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Community Empowerment Partners (CEPs): A breast health education program for African-American women

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Abstract

Introduction—Peer educators have been shown to provide effective interventions in breast cancer screening. Few studies have compared the effects of peer education on breast cancer knowledge among peer educators and the community members who are subsequently reached through the peer education. Further, little is known as to whether those who received the education then go on to educate others in the community. The purpose of this study is to address those gaps.

Methods—Using a pre- and post-test study design, we trained peer educators, provided the educators with resources to train community members, and assessed changes in knowledge. We sought to train 10 educators and recommended each train 10 community members in breast cancer knowledge and screening strategies.

Results—A total of 14 peer educators were trained, who subsequently trained a total of 121 community members, of whom 94 were African American women. Peer educators and community members, showed comparable increases in knowledge. Community members who were educated also increased intention to discuss breast cancer and breast cancer screening with their family, friends, and acquaintances.

Conclusions—Our study suggests that it is feasible to train peer educators to increase knowledge among community members to the same level that they themselves experience when trained. Further, community members are interested in sharing information learned related to how much they learn from peer educators.

Keywords

peer educators; lay health advisors; social engagement; breast cancer education; breast cancer screening; cancer education; African-Americans; mammography

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INTRODUCTION

In 2016, the American Cancer Society estimated that 246,660 women in the United States (US) would be diagnosed with breast cancer; among women, it is the leading cause of cancer incidence, and the second leading cause of cancer death.(1) The US Preventive Services Task Force recommends biennial mammography for the early detection of breast cancer among women aged 50–74; evidence supports that mammography screening can detect breast cancer in its earliest stages, which reduces breast cancer mortality rates.(2) In the US, there has been a 36% decrease in breast cancer mortality between 1989 and 2012.(3) Not every woman has benefited, however.(4) From 2008–2012, there were 31.0 deaths per 100,000 among African American women compared to 21.0 deaths per 100,000 among non-Hispanic White (NHW) women.(3) The nationwide survival rates for regional stage and distant breast cancer are 74.6% and 16.4% in African American women compared with 86% and 26.2% for NHW women.(5)

Biological, individual, and societal-level factors contribute to breast cancer disparities in the US. Relative to their NHW counterparts, African American women are likely to have more aggressive breast cancer subtypes, which influence stage at diagnosis and survival.(6, 7) African Americans have less access and lower adherence to guideline-concordant breast cancer screening and diagnostic care (8, 9) due to multiple barriers, including lack of insurance, medical mistrust and experiences with racial discrimination.(6, 10–12) Finally, societal injustice, concentrated poverty, and cultural norms also impact breast cancer disparities between African American and NHW women.(13–15)

Since the 1970s, the training of respected and trusted community members to serve as peer educators in health interventions has gained traction in the US.(16–18) A common thread through these interventions is that, as community members, peer educators are likely to share the same cultural, ethnic, and socioeconomic characteristics as the community being reached, and therefore have the ability to serve as “cultural brokers”.(16, 17) Interventions using peer educators may thus offer an opportunity to provide culturally relevant community-based education, navigation, resources and social support to enhance healthcare experiences - particularly for communities where health disparities exist.(17, 19)

Interventions using peer educators have been effective tools for increasing health knowledge and encouraging behavior change (20, 21), including the promotion of breast health in underserved populations such as African American women.(16–18, 22–27) In the African American community, women may often seek health-related advice from female friends and relatives when dealing with health problems such as breast cancer. The visibility of women as role models for self-care and self-efficacy is important and contributes to the effectiveness of peer educator programs.(28, 29) Trained peer educators are able to deliver information to address unique individual-level barriers, including a lack of knowledge about biological risk factors (e.g., aggressive cancer subtypes) and long-term fears regarding the medical system (e.g., due to the Tuskegee tragedy).(11, 30) Peer educators who engage community members in learning also can foster the empowerment of community members who can then, in turn become motivated to serve as peer educators themselves. In this way, the knowledge they learn can be spread throughout their own social networks. In the long term, this interpersonal

contact could support the diffusion of information through social network engagement. Changes in knowledge could drive changes in beliefs, social norms, and promote adoption of health behaviors through promoting individual and collective agency.(31, 32)

