

EMPOWERING FACTORS FOR REGULAR MAMMOGRAPHY SCREENING IN UNDER-SERVED POPULATIONS: PILOT SURVEY RESULTS IN TENNESSEE

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Background: Mammography screening can reduce breast cancer burden, however it continues to be underutilized by low-income women even though their health insurance provides free mammograms. While a vast majority of eligible women in Tennessee do not receive the free mammograms available to them, 25% of women with comparable backgrounds do.

Objective: To describe the influences that may have led these women to adhere to mammography screening guidelines in order to develop a case-control study for further research.

Design: Healthcare workers conducted personal interviews on mammography knowledge, attitudes, and behaviors.

Setting: In-home.

Participants: All were members of the Managed Care Organization Access MedPlus with incomes <200% above poverty. All were adherent to mammography guidelines per medical records. Fifty-eight respondents were Black, 27 were White, and all were at least 40 years old.

Results: Participants recognized breast cancer risk factors, warning signs, and the importance of early detection to survival. 75% reported a family history of any cancer type, 77% knew someone who had breast cancer, and 52% knew someone who had died from it. These women expressed that screening strongly reassured them. Willing to work with their doctors, they trust the health system's ability to treat breast cancer and are generally satisfied with their health care.

Conclusions: Repeat regular mammography screening is positively associated with higher knowledge about risk factors, warning signs, screening, and treatment. Trust in the health-care system, ability to work with physicians, and support by family and friends lead low-income, adhering women to be proactive in seeking mammography screenings. (*Ethn Dis.* 2005;15:387-394)

Key Words: Breast Cancer, Empowering Factors, Mammography, Patient Compliance, Under-served

INTRODUCTION

The present paper describes the profile of under-served women who are adherent to repeat mammography screening guidelines. The findings are drawn from the analysis of results from an empowering factors pilot survey that followed qualitative research conducted within the same population and provided direction for a hypothesis-driven, statewide survey currently in progress.

Approximately 40,000 women will die of breast cancer in 2004/2005, making it the second-leading cause of cancer death among women in the United States.¹ One in every eight American women will develop the disease during her lifetime.² The death rate from breast cancer could be decreased significantly through regular mammography screening for early detection and subsequent treatment.³ Although some research has questioned the value of mammography screening,⁴ most well-designed clinical studies support the benefit of mammography use,⁵ and nearly all North American health organizations recommend regular mammography screening for women 40 years of age and older.

Despite numerous research and intervention efforts,⁶⁻¹¹ all groups of eligible women, and especially low-income, minority, and elderly women, un-

derutilize mammography screening¹² with estimates that the rate could be as low as 21% for under-served populations.¹³ While the *Healthy People 2010* mammography screening objective (70% overall adherence) had nearly been achieved in 2000 for Black and White women, with 68% and 71% adherence,³ respectively, much work remains to be done for the poor (55%) and undereducated (57%) of all races.¹⁴ Studies have found that approximately 20% of eligible women adhere to screening guidelines during a contiguous two- or three-year period,¹⁵⁻¹⁹ and though research shows that 19% had received four mammograms in five years, <1% received five in that time period.²⁰⁻²²

Efforts to improve mammography rates have had varying degrees of success, but they have not appropriately addressed the actual needs of target groups, particularly in under-served populations.²³ Although lack of insurance was believed to be the most common obstacle, recent changes in health-care insurance options have effectively removed this barrier. These changes, however, have had little effect on screening mammography rates. Most low-income women of the recommended age bracket do not seek free mammograms.²⁴ However, a small group of low-income women, accounting for slightly more than 25%, have obtained regular mammograms or adhere to screening recommendations. Although multiple studies, indeed most social health studies, have examined why certain populations fail to practice healthy behaviors,^{23,25-27} little attention has been paid to how some women, such as the 25% mentioned above, are successful, despite

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barriers to getting regular mammograms.

