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## Reaching hard to reach populations with hard to communicate messages: Efficacy of a Breast Health Research Champion Training Program

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## Abstract

A Breast Health Research Champion training program was developed targeting self-identified community breast health advocates from a predominantly African American community with a significant breast cancer mortality disparity. Twelve individuals completed the program that provided training in breast cancer risk and screening, breast cancer research, biospecimen in cancer research, and human research subject protection. The training emphasized four key messages to be disseminated to the community. Trainees hosted a minimum of two social chats with individuals from their social networks, and functioned as community researchers, acquiring consent and gathering follow-up data from attendees. Trainees reached 199 individuals from their social networks, and chats were diverse in the venue selected, mode of message transmission, and the audience reached. Post/pre questionnaire data from attendees at the *chats* showed significant improvement in knowledge, attitudes and intended behaviors as it relates to breast cancer screening, clinical research and biospecimen in research. Forty percent of attendees provided 4 week follow-up information. Of respondents eligible for mammography, 38% had taken action to be screened, and 86% of respondents had spoken about the information to someone else in their social network. Trainees expressed feelings of empowerment after completing the project, "feeling like the expert," and all trainees were surprised at the enthusiastic response from attendees of their

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chats. Trainees continued to disseminate the information learned from the training program during the six months following the training, reaching an additional 786 individuals in the community.

#### Keywords

Breast cancer disparity; Clinical research; Biospecimen; Training program; African American

## INTRODUCTION

Cancer research holds the key to continued progress in the prevention, early detection, treatment and control of cancer. The increased identification and use of genetic markers to evaluate cancer risk and treatment, and the potential of targeted drug therapies for cancer treatment have increased the importance of biospecimen in cancer research. Currently, fewer than 3% of cancer patients participate in clinical research and among these, racial/ethnic minorities are under-represented.[1,2,3] This underrepresentation of specific population groups in cancer trials results in the failure to capture differences in response to investigational agents and procedures within those groups, and limits the broad applicability of findings. Low cancer clinical research participation rates are a significant barrier to progress in cancer prevention, control, and treatment, particularly for under-represented population groups.

African Americans have the highest cancer mortality rates for the majority of cancers including breast cancer,[4] and they remain under-represented in cancer clinical trials.[5,6] To impact cancer outcomes in African Americans, equitable representation in cancer research is critical to ensure applicability of research findings. Studies of the barriers to clinical trial participation of African Americans show that lack of knowledge about cancer research and negative perceptions of clinical trials are significant barriers to participation. [7,8,9] Additionally, a historic mistrust of the health care system represents a distinct barrier to research participation.[10] Programs that target knowledge and perceptions may increase willingness to participate in cancer research. Utilizing trusted individuals from within the community to impart this knowledge may break down barriers of mistrust.

Community education and train the trainer programs providing education to community advocates and lay people are effective at increasing cancer knowledge of screening guidelines in various populations. [11,12,13] Programs adapted for specific populations, including African Americans, and using a train the trainer model have been shown to be effective in preparing lay educators to transmit cancer clinical trials information and effect change in research knowledge, attitudes, and behavior.[14,15] Training models based on social networking theory that prepare lay educators to transmit information about bio specimen in research have been less well studied.

Petersburg, the community of focus for this project is within the Crater Health District and has a population that is predominantly African-American (79%). The Crater Health district has the second highest cancer incidence and mortality rates in the State, and ranks 13<sup>th</sup> out of 35 health districts in breast cancer mortality. [16] Cancer is the second leading cause of death in Petersburg with a mortality rate of 244/100,000 (Virginia = 186/100,000). [17] We

conducted a breast cancer needs assessment of the community in 2010 to evaluate the contributing factors to the cancer disparity and identify assets within the community to address the issue. [18] A Community Health Educator dedicated to the area facilitated the assessment in partnership with a breast cancer coalition, Paint It Pink Petersburg (PIPP). PIPP is composed of key community organizations, breast cancer survivors, mammography centers, and non-profit organizations. Outcomes of the assessment included development of a culturally and locally relevant breast health education tool to disseminate positive breast cancer screening messages and local resource information. Additionally, a breast cancer support group was formed that became a significant resource for the current project.