A growing body of literature has evaluated the potential of peer education to eliminate breast cancer disparities among African American women.(22, 25, 26) Research has focused on either the feasibility or sustainability of peer education programs (33–35) or the effect on recipients of the peer education intervention.(25, 27, 36) We are not, however, aware of any study with the African American community that has assessed changes in knowledge among the peer educators and their advisee audience simultaneously. Such data are necessary to assess if the *amount* of knowledge gained by peer educators is comparable to the *amount* of knowledge that is retained by the individuals they educate. Research on diffusion of knowledge suggests that the amount of information transmitted may be attenuated with each cycle. Given this, peer educators may be acceptable sources of knowledge, but may not transmit as much information as they learn, requiring booster sessions.

We also are not aware of studies that have assessed how receiving education from a peer educator results in community participants becoming motivated to educate others about breast cancer. Theoretically, this ‘diffusion’ effect likely would be due to changes in community participants’ knowledge and awareness of breast cancer, leading them to take on the topic as a priority for their community.(37) That relationship has not been well-tested, and such data are important to understand how peer education may change community-level knowledge, norms, and practices via social networks.(38, 39)

This study addressed these gaps through a community-academic partnership, as depicted in Figure 1. The four objectives began with an examination of a peer educator intervention; in short, would it be effective in increasing breast cancer knowledge among African American peer educators (“CEPs”) themselves? Secondly, would the intervention increase knowledge among African American peers receiving the information (“workshop participants”)? Our third objective was to examine if workshop participants intended to share information they learned from peer educators; and, if so, which individuals did they intend to share the information with? Finally, we examined if an increase in knowledge among the workshop participants was associated with their intention to talk about breast cancer with their family and friends.

METHODS

Setting

This study was conducted in the greater Seattle, WA area. This area has a relatively small African American population – approximately 6.5% in the greater Seattle, WA area compared to 12.6% in the US overall.(40) Nonetheless, breast cancer disparities in greater Seattle are similar to national disparities. African American women have higher breast cancer mortality rates (28.1) compared to NHW women (20.7) in Washington State.(41) In addition, 32% of diagnoses for African American women are at a regional or distant stage compared to 25% of diagnoses for white women.(41)

The intervention was implemented by Cierra Sisters, Incorporated (Cierra Sisters) with support from Fred Hutchinson Cancer Research Center (FHCRC), a National Cancer Institute-designated comprehensive cancer center. Cierra Sisters is a community-based non-profit breast cancer education and support organization that has served African American women in the greater Seattle area for over 20 years. Its founder, Bridgette Hempstead (BH), is a graduate of the Harold P. Freeman Patient Navigation Institute and has been actively engaged in patient education and advocacy for nearly two decades. In her years with Cierra Sisters, BH has worked with members of the African American community and trained them to become breast cancer and healthcare advocates. This intervention and its evaluation thus stems from a program developed by African American women for African American women.

This research involved human participants. All procedures and instruments were reviewed and approved by the FHCRC Institutional Review Board (File #7291). All participants, peer educators and community members, were consented in writing prior to participating.

Phase 1: Peer educators-Community Empowerment Partners (CEPs)

Recruitment—The initial part of the study required the training of African American women to become peer educators for other members of their community. These peer educators, called Community Empowerment Partners (CEPs), were recruited by the Cierra Sisters director (BH), who followed up with past Cierra Sisters' volunteers who had expressed interest in doing more dedicated educational outreach in the community. At the study onset, it was planned to recruit at least ten women to become CEPs. To participate, women had to be African American and commit to attending a one-day training workshop; subsequently, each trained CEP was asked to conduct at least two community breast cancer education workshops reaching a minimum of 10 community members each. CEPs attended human subjects training and were required to maintain documentation of the peer trainings they completed, including informed consent and pre- and post- surveys from participants.

