.**

Roundtable: FDA Approval Process — Meeting the Need for Promising Therapeutics for Patients with Serious and Life-Threatening Disease

Update: Colorectal Cancer Guidelines

Update: Cancer-Related Fatigue Guidelines

Update: Prostate Cancer Guidelines

Risk Assessment in Prostate Cancer

**March 15, 8 a.m.—3 p.m.**

Update: Gastric/Esophageal Cancer Guidelines

Management of Gastric Cancer: A Japanese Perspective

Applications of Oral Fluoropyrimidines in Colon Cancer: Their Role and New Directions

Reimbursement for Oral Chemotherapy

Update: Breast Cancer Guidelines

Management of Opioid-Induced Bowel Dysfunction

Quality Assurance in Cancer Care: A Managed Care Perspective

Collaboration in the Delivery of Breast Cancer Care Across Institutional Settings  
Oncology Business Update

**March 16, 8 a.m.—12 p.m.**

Update: Thyroid Carcinoma Guidelines

Implementation and Application of Anemia Clinical Practice Guidelines

Interactions between Alternative and Complementary Therapies and Conventional Therapies