The project reported here developed a Breast Health Research Champion (BHRC) training program targeting women from Petersburg. The program was designed to train selfidentified community breast health advocates to motivate women in their social circles to be screened for breast cancer, increase knowledge of cancer research and biospecimen collection, and influence future research participation and biospecimen donation. The model for transmission of health messages tested is unique, in that it trained individuals not only in breast cancer screening guidelines and breast cancer research, but also on a relatively unknown and misunderstood topic of bio specimen in research. In addition, this program provided training in human subject protection and required BHRC's to take the role of a researcher, acquiring consent and collecting data from attendees at their presentations.

We evaluated the training program for its impact on knowledge and attitudes of the trainees, the effectiveness of trainees in changing the knowledge, attitudes, and behaviors of attendees at their presentations, the variety of outreach methods used, and audiences reached by the trainees. The extent to which the trainees continued to disseminate information in the six months following the end of the project was catalogued.

## MATERIALS AND METHODS

#### Training program development and evaluation

The program was designed to train residents of Petersburg interested in promoting breast health and research in their community in four areas; best practices for breast cancer early detection, cancer clinical research, the role of biospecimen in cancer research, and human subject protection in research. Additionally, they were provided training in facilitation of an educational event. Participants agreed to conduct two "*chats*" with individuals within their social networks to impart the information learned during the training program. They were allowed to conduct their *chats* in a venue of their choice and no restriction was placed on the number of people at the event. The training program emphasized four key takeaway messages that were reinforced at the beginning and end of each session, and were designed to facilitate participant preparation for their own *chats*, (1) Early breast cancer detection saves lives – get screened, (2) Today's breast cancer treatment was yesterday's clinical trial, (3) Tomorrow's treatment comes from today's biospecimen donation, (4) You can help find the cure for breast cancer.

The four training sessions followed a similar format beginning with a review of information from the previous session, presentation of the takeaway message for the new topic area,

presentation of the information, a planning activity for incorporating the information in their *chats*, and a wrap up. Certain sessions had key components that were felt to be important to the training. An outline of key content is provided in Table 1.

The training program was facilitated by a Community Health Educator. Individuals with expertise in the topic area presented the information pertinent to each training session. A representative from Susan G Komen for the Cure provided the presentation for session one. A key component in this session was a presentation by a breast cancer research advocate active at the State and National level. Breast cancer risk factors and guidelines for breast cancer screening were presented. Session two covered information on cancer clinical trials. The presentation for this session was adapted from information in the NCI Understanding Clinical Trials series, [19] and was presented by the Minority Clinical Trial Recruitment Liaison from the academic cancer center. Key components in this session were a discussion of past abuses in clinical research and the current regulations for the protection of human subjects, as well as a video testimonial of a clinical trial participant of similar racial/ethnic background as trainees.

Session three on biospecimen in research was presented by a genetic counselor from the academic cancer center. The presentation included information on genetic determinants of cancer risk and the role of biospecimen acquisition in cancer research. A key component to this session was a tour of a biospecimen banking facility at the academic cancer center, and a conversation with a breast cancer researcher. A technician from the bio bank provided the tour and presented information on the process of tissue acquisition and storage, including patient consent. The fourth session was facilitated by the Community Health Educator, and covered human subject's protection in research. The information presented was patterned after the university's IRB approved course for community members engaged in research. Key to this session was ethical scenarios relevant to research presented in the form of role play. Trainees were provided with tips on planning their events and facilitating their *chats*.

Upon completion of the training sessions, the Breast Health Research Champions (BHRCs) were asked to schedule 2 *chats* with people from their social networks. BHRC's were required to get verbal consent from *chat* participants before each event, collect a survey from their participants, and call participants 4 weeks post-event to gather information about actions taken as a result of the presentation. A final meeting was held upon completion of the *chats* to present the BHRC's with a certificate of completion and celebrate their accomplishments. A discussion group about the BHRC's experiences and their recommendations for the training program was conducted.