Training and assessment—The CEPs participated in a one-day (6 hour) training workshop at FHCRC in June of 2015. CEPs were consented and completed a baseline assessment at the beginning of the training. FHCRC health professionals then provided a comprehensive training, which included an overview of breast cancer, discussed the importance and implications of early detection of breast cancer, and debunked myths about mammogram screening and breast cancer. In addition, information on resources for cancer screening, social and financial resources for women in breast cancer treatment, and strategies for enhanced patient-provider communication were provided during the training. The Cierra Sisters director (BH) provided a presentation on how to provide peer education and support, and went over the CEP Toolkit. This toolkit included an educational flipchart which CEPs would use to provide breast cancer education, handouts of the flipchart for participants, a postcard with questions women could use to ask their doctor about breast cancer, and a county community resource list that CEPs could use to provide referrals to women who requested information about health insurance, sites and clinics for screening, financial assistance, counseling, housing, and childcare. FHCRC staff provided an overview of the workshop's pre/post assessments and taught CEPs how to log details about the

workshop sessions they would facilitate. At the completion of the training, CEPs completed a post-intervention assessment based on the FHCRC training. CEPs were given a modest meal and a small stipend (\$75 gift card) to compensate them for their time and effort. Each CEP was given a tote bag containing all the materials to be used for the two community workshops she was expected to conduct, including pre-printed and numbered packets to administer consent and pre/post assessments. Subsequently, BH was available on a one-to-one basis to provide support, such as role playing, as needed, to CEPs. If needed, she was also available to support CEPs during their community workshops.

Phase 2: Community members – Workshop participants

Recruitment—CEPs recruited workshop participants by distributing flyers at local venues, such as community centers, churches, and local shops. Community education workshops were held between July and November 2015 at two community venues and in CEPs' homes. In order to participate in a community education workshop, women had to live in Pierce or King County, Washington and be 18 years of age or older.

Training and assessment—CEPs recruited community participants and used the CEP toolkit in facilitating the breast cancer education community workshops in the greater Seattle area. Participants in the community workshops were consented and completed a baseline assessment at the beginning of the workshop. The CEP then used the Toolkit to provide education. She covered breast cancer early detection, myths about mammogram screening and breast cancer, resources for cancer screening, social and financial resources for women in breast cancer treatment, and strategies for enhanced patient-provider communication. At the completion of the educational workshop, participants completed a post-intervention assessment. Participants in the workshop also were given a resource booklet, a postcard with questions to ask their doctors about treatment and test results, a meal and a \$5 gift card as an incentive. Workshops ranged from about 60 to 90 minutes, depending on how many questions and discussion participants generated.

Assessment Technology and Measures

Study data at baseline and post-intervention assessments were managed with REDCap electronic data capture tools hosted at FHCRC.(42) REDCap (Research Electronic Data Capture) is a secure, web-based application designed to support data capture for research studies, providing 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources.

Demographic, healthcare and breast cancer-related factors—During the baseline assessment, CEPs and workshop participants answered questions concerning age, years of educational attainment, insurance status, lifetime history of discussing breast cancer with family or friends (yes/no), comfort level in discussing mammograms and breast health with provider (very comfortable, comfortable, somewhat comfortable, not comfortable), lifetime history of breast cancer screening (mammography or clinical breast exam), and lifetime receipt of a breast cancer diagnosis (yes/no). Based on preliminary assessment of frequency

distributions, we reclassified insurance status to be private healthcare insurance (yes/no) as very few of the workshop participants had public health insurance.

Knowledge—At baseline and post-intervention assessments, CEPs and community workshop participants answered an index of 10 statements/questions concerning breast cancer etiology and breast cancer screening. Sample items include “Breast cancer is more common in 64-year old women than in 40 year old women” and “For some women, being overweight increases their risk of developing breast cancer.” Response categories were “agree” or “disagree” for all questions except for one (“At what age do you think women should start having a mammogram?”). For that particular continuous question, we classified answers as correct or incorrect based on American Cancer Society and US Preventive Services Taskforce screening guidelines at the inception of the study (1 = 40 or 50 years old; 0 = all other answers). This survey has been previously validated with Hispanic/Latina women.(43) Items were summed, resulting in an actual range of 0–10 for pre-test and post-test scores. We then created a change variable to assess the magnitude of pre-post change in knowledge through the difference of post- and pre-test scores (Actual Range: –10 to 10).

Post-intervention intention to discuss information with family and friends—After participating in the intervention, community workshop participants answered an index of three statements, regarding whether they intended to discuss breast cancer screening with family, friends, and acquaintances in the future. This survey has been previously validated with Hispanic/Latina women.(43) Items were summed, resulting in an actual range of 0–3 for pre-test and post-test scores. Given preliminary review of the frequency distribution (see below), we reclassified social engagement intention to be intention to discuss breast cancer screening with family, friends, and acquaintances (yes/no).