The present study has its theoretical roots in “positive deviance” research,^{28–30} which focuses emphasis upon populations that deviate positively from an expected norm. In health research, these populations adhere to healthy behaviors, though they exist within sociodemographic groups that are generally non-compliant, predominantly the poor and under-served. We conducted in-depth focus group discussions with under-served women adherent to repeat mammography and gathered information about their facilitating factors in overcoming barriers to regular mammography screening. Guided by the results of this focus group study, published elsewhere,³¹ we developed a questionnaire by incorporating the focus group findings and choosing aspects from the Health Belief Model³² and Precede-Proceed Model^{32,33} as appropriate to form a theoretical basis for exploring what factors empower these under-served women to be successful in their health-seeking behaviors, including mammography screening. This refined questionnaire was administered in a pilot survey of 85 under-served women, all members of the Managed Care Operation (MCO) Access Med Plus, whose records indicated adherence to mammography screening guidelines.

Table 1. Demographic, health, and family history of cancer characteristics by race (%)

Demographics	White n = 27	Black n = 58	Total N = 85*
Education (mean ± SD)	10.8 (2.6)	9.7 (5.1)	
No formal education	18.5	3.4	8.2
Less than high school	29.6	43.0	38.9
High school	29.6	44.8	40.0
More than high school	22.2	8.5	13.0
Income			
≤\$10,200	14.3	21.6	19.4
\$10,201–\$15,600	57.1	62.7	61.1
≥\$15,601	28.5	15.7	19.4
Employment status			
Unemployed	63.0	63.8	63.5
Employed part-time	18.5	15.5	16.4
Employed full-time	18.5	20.6	20.0
Marital status			
Married	59.3	17.5	31.0
Single (never married)	7.4	19.3	15.5
Divorced	18.5	29.8	26.2
Legally separated	0.0	14.0	9.5
Widowed	14.8	19.3	17.9

* Percentages calculated from variability of response rate, not total N.

METHODS

Participants

The empowerment factors study targets under-served, low-income women who were members of the TennCare program, the State of Tennessee’s health-care finance reform program that superseded Medicaid in 1994. TennCare members include women and families up to 200% above the poverty level. For example, a maximum annual income of \$36,200 makes a family of four eligible for membership benefits.³⁴ Uninsurable individuals are eligible to buy into the program as well. For the pilot survey, we selected women from the target populations who satisfied all the following criteria: 1) age 40 and above and enrolled in the TennCare program; 2) members of the Access MedPlus managed care organization that managed portions of Medicaid benefits through Tennessee’s TennCare program; 3) adherent to screening mammography guidelines for four years prior to the study according to TennCare mammo-

gram claims data; and 4) residents of the state of Tennessee.

Questionnaire

In order to conduct a quantitative study on our target population, we developed a questionnaire based on the results of the focus group discussions from the qualitative study^{31,35} and incorporated questions from the Cancer Supplement of the National Health Interview Survey and Behavioral Risk Factors Surveillance Survey. Questionnaire components included sociodemographics, cancer awareness, knowledge of risk factors, health-seeking behaviors/practices, barriers, empowering factors, and open-ended descriptions of how respondents overcame difficulties in getting regular mammograms.

Interview Process

Permission for gathering patient information was obtained from the TennCare Bureau, Medical Director and Health Services Committee of Access MedPlus, as well as from the Meharry

Table 2. Healthcare access, utilization, satisfaction and health risk characteristics (%)

	White n = 27	Black n = 58	Total N = 85†
I have a regular healthcare provider	100.0	94.8	96.5
Usual place of care‡:			
Doctor's office	88.9	81.0	83.5
Doctor's office and emergency room	7.4	22.5	17.7
Emergency room only	3.7	3.4	3.5
Preventive screening			
Regular check-up	76.9	86.0	83.1
Blood pressure	100.0	100.0	100.0
Blood sugar	85.2	77.6	80.0
Cholesterol	77.8	74.1	75.3
Pap smear	69.2	84.2	79.5
Eye exam	81.5	84.5	83.5
Dental exam	55.6	47.4	50.0
Hearing exam	22.2	22.8	22.6
Rectal exam	53.8	57.1	56.4
I am satisfied with the service	96.3	87.7	90.5
Doctor interested in my health§	61.5	76.5	71.4
Doctor answers my questions	46.2	66.7	59.7
Doctor listens	69.2	74.5	72.7
I am respected by the doctor and staff	53.8	60.8	58.4
It is easy to get an appointment	34.6	58.8*	50.6
Doctors take their time when explaining medical procedures	84.6	85.9	85.5
The location of my last mammogram was convenient	88.9	94.8	92.9
I feel better that my mammography records are kept in one place	100.0	96.6	97.6
Overweight	73.1	63.8	66.7
Interest or participation in weight loss program	40.7	53.4	49.4
Exercises regularly	37.0	41.4	40.0
Interest or participation in exercise program	33.3	55.2	48.2
Current smoker/tobacco user	56.3	45.9	49.1
Using prescription drugs	96.3	87.9	90.6
Previous other breast condition	55.6	50.9	52.4