#### **Breast Health Research Champion Recruitment**

The project was approved by the Virginia Commonwealth University Institutional Review Board prior to beginning any recruitment or research activities involving human subjects. Fifteen trainees for the Breast Health Research Champion training program were consented from the target community. Advertising through fliers, e-mail, and word of mouth targeted individuals who had been impacted by breast cancer either as a survivor, caregiver, or relative/friend of someone affected by breast cancer. Interested individuals were screened to assess their experience with breast cancer, previous activities in breast health advocacy, and

enthusiasm to become active in breast cancer research advocacy in their community. Those evaluated to have potential to be active advocates for breast health and research by the research team were consented for the study.

#### Training program evaluation and modification

Multiple methods were used to evaluate and modify the training program for improved effectiveness. A questionnaire was given before and after the clinical trials and biospecimen training sessions that evaluated knowledge and attitudes about the topics discussed. Questionnaires consisted of nine true and false knowledge questions and 6/7 attitudinal questions using a 5 point Likert scale. Questions addressed commonly held misconceptions about clinical research and biospecimen collection. Descriptive analysis of results from the pre/post questionnaires were evaluated after each session to identify areas in the training that should be enhanced to ensure appropriate transmission of message. A post-test correct response rate of < 85% for knowledge questions resulted in a modification of training material content, and the information was discussed at the beginning of the following training session to be sure of accurate understanding by trainees.

In addition to the questionnaires, detailed notes were taken during each training session. A debriefing session was held by the research team immediately after each session to review the events of the session and document impressions. Upon completion of the program and the *chats*, Breast Health Research Champions participated in a discussion group. Their perspectives on the training process, the impact of their role as disseminators on their knowledge and attitudes, and recommendations for improvement of the program were discussed. Written impressions about specific aspects of the program were solicited from the BHRCs at that time.

Notes from the training sessions and debriefings were reviewed and information related to key session component effectiveness, topic presentation content, and general training manual utilization collated. The research team reviewed the findings, and identified program areas requiring modification. This information was combined with BHRC recommendations provided during the final discussion group to make final program modifications.

#### Evaluation of BHRC message dissemination

The BHRC's impact on knowledge, attitudes, and behaviors of attendees at their *chats* was evaluated through a post/pre questionnaire. Additionally, BHRC's contacted all chat participants 4 weeks post-event to ask if they had talked to individuals in their social circle about the information, and if they had taken action to be screened for breast cancer, if applicable. To gather information about the BHRC's experience hosting the *chats* they were asked two questions after each event, "How did you feel giving the presentation," and "What are your general impressions of the event?" This information was collated by the research team, and evaluated for major themes.

The post/pre survey taken by attendees at BHRC *chats* were scored on a Likert scale ranging from 1 to 5. Questions targeted key information and common myths emphasized during the BHRC training sessions, and were developed using a combination of standardized questions

from the literature, questions used in established breast health training programs, and questions developed specifically for this program. [20] The questionnaire went through a review process by the research team. Subsequently, it was reviewed by the BHRC's for clarity, literacy level, and applicability and were modified according to their recommendations. Participants were asked to respond to items first as they typically would on a posttest, and then to reflect how they would have responded prior to the chat. This "Post-then-Pre" survey strategy has been proposed as a particularly appropriate assessment when the subject material is unfamiliar. [21] Participants responded to 11 items measuring knowledge, attitudes, and intended behaviors. Summed scales were considered to group items in each of these domains (knowledge, attitudes, and intended behaviors). However, Cronbach alpha was low (<0.60) for knowledge about clinical trials versus knowledge about breast cancer). Items measuring intended behaviors, however, were well correlated (Cronbach alpha = 0.80), so a summed scale was created to analyze those four behavior items. (Table 2)

Descriptive statistics were calculated for individual survey items and for the summed behavior scale. Changes in before- and after-chat responses were primarily assessed with paired t-tests. Our study design was complex in that *chats* were administered by 12 different BHRCs, and each BHRC conducted two sequential *chats*. To account for this study design, we also assessed before/after differences through mixed model regression with BHRC designated as a random variable. We included an interaction term in the models to see if the effect of the chat differed between the first and second *chats*. Statistical significance was determined with alpha=0.05.