Analysis

Analyses were performed using IBM SPSS 19.0. For all analyses, we first examined the distribution of knowledge using histograms and QQ-plots. To identify covariates, we assessed relationships of any demographic, healthcare, and breast cancer-related variables with changes in knowledge among CEPs and workshop participants. We also assessed if CEPs’ demographic, healthcare, and breast cancer-related variables were associated with changes in workshop participants’ knowledge. Next, we addressed our first objective, which was to determine if the training of African American women to become peer educators (CEPs) increased their breast cancer knowledge. Secondly, we examined if participation in a workshop increased breast cancer knowledge among workshop participants. For each group, we conducted a Generalized Estimating Equations (GEE) model. For each analysis, we included the pre-test and post-test knowledge scores as outcome variables. Predictors included: time (pre- to post-test) and identified covariates. To make final model decisions about variable distribution and correlation structure, we examined the relative quasi-likelihood information criteria (QIC) model fit among GEE using varying assumptions (44). The best fitting models defined both knowledge and social engagement likelihood as having a Poisson loglinear distribution and assumed an exchangeable correlation structure. Preliminary analyses suggested variation in cluster size was not random; thus, we included peer educator identity as a fixed effect. Our next objective was to examine if changes in

knowledge predicted post-intervention social engagement intention among community workshop participants. We conducted a multivariable logistic regression model. The outcome was the dichotomized post-intervention social engagement intention variable. Predictors included the change variables (post-pre test scores for knowledge) and previously identified covariates.

RESULTS

We anticipated training 10 women as peer educators; four additional women participated, yielding a total of 14 women who were fully trained as Community Empowerment Partners (CEPs). The CEPs were then expected to train an additional 10 community participants each. A total of 121 women from the community were trained, yielding an average of 8.6 trainees per CEP. Of the 121 workshop participants, 94 self-identified as African American. Given the study's focus on African American breast health, only those 94 workshop participants were included in the analytic sample. We had less than 5% missing data among African American CEPs and community workshop participants. Given this, we used pairwise deletion techniques.

Table 1 provides study sample characteristics. Among the CEPs, most were over 40 years old (84.6%), had obtained more than a high school degree (100%), had private healthcare insurance (71.4%), had obtained breast cancer screening in their lifetime (78.6%), and had talked to family and friends prior to the intervention about breast cancer screening (92.9%). A little more than half of these CEPs were breast cancer survivors (57%). The average number of workshop participants they reached after their training was 8.64. Among the workshop participants, most were 40 years or older (69.1%), had more than a high school education (78.7%), had obtained breast cancer screening in their lifetime (77.7%), and had talked to family and friends prior to the intervention about breast cancer screening (69.1%). Relative to CEPs, community workshops were less likely to be breast cancer survivors (5.3%) and to have private healthcare insurance (53.2%).

We next conducted bivariate analyses to identify covariates. Among CEPs, there were non-significant associations between change in knowledge and private healthcare insurance status and lifetime receipt of breast cancer screening ($p = .09$ for both). Although workshop participants' demographic, healthcare, and breast cancer-related variables were not significantly associated with changes in knowledge among workshop participants, CEPs' private healthcare insurance status was associated with changes in knowledge among the community partners ($p < .0001$). Given these findings, all analyses included private healthcare insurance status and lifetime receipt of breast cancer screening. Further, for workshop participants, CEPs' private healthcare insurance status was included as a covariate, in addition to peer educator identity.

Changes in knowledge among CEPs and workshop participants

Pre and post knowledge scores across the different groups as well as regression coefficients and 95% confidence intervals are found in Table 2. Both CEPs and workshop participants experienced a significant increase in knowledge about breast cancer and breast cancer screening, after adjusting for covariates.

Intention to share information learned among workshop participants

During post-intervention assessments, the majority of workshop participants indicated that they intended to discuss breast cancer screening with people within their network. Approximately 88% (n= 83) indicated they would talk to family about breast cancer screenings, 89% (n = 84) indicated they would talk to friends about breast cancer screenings, and 82% (n=77) indicated they would talk to acquaintances among mammograms for breast cancer screening. Overall, 78% of community workshop participants (n=74) indicated that they intended to discuss breast cancer screening with their family, friends, and acquaintances.