* $P < .01$.

† Percentages calculated from variability of response rate, not total N.

‡ Multiple responses were possible; total is more than 100%.

§ Subset applies to those satisfied with service. White N = 26, Black N = 51.

Medical College Human Subjects Review Board. Informed consent was obtained from all participating women. Our study health educator/coordinator trained community health outreach workers from Access MedPlus who, supervised by regional team leaders, gathered data through personal interviews during home visits.

Statistical Methods

For this segment of the empowering factors study, we selected a stratified, random sample of 90 women from a pool of 5,518 women in the target group. Stratification considered race,

age, and regional distribution. After the survey, we entered data into an MS Access database and exported them to SPSS version 11³⁶ for analysis. A descriptive approach was used to categorize responses from individual survey items. To compare the data between Blacks and Whites, we used independent chi-square or z tests to explore any significance differences. A conventional P value of .05 or less determined significance. Since racial differences were minimal to nonexistent, we primarily report overall results in this paper. However, we highlight racial differences when distinct or significant.

RESULTS

Sample Demographics

Demographics are shown in Table 1. Of the 90 women asked to participate, 85 completed the questionnaire, a response rate of 94%. Twenty-seven (32%) of the respondents were White, and 58 (68%) were Black. Within this group, a few significant differences were observed between Blacks and Whites concerning demographic characteristics. The difference in mean educational attainment was not significant, though some differences stand out when grouped by grade level attainment. Ta-

Table 3. Critical life events, knowledge, attitudes, and screening practices (%)

	White n = 27	Black n = 58	Total N = 85‡
<i>Critical life events and family history of cancer</i>			
I personally know someone who had breast cancer	68.0	81.0	77.1
I personally know someone who died from breast cancer	32.0	60.3*	51.8
Relative with breast cancer	60.0†	27.3	37.5
First-degree relative	35.0*	13.6	20.3
Relative with cervical cancer	15.0	20.5	18.8
Relative with cancer (any type)	74.1	75.9	75.3
<i>Recognized risk factors</i>			
Family history (mother or sister)	92.6*	77.2	82.2
Having relatives who had breast cancer increases the likelihood of getting the disease	84.0*	53.4	62.6
Age (over 50 more likely)	73.1	59.7	63.9
The disease strikes only older people	4.0	5.1	4.8
Diet (high fiber food)	48.0	53.5	51.8
What people eat or drink doesn't affect whether they will get breast cancer	16.0	25.0	22.3
<i>Identified warning signs</i>			
Lumps	100.0	93.9	95.9
Pain/soreness in breast	89.5	97.5	94.9
Discharge from nipple	94.4	92.9	93.5
Swelling or enlargement of breast	90.0	92.3	91.7
Change in shape of breast or nipple	100.0	90.5	93.5
I believe if I had breast cancer I would be able to look at my breast and know	22.2	10.5	14.3
Knows how to examine breasts for lumps	96.2	94.8	95.2
Practices monthly breast self exam	53.9	61.4	59.1
Knew correct frequency for CBE (yearly)	81.5	70.7	74.1
<i>Last clinical breast exam</i>			
Within a year	77.8	91.4	87.1
Between 1 and 2 years ago	14.8	5.2	8.2
Between 2 and 5 years ago	7.4	3.4	4.7
Knew recommended frequencies for mammography (<50 once every two years/≥50 yearly)	96.2	96.6	96.5
<i>Recollection of last mammogram</i>			
Within a year	74.1	84.5	81.2
Between 1 and 2 years ago	25.9	10.3	15.3
More than 2 years	0.0	5.1	3.6
<i>Primary reason for most recent mammogram</i>			
Self interest/initiation	45.1	51.7	49.5
Doctor recommended	37.0	27.6	30.6
Breast problem	15.4	17.2	16.5
Had cancer	3.7	1.7	2.4
<i>Severity and susceptibility</i>			
Breast cancer is a very serious problem	96.3	81.0	85.7
Any woman is likely to get breast cancer	96.2	89.3	91.5
Many women are concerned about getting breast cancer	96.3	86.2	89.4
I worry about getting breast cancer	55.5	43.1	47.0
Breast cancer is likely in my lifetime	44.4	18.9	27.1
Mammography is not needed if breast cancer does not run in the family	7.7	1.7	3.6
I am too healthy to get breast cancer	0.0	3.4	2.4
<i>Perceived benefit</i>			
If breast cancer is found and treated early it can be cured	96.3	91.4	92.9
If treated early one is more likely to return to a normal life	92.0	94.5	93.8
Getting proper treatment is easy	80.0	76.8	77.8
Cancer treatment is worth going through if there is at least a small chance of saving my life	96.2	94.7	95.2
Having a check-up once a year is worth the time and effort	96.1	94.7	95.2