## RESULTS

#### Results of the Breast Health Research Champion Training Program

Recruitment for the BHRC program resulted in 18 women being screened, 15 women consented and 12 who completed the training program and held two *chats*. Of the three women who did not complete the training, one had a reoccurrence of cancer during the training, one had health complications with stage four breast cancer, and the third woman was her daughter who left the study to support her mother.

Nine of the women completing the program were residents of Petersburg, VA with the remaining BHRC's living in neighboring communities. Ten of the BHRC's were African American women, one was Hispanic and one was Caucasian. Nine of the woman were breast cancer survivors with survival times ranging from 2 to over 25 years. Two had immediate family members impacted by breast cancer and one participant was interested in woman's health. The age of the participants varied with six between the ages of 35–55, four > 65 years of age and two under the age of 35. The four older women were active volunteers in their church, hospice facility and/or working part-time at a senior day center. Participants who worked were employed in public school systems, the university, in healthcare, public health or social services arenas. All the participants had volunteer roles in various settings including school systems, churches, sororities, and public health. Most of the women identified themselves as breast health advocates prior to participating in the program. Two

BHRC's had participated in a clinical trial and were avid supporters of research. The remaining women were still formulating opinions about clinical research.

#### Evaluation of the training sessions

Pre and post questionnaire analysis of the clinical trials training session showed that the session effectively transmitted information about the level of care and type of treatment received during a clinical trial, the positive experience of patients on clinical trials, and the percentage of adult cancer patients who participate in research. Post session knowledge was low for the topics of insurance coverage for clinical research and the frequency with which cancer patients are told about clinical research. Although knowledge clearly improved about the importance of minority participation in research, and the existence of regulations for the protection for research participants, correct responses did not reach 85%. Information provided in the training sessions about these topic areas were enhanced as a result. Mean Likert Scale values for attitudes about the importance of clinical trials, the role of the trainee in informing their community about research, and their motivation to transmit messages increased after the training for all questions. All means fell between "Agree" and "Strongly Agree" for the pre-test, reflecting the motivation of trainees for breast health advocacy.

Pre and post questionnaire analysis of the biospecimen training session showed that the session effectively transmitted information about what a bio bank is, who can donate, use and applicability of biospecimen research, and regulations protecting donors. Personal control of donated tissue, and tissue use for personal treatment decisions were areas that showed insufficient post-session knowledge. The training materials related to these two topics were modified to improve understanding. Unlike the clinical trials training session, in pre-test responses participants were generally neutral or less confident in their attitudes about and willingness to participate in bio banking, regulations protecting a donor, and their skills to transmit information about bio banking. Trainees showed noted improvement in these areas after the training session.

Qualitative information from training session notes and commentary from the trainees during the final discussion group informed modifications of the training program. The breast cancer research advocate testimonial at the beginning of the training program was identified as impactful. The information given by the Susan G. Komen representative was well received and the use of small prizes as incentives for participation in discussion was later used by the majority of the BHRCs during their *chats*. The Clinical trials presentation was considered effective and a time for discussion of past research abuses particularly important. Attendees related to the video of testimonials of people who had participated in research. Areas requiring modification included clarifying information on insurance coverage of clinical research. There was a noted attitude shift about clinical trials after the presentations, "My perspective has totally changed about clinical trials."

Key training components identified as having an impact for the biospecimen training session included meeting a breast cancer researcher and touring the Tissue Data Acquisition and Analysis Core (TDAAC). The level of knowledge of the trainees about tissue banking was minimal, and many had misconceptions about what tissue collection entails. The TDAAC tour was very impactful, with the visualization of the facility providing perspective on the

size and method of storage of tissues; "This (the stored samples) represents so many people."