Knowledge and social engagement intention among community workshop participants

Finally, we conducted a multivariable logistic regression model, adjusting for workshop participants' private healthcare insurance status and lifetime receipt of breast cancer screening as well as CEPs' identity and private healthcare insurance status. Change in knowledge was associated with significantly greater odds of intending to talk about breast cancer screening with family, friends, and acquaintances, OR = 1.75, 95%CI [1.25, 2.46], p = .001.

DISCUSSION

Overall, our study adds to a growing body of literature concerning the potential of peer education to address the disproportionate burden of breast cancer faced by African American women. Similar to other studies (17, 33, 35, 45), our project indicated that it is possible to recruit, train, and enable African American women to serve as peer educators. This pilot project had a greater reach than expected supporting premises that peer educator models may be particularly appealing and feasible for African Americans. First, we aimed to recruit 10 CEPs; subsequently, as word of mouth spread about this leadership opportunity, a total of 14 CEPs were recruited and trained. Second, in less than four months, CEPs reached 121 community participants, including 94 African American women.

We confirmed a train-the-trainer model worked for increasing knowledge about breast cancer and breast cancer screening among both peer educators (CEPs) and community members they taught (workshop participants). Previous research (25) suggests that both peer educators and community members they taught would have some level of increase in breast cancer knowledge. This may particularly have been the case for peer educators, half of whom were breast cancer survivors. Less expected was the comparable amount of increased knowledge between peer educators and the community members they taught. Such pilot data are interesting, given ripple effects. In this case the level of knowledge transferred was theorized to attenuate; however, we found that resulting increases in knowledge were comparable. Such data add to a growing body of work that indicated that peer educators are not only acceptable, but also effective at comparable levels as the health professionals who train them.

This study also found that women attending the workshops were likely to talk with others about breast cancer. Most workshop participants indicated that they intended to disseminate

information learned about breast cancer to their family, friends, and acquaintances. They were, in particular, willing to share the information with family and friends. Similar findings have been found with a Hispanic/Latina rural population (43).

Interestingly, workshop participants' interest in disseminating information was directly associated with changes in knowledge about breast cancer and breast cancer screening. That is, intention to disseminate information to family, friends, and acquaintances was associated with greater changes in knowledge, suggesting that knowledge equips and empowers African American women to shift from "information recipient" to "advisor." Such work aligns with Freire's Theory of Education as empowerment (46) and supports growing interests in popular opinion leader network interventions (38, 39).

Limitations

This study has some limitations. One limitation is the small sample size. Another limitation is that it was not a randomized control trial and there was no follow-up. Pre/post-tests helped measure changes in knowledge and social engagement intention, but is not an indicator of participants' ability to retain the information, or participants' actual behaviors with regard to social engagement or mammography screening. In addition, the amount of knowledge transfer has the potential to be tied to accountability measures for the CEPs (gathering informed consent, reporting on community workshop implementation, administering pre/post tests, and receipt of financial incentive).

Although this study has documented changes in knowledge and potential for community-wide dissemination, future work could explore the fidelity of knowledge transfer at different time intervals after the training. Future work could also study reasons why increases in knowledge influenced social engagement intention. For example, did peer education using evidence-based information dispel myths and uncertainties about breast cancer among community members? Further, future research could explore changes in breast cancer-related communication and actions that may result from such peer education models. For example, it would be beneficial to explore how a peer educator may influence mammography screening among the women she reaches. Such work is an important next step toward documenting the role of such programs in influencing long-term behavior change to decrease breast cancer health disparities for the African American community in the greater Seattle area through community empowerment.

CONCLUSION

In summary, this study demonstrated that lay African American women can be trained to deliver breast cancer information as peer educators and they could be empowered to go out and teach what they had learned to other African American women. In doing so, they were able to increase knowledge about breast cancer, and the women who were trained were willing and able, in turn, to share the knowledge they had gained with family and friends. This study contributes to the literature recognizing the use of peer educators as a behavior change strategy. Using peer educators is a culturally relevant and effective way to reach African American women with breast cancer information in efforts to increase mammography screening knowledge to address breast cancer disparities. Further, our study

indicates peer education programs are sustainable outreach and should be integrated into health care practice. Peer education programs are important in addressing social and cultural barriers to breast cancer screening among African American women, and should be coordinated with efforts that influence public policy to address systemic barriers that affect access to care. If effective, a sustainable model for the development of peer educators, such as insurance reimbursement for their services, should be explored as a way to integrate them into health care practice.