* P<.01; † P<.001.

‡ Percentages calculated from variability of response rate, not total N.

ble 1 shows that 3% of Blacks had no formal education compared to approximately 19% of Whites. Approximately 9% of Blacks continued education past high school, compared to 22% among Whites.

Nineteen percent of the women had incomes at or less than \$10,200 a year: 22% of Blacks and 14% of Whites. Sixty-one percent had incomes between \$10,200 and \$15,600. Nineteen percent had incomes above \$15,600: 16% of Blacks and 29% of Whites. Employment rates were similar across race; of the 85 participants, approximately 64% were unemployed, 16% were employed part-time, and 20% were employed full-time.

Overall, 16% of the participants were single, and approximately 53% were either divorced, legally separated, or widowed. Approximately 60% of Whites were married compared to 18% of Blacks.

Healthcare Access, Utilization, and Satisfaction

Virtually all (97%) of our women reported that they had a regular provider (Table 2); most (83%) received health care in a doctor's office, with approximately 18% saying they also go to an emergency room. Approximately 4% went to an emergency room exclusively. In the past 12 months, all participants reported they had their blood pressure checked, as well as other health examinations: most (>75%) had an eye exam, a regular check-up, a blood sugar test, a Pap smear, and a cholesterol test.

Although significantly more Whites (65%) than Blacks (40%, P<.01) found obtaining an appointment difficult, nearly all (91%) indicated they were satisfied with the health service provided, and 86% indicated the doctor takes time when explaining medical procedures. Of those reporting satisfaction with services, most felt respected by the doctor and the staff (58%), that the doctor listens (73%), shows interest in their health (71%), and answers their

Table 4. Barriers faced in mammography screening (%)