The session on ethics in human research subject protection served to make concepts about clinical research and biospecimen collection tangible for the trainees. Ethics scenarios were discussed in small groups and Trainees related the information to what they would need to do during recruitment and consenting of participants in their *chats*. Trainees were engaged and took ownership during this session; "*I feel like I am empowered*," "You don't have to have been diagnosed with cancer to help find a cure," "I am excited about being a carrier of this message."

Information provided by the BHRCs during the final discussion group coincided with impressions during the training sessions. They indicated that the direct engagement with breast researchers and the tissue banking facility was an impactful component of the training program. In addition, the presentation by a person with a history of breast health advocacy as an example was important.

#### **Evaluation of BHRC message dissemination**

After completing the training sessions, BHRCs held two educational events in a venue and to an audience of their choosing. BHRC events were diverse in the venue selected, mode of message transmission, and the audience reached. Venues included BHRC's homes, places of employment, a senior center, a low income housing unit, a military base, a conference, church, and during family reunions. Two BHRCs held their *chats* using social media, a discussion board and via Skype, while a third approached patrons at a public coffee house. The audience was of all adult age ranges and included friends and family, colleagues, sorority sisters, strangers purposefully encountered at a coffee house, and housing residents. Individuals reached and the styles of presentation were as varied as the BHRC's, which is in line with social networking theory. These individuals were able to reach people from within their social circle, many of whom might not have been reached by traditional outreach methods. In total, 199 people attended the BHRC educational events, with attendance per event ranging from 1 to 26.

Evaluation of BHRC responses to the two questions after each chat showed that nine out of the twelve BHRC's were comfortable giving their first chat, with all feeling that their level of comfort increased during the second event. The three BHRC's who expressed initial nervousness did not have much speaking experience or held a position that did not require public speaking. The major themes coming from the second question fell into four categories, self-actualization, attendee response, unexpected outcomes, and future opportunities.

BHRC's expressed feelings of self-actualization after their events. Two BHRC's said that they felt empowered or like the "experts" by having the knowledge to provide the presentation. One BHRC expressed, "*I had no idea I could have this kind of impact.*" Another commented; "*I was excited and knew my stuff...*"

All of the BHRC's indicated positive attendee response with their audiences being very engaged at one or both of their events, often to their own surprise. "I had invited them to spend 45 minutes with me today, but we went an hour and I ended it at that point…however they wanted to go longer," "The attendees were extremely interested and actively involved in the discussions," "Awesome .... We had so much fun; we didn't realize what time it was when the session was over."

An unexpected outcome from the perspective of the BHRC's was that many received requests to give the presentations to other groups and organizations. In one case, a chat attendee's family member searched clinical trials related to throat cancer and was eligible to participate. The family now advocates for clinical research due to positive results of his participation. For another, the presentation stimulated open family conversation about cancer for the first time. In a third scenario the genuine interest of younger people that she presented to, and the extent of their questions was surprising. Finally, three BHRC's mentioned multiple questions about male breast cancer and they recommended that it be included in the BHRC training.

Results from the Post/Pre questionnaire showed significant increases in knowledge, attitudes, and intended behaviors for all items except two related to knowledge about breast cancer risk factors. No significant changes were found for level of agreement with "How old I am affects if I can get breast cancer or not," and "No one in my family has cancer so I won't get cancer." Statistical conclusions were the same for paired t-test and mixed model analyses. No interaction effect was found that would suggest a different impact between the first and second *chats*. (Table 2)

Seven BHRC's provided follow-up information from attendees at their chat events. Out of the 95 chat attendees for these BHRC's, 79 (83%) responded to the follow-up questions. 66 answered the question related to screening, and 78 responded to the question about their communication of information learned to others. Of women eligible to get a mammogram (N=66), 38% had taken action to get a mammogram. The majority (86.3%) indicated that they had spoken to someone in their social network about the information discussed during the chat. Ten of the BHRCs provided information about their outreach activities for the six months following the training. On average, the trainees held 6.1 (range 1 - 13) informal or formal events during the 6 month period, reaching a total of 786 individuals with the key messages. Age ranges reached were from 19 to > 65 years of age, of both genders, and of race/ethnicities primarily African American, but also including Caucasian Americans, and Hispanics. One BHRC developed an online program to disseminate the messages, and estimated that she reached over 6000 people.