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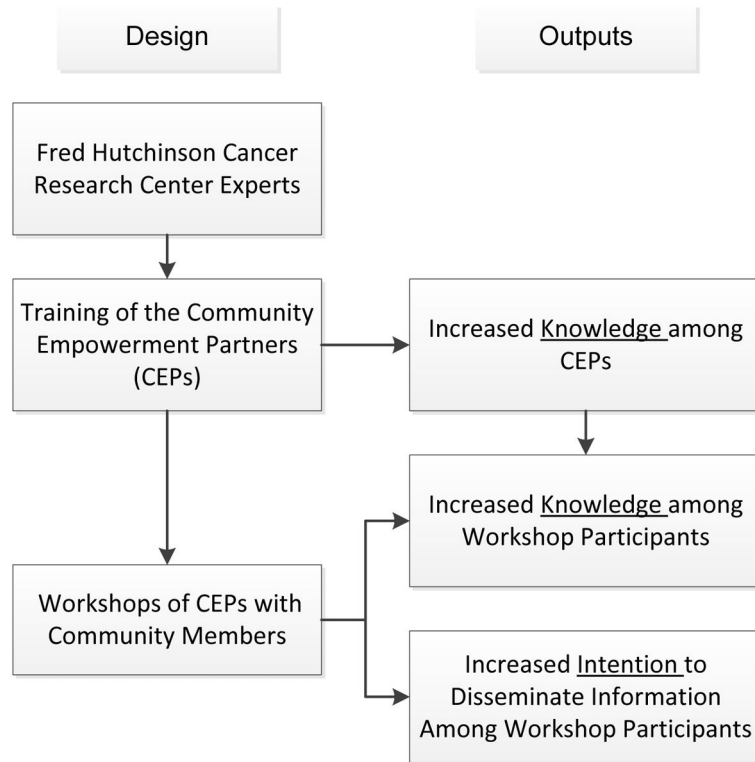


Figure 1.
Schematic of the Design and Outputs

Table 1

Study sample characteristics. *

	CEPs (n = 14)	Workshop Participants (n = 94)
	N (%)	N (%)
Age		
<40 years old	2 (15.4)	25 (26.6)
40 years old	11 (84.6)	65 (69.1)
Education		
High school	0 (0)	18 (19.1)
>High school	14 (100.0)	74 (78.7)
Private healthcare insurance		
Yes	10 (71.4)	44 (46.8)
No	4 (28.6)	50 (53.2)
Lifetime breast cancer screening		
Yes	11 (78.6)	73 (77.7)
No	2 (14.3)	19 (20.2)
Talked to family/friends about breast cancer screening pre-intervention		
Yes	13 (92.9)	65 (69.1)
No	1 (7.1)	29 (30.9)
Previous breast cancer diagnosis		
Yes	8 (57.1)	5 (5.3)
No	6 (42.9)	88 (93.6)
	M (SD)	M (SD)
Number of community participants	6.64 (7.83)	--

* Numbers are based on complete responses.

Models assessing intervention-based changes in breast cancer and breast cancer screening knowledge, after adjusting for covariates.

Table 2

	Pre		Post		N	Intercept	Estimate	95%CI	p-value
	M (SE)	M (SE)	M (SE)	M (SE)					
CEPs ¹	6.25 (0.29)	7.50 (0.45)	7.50 (0.45)	7.50 (0.45)	13	2.06	-0.18	-0.31, -0.06	0.005
Workshop Participants ^{1,2}	6.40 (0.15)	7.38 (0.15)	7.38 (0.15)	7.38 (0.15)	92	7.39	-0.70	-1.09, -0.30	0.001

¹ Adjusted for individuals' private healthcare insurance status and lifetime receipt of breast cancer screening.

² Adjusted for CEPs' identity and private healthcare insurance status.