	White n = 27	Black n = 58	Total N = 85‡
<i>Fatalism</i>			
Getting the disease is a death sentence	12.0	20.0	17.6
It's too late for me to start worrying about getting breast cancer	8.0	8.9	8.6
Getting treated is worse than having breast cancer	16.0	17.9	17.3
There is very little a person can do to reduce their chances of getting cancer	42.3	38.6	39.7
If women have a lump in their breast it is almost always breast cancer	3.7	6.9	5.9
<i>Fear</i>			
I have doubts about some things doctors say they can do for me	26.9	58.1*	43.8
Having an operation for the disease can expose it to air and cause it to spread	40.0	55.3	50.6
Exposure to radiation during a mammogram concerns me	15.4	57.9†	44.6
I am usually afraid of what the doctor will find	26.9	26.8	26.8
If I had the disease, I would rather not know	24.0	12.3	15.8
Getting tested for breast cancer is painful	20.0	35.8	30.9
The chance of finding something keeps me from seeking medical advice	0.0	6.9*	4.8
I am afraid of the pain I may feel when I visit a healthcare facility	8.0	12.3	11.0
Doctors make me feel uncomfortable	16.0	5.2	8.4
Breast exams embarrass me	15.4	7.1	9.6
<i>Cost</i>			
The cost of medical care keeps me from going to the doctor	11.5	13.8	13.1
I have delayed getting treatment due to a high deductible	7.4	1.7	3.5
Treatment costs so much that I probably can't afford it	36.0	41.1	39.5
I would seek more medical services if they were not expensive	44.0	47.3	46.3
Not having transportation makes it difficult to keep medical appointments	4.0	22.8*	17.1
<i>System</i>			
It takes too long to get an appointment	28.0	24.1	25.3
I would have a mammogram only if my doctor recommended it	30.8	37.5	35.4
It is difficult to get time off of work to see a doctor	13.6	3.8	5.3
I prefer female doctors	44.4	32.8	36.5
I have delayed seeking medical care because of worries over insurance	8.7	9.1	9.0
I receive inferior treatment because of my race	0.0	1.7	1.2
I receive inferior treatment because I have little money	3.7	10.3	8.2

* $P < .01$; † $P < .001$.

‡ Percentages calculated from variability of response rate, not total N.

questions (60%). Ninety-three percent believed that the location of their last mammogram was convenient, and nearly all (98%) felt better that their mammogram records are kept in one location.

Risk Characteristics

With regard to personal health risks, about half (52%) indicated a previous breast condition other than cancer (Table 2). Nearly all (91%) were using pre-

scription drugs. Most (67%) believed they were overweight, with not quite half (49%) indicating they were interested in participating in a weight-loss or exercise program. Forty-nine percent of the respondents reported they currently used tobacco.

Critical Life Events and Family History of Cancer

Fifty-two percent of our respondents knew someone who had died of cancer

(Table 3), Blacks significantly more so than Whites (60% to 32%, $P < .01$). Though 38% overall reported a relative with breast cancer, racial differences were highly significant ($P < .001$); 60% of White women, compared to 27% of Black women, reported having a relative with breast cancer. Additionally, 35% of Whites and 14% of Blacks ($P < .01$) had a first-degree relative with breast cancer.

Significantly more Whites than Blacks understood that having relatives with breast cancer is associated with higher personal risk (84% of Whites and 53% of Blacks, $P < .01$) and recognize breast cancer in a mother or sister as a personal risk factor (93% of Whites and 77% of Blacks, $P < .01$). Overall, 64% knew that women older than 50 years are at a higher risk. Across an array of indicators, 92% to 96% of the respondents could correctly identify warning signs of breast cancer.

Breast Cancer Screening Behavior

Approximately 50% of the women initiated their most recent mammogram, while 31% said that the most important reason for it was a doctor's recommendation (Table 3). Nearly all respondents reported they know how to examine their breasts for lumps, knew the recommended mammography intervals for their age group, and had a clinical breast exam in the past 12 months.

Perceived Severity and Susceptibility

Most (86%) of our pilot women considered breast cancer a very serious health problem for women and believed (92%) that any woman is likely to get breast cancer. While 89% believe many women are concerned about getting breast cancer, less than half (47%) of the respondents said they, personally, were worried about it, and 27% thought breast cancer is likely in their lifetime.

Perceived Benefit

When asked about their trust in detection and treatment methods, about

Table 5. Underlying factors empowering women for screening (%)