#### DISCUSSION

This project successfully developed an effective Breast Health Research Champion training program for women interested in becoming advocates for breast cancer screening and research in their community. The program stemmed from an ongoing collaboration between the community and the academic cancer center. It is unique in that it provides training in the importance of biospecimen in cancer research and requires trainees to take on the role of a

researcher as a way of experientially impacting attitudes about research. Our findings indicate that the program increases knowledge and changes attitudes of trainees about cancer research and biospecimen collection, and increases their confidence to transmit key messages related to these topics to individuals in their social networks. All BHRC's successfully organized and conducted two social events, *chats*, to disseminate the key messages. There was strong evidence that they were effective at increasing cancer research and biospecimen knowledge and changing attitudes and behaviors of attendees of their *chats*. Over one third of attendees queried had taken action to get breast cancer screening, and the majority had spoken to someone else about the information learned. The BHRC's continued to reach out to individuals in their community in the six months after completion of the program.

The population this project reached, a predominantly African American community with high breast cancer mortality, has a history of distrust of the medical community. This mistrust can result in reduced participation in clinical research and biospecimen donation, as can a lack of knowledge [8, 9]. Using individuals from the community to provide accurate information about research and biospecimen in a manner that is culturally congruent is a strategy to address the mistrust barrier and affect a change in behavior. Breast Cancer Research Champions from the community were able to provide information on breast cancer screening, clinical research, and biospecimen donation through established cultural and social networks.

Challenges exist when using community members to develop effective training programs, particularly when they become the agents for data acquisition. Compliance with the 4 week follow-up by the BHRC's was low with 7 of the 12 BHRC's providing this follow-up data. Despite this, those who did provide the information had a good response rate (83%) from their attendees. The BHRC's themselves were enthusiastic about ongoing engagement with the academic cancer center for continuing education, with 83% of them attending regular educational events and providing follow-up data about their activities.

The theoretical framework upon which the intervention is based is the social network theory. This theory emphasizes the importance of social networks, i.e. formal and informal community organizations and individuals and the linkages that connect them. These networks can be instruments by which awareness of health behaviors can be raised, and provide opportunity for members to engage in healthy behavior.[22–24] Social network theory views social relationships in terms of individual actors within the networks, and the relationships between the actors. There are many possibilities for the types of connections between individuals. In its basic form a social network consist of all the relevant ties between individuals from work, to personal relationships, to online socializing. [25] The BHRC's utilized a broad range of social "ties" to disseminate the four key messages learned during the training and the attendees at their sessions continued to disseminate the message along their own social connections.

Components of the program that were identified as key to effective BHRC training included a presentation by a person actively engaged in breast health and research advocacy, an open discussion about past clinical research abuses, particularly with the African American

community, and testimonials by culturally congruent clinical trials participants. A physical tour of the tissue banking facility at the academic cancer center served to dispel misconceptions about the acquisition and storage process, as well as the fear some participants had about the process. Finally, the act of functioning as researchers, acquiring verbal consent from their participants, and collecting data to evaluate the program changed trainee's attitudes about research and researchers.

A limitation of our study is the lack of detailed data collection on the attendees at the BHRC's *chats*, and the individuals who they spoke to about the topic. Further detail on demographics, their role in the community, and their relation to the BHRC would allow analysis of the patterns of information dissemination. Additionally, the small number (12) of BHRC's that completed the training did not give us power to evaluate trainee pre/post questionnaire data for statistical significance. The information was used descriptively to evaluate trainee knowledge acquisition and attitude change, and was valuable for program modification, but could not provide the statistical validity. The program is being repeated in two additional locations, an urban center and a rural community, which will allow for validation of the current findings and evaluation of the applicability of the program in various settings.

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#### Table 1

#### Key Components of Breast Health Research Champion Training Session Content

| Training Session One: Best practices for breast cancer early detection | Breast cancer research advocate testimonial<br>Review of risk factors for breast cancer and guidelines for screening   |
|--|--|
| Training Session Two: Cancer clinical research                         | Discussion of past abuses of clinical research<br>Current regulations for the protection of research subjects<br>Video of clinical trial participant testimonial |
| Training Session Three: Bio specimen in cancer research                | Tour of tissue data acquisition and analysis core<br>Meeting with a breast cancer researcher<br>Review of role of genetics in research                           |
| Training Session Four: Human subject protection in research            | Role play of research ethics scenarios<br>Review of informed consent process for CHAT participants   |

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#### Table 2

#### Chat Participants' Knowledge, Attitudes, and Behaviors

| Questionnaire Item   | Before <sup>a</sup><br>M (SD) | After <sup>a</sup><br>M (SD) | Change <sup>a</sup><br>M (SD) | P-value <sup>b</sup> |
|--|-------------------------------|------------------------------|-------------------------------|----------------------|
| Knowledge and Attitude Items   |                               |                              |                               |                      |
| How old I am affects if I can get breast cancer or not.  | 2.8 (1.47)                    | 2.9 (1.65)                   | 0.1 (1.39)                    | 0.373                |
| No one in my family has cancer so I won't get cancer either.   | 4.3 (0.96)                    | 4.5 (1.00)                   | 0.2 (1.12)                    | 0.066                |
| When a person participates in a clinical trial they might not get any real treatment.                                | 3.4 (1.27)                    | 4.0 (1.30)                   | 0.6 (1.56)                    | < 0.001              |
| Most patients who participate in clinical trials said they felt like a guinea pig.                                   | 2.9 (1.16)                    | 3.6 (1.23)                   | 0.8 (1.55)                    | < 0.001              |
| Getting screened for breast cancer is a priority in my life.   | 4.0 (1.27)                    | 4.6 (0.79)                   | 0.6 (1.10)                    | < 0.001              |
| There are enough rules to protect people who participate in cancer research.   | 3.1 (1.17)                    | 3.8 (1.27)                   | 0.6 (1.25)                    | < 0.001              |
| Patients of all races with cancer should be included in research.  | 4.2 (1.12)                    | 4.6 (0.95)                   | 0.4 (1.07)                    | < 0.001              |
| Behavior Items <sup>C</sup>  |                               |                              |                               |                      |
| How likely are you to to follow the age appropriate breast cancer screening recommendations?                         | 4.1 (1.17)                    | 4.6 (0.80)                   | 0.5 (1.08)                    | < 0.001              |
| I would likely consider participating in a cancer research study.  | 2.8 (1.30)                    | 3.7 (1.12)                   | 0.9 (1.14)                    | < 0.001              |
| I would be likely to donate my blood or tissue to a research study to help to find ways to prevent and treat cancer. | 3.0 (1.4)                     | 3.8 (1.09)                   | 0.8 (1.22)                    | < 0.001              |
| I would likely talk to my friends and family about preventing cancer and cancer research trials.                     | 3.6 (1.32)                    | 4.4 (0.90)                   | 0.8 (1.30)                    | < 0.001              |
| Summed Behavior Scale <sup>C</sup>   | 13.6 (4.13)                   | 16.5 (2.81)                  | 2.9 (3.60)                    | <0.001               |

 $^{a}$ Scores range from 1 to 5. Higher scores reflect greater knowledge, more favorable attitudes, and greater intentions to participate in screening and research

<sup>b</sup>Results of paired t-tests

<sup>C</sup>Scale represents summed score for each subscale item.