	White n = 27	Black n = 58	Total N = 85†
<i>Priority concerns</i>			
Health	55.6	62.1	60.0
Finance and money	37.0	33.3	34.5
<i>Self-efficacy/locus of control</i>			
<i>Primary trust for health advice</i>			
Self	29.6	28.1	28.6
Doctor or nurse	66.7	50.9	56.0
I am aware of health services in my community	88.4	84.2	85.6
I would ask the doctor questions even though he/she is busy	92.0	89.4	90.3
I am not ashamed of my body	80.0	79.3	79.6
There are things I can do to prevent getting breast cancer	68.0	45.7	52.4
It is up to me and my doctor to protect me from cancer	100.0	100.0	100.0
Having a mammogram reassures me that I am protecting my health	100.0	100.0	100.0
<i>Source of support</i>			
Having regular mammograms is very important to my family	96.0	93.1	94.0
Having regular mammograms is very important to my friends	84.0	79.3	80.7
I am able to talk about health issues with my friends	92.0	98.3	96.4
My spouse/partner encourages me	75.0*	37.5	48.5
<i>First learned about mammography from</i>			
A healthcare worker or facility	69.2	82.1	78.0
Friends or family	15.3	8.9	10.9
Advertisements or reading material	15.3	8.9	10.9

* $P < .01$.

† Percentages calculated from variability of response rate, not total N.

93% of the respondents said that breast cancer could be detected early and cured, agreeing that early detection and treatment could lead to the return of a normal life. Seventy-eight percent believed that proper treatment for the disease is easy and 95% believed that cancer treatment is worth going through if there is a small chance that it would save their life, feeling that yearly check-ups are worth the time and effort.

Fatalism and Fear

Of the participants, 40% believed a person could do little to avoid cancer, and 18% believed that getting breast cancer is a death sentence (Table 4). When expressing fears, 58% of Blacks and 27% of Whites ($P < .01$) said they doubt what doctors say they can do for people. Half of the respondents believed that having surgery could expose cancer to the air and cause it to spread. Highly significant differences were found be-

tween Blacks' (58%) and Whites' (15%, $P < .001$) being concerned about exposure to radiation during mammography. Twenty-seven percent agreed that they are usually afraid of what the doctor may find, but 83% would rather know if they had breast cancer. Eight percent felt that doctors make them uncomfortable, and 10% felt embarrassment from breast exams.

System Barriers and Cost

Approximately one third of the women prefer female doctors and would only get a mammogram if their doctor recommended it. Perceived cost is an issue for approximately 40% who said they probably cannot afford treatment or that medical services are expensive. Transportation is a significant issue for Blacks; 23% said not having it makes keeping medical appointments difficult, while 4% of Whites found it a barrier ($P < .01$).

... They [the under-served women of the study] are empowered by the benefits of screening and supported by their friends and families to deal with the barriers they encounter.

Empowering Factors

Most of the respondents rated health as primary among their personal priority concerns and rated it primary twice as often than the next most cited category: finance and money (Table 5).

On questions related to self-efficacy and locus of control, all believed it is up to them to work with their doctors to protect themselves from cancer, and having a mammogram reassures them they are doing their part. Having regular mammograms is also important to their families and their friends. Overall, approximately 38% of Black and 75% of White respondents stated that their spouse or partner encourages them to obtain a mammogram ($P < .01$). Of those married, 86% of Whites ($n = 14$) and 40% of Blacks ($n = 10$) reported being encouraged by their spouses. Nearly 80% said they first learned of mammography through their doctor, nurse, or healthcare facility, approximately 11% learned of mammography through friends and family, and another 11% from advertisements and reading material.

Discussion

Under-served women share many similar concerns and competing daily priorities. However, despite difficulties, some women seek regular repeat mammography screening. Our women are well informed; knowledgeable about the

risk factors, warning signs, and the importance of early detection; and trust their ability to work with the healthcare system to reduce the risk of getting cancer. They are alert to their perceived susceptibility, a perception possibly driven by critical life events. They are empowered by the benefits of screening and supported by their friends and families to deal with the barriers they encounter.

The empowering factors pilot study survey yielded responses similar to the results of our focus group interviews for this population.^{31,35} Based on these results, we are currently conducting a statewide survey of insured, low-income women for a case-control analysis design comparing adherent and nonadherent women. We anticipate that Tennessee women who overcome the barriers to screening have several characteristics in common with those in our focus groups and pilot study, and we expect to uncover which modifiable characteristics their nonadherent counterparts do not share. More specifically, we hypothesize that repeat regular mammography screening is positively associated with higher awareness, knowledge (about risk factors, warning signs, and screening and treatment procedures), trust in the healthcare system, the ability to work with physicians, and empowerment by family and friends.

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