

Published in final edited form as:

J Cancer Educ. 2014 December; 29(4): 669-679. doi:10.1007/s13187-014-0621-2.

"Don't Know" and Accuracy of Breast Cancer Risk Perceptions Among Appalachian Women Attending a Mobile Mammography Program: Implications for Educational Interventions and Patient Empowerment

Traci LeMasters,

Department of Pharmaceutical Systems and Policy, School of Pharmacy, West Virginia University, Morgantown, WV, USA

Suresh Madhavan,

Department of Pharmaceutical Systems and Policy, School of Pharmacy, West Virginia University, Morgantown, WV, USA

Elvonna Atkins,

Department of Pharmaceutical Systems and Policy, School of Pharmacy, West Virginia University, Morgantown, WV, USA

Ami Vyas,

Department of Pharmaceutical Systems and Policy, School of Pharmacy, West Virginia University, Morgantown, WV, USA

Scot Remick, and

Mary Babb Randolph Cancer Center, West Virginia University, 1801 MBRCC, PO Box 9300, Morgantown, WV 26506-9300, USA

Linda Vona-Davis

Department of Surgery, West Virginia University, 7300 HSS, Morgantown, WV 26506-9238, USA

Traci LeMasters: tlemasters@hsc.wvu.edu; Suresh Madhavan: smadhavan@hsc.wvu.edu; Elvonna Atkins: eatkins@hsc.wvu.edu; Ami Vyas: avyas@hsc.wvu.edu; Scot Remick: sremick@hsc.wvu.edu; Linda Vona-Davis: lvdavis@hsc.wvu.edu

Abstract

Risk perceptions are motivating factors for engaging in preventive health behaviors. Yet, almost one third of women attending a mobile mammography program targeted to rural and medically underserved Appalachian women respond "don't know" to their perceived 5-year risk of breast cancer. This study used cross-sectional data from women aged 40 years participating in Bonnie's Bus Mammography Screening and Preventive Care Survey from 2009 to 2011 to identify factors associated with "don't know" responses and accuracy of perceived risk according to constructs of the health belief model and sociodemographic characteristics. Women who responded "don't know" were more likely to be less educated, of lower income, insured by Medicaid, and less knowledgeable about breast cancer. Conversely, women who accurately perceived their risk were

more likely to be of higher education, more knowledgeable about breast cancer, and have a family history of breast cancer. However, women with a high objective 5-year risk of breast cancer and older age at childbirth or were nulliparous were less likely to accurately perceive their risk. These findings suggest that women who indicate "don't know" responses and hold inaccurate risk perceptions are a population vulnerable to health disparities and may benefit from educational interventions focused on improving breast cancer knowledge and perceptions to empower them to take an active role in their preventive health and make informed decisions based on their individual level of risk.

Keywords

Breast cancer; Perceived risk; Mammography screening; "Don't know" risk; Accuracy of perceived risk

Introduction

Breast cancer is the most common cancer among women with an estimated 226,870 incident cases and 39,510 attributable deaths in the USA in 2012 [1]. However, breast cancer has relatively high 5-year survival rates, compared to other cancers, particularly when diagnosed at an early stage [2]. Routine mammography screening is accepted as the most effective method for detecting breast cancer at an early stage [3]. Despite these recommendations, only 75.4 % of US women aged 40 years and older reported having had a mammogram within the past 2 years, with lower rates observed among various vulnerable populations of women [4, 5]. One such population of women with historically low rates of mammography utilization, alongside higher rates of late-staged breast cancer and breast cancer mortality, are those residing in the Appalachian region [6, 7]. West Virginia (WV) is the only state to lie entirely within the Appalachian region. The Mary Babb Randolph Cancer Center at West Virginia University launched the Bonnie Wells Wilson Mobile Mammography Program (Bonnie's Bus) in 2009 with the goal of increasing rates of mammography utilization among rural and medically underserved women in WV. Bonnie's Bus has eliminated the access barrier, but targeted educational interventions are still needed to emphasize the importance of early detection and encourage adherence to mammography screening guidelines [8]. Mammography appointments require physician referral and utilize a third-party billing system. Bonnie's Bus works with the WV Breast and Cervical Cancer Screening Program (WV BCCSP) to assure that women without insurance or who have difficulty paying are not turned away. Additional details of Bonnie's Bus are described elsewhere [9, 10].

A recent study of women attending Bonnie's Bus found that adherence to mammography screening guidelines was predicted by having a family history of breast cancer, personal history of breast problems, previous breast biopsy, seeing an obstetrician/gynecologist (OB/GYN) in the past year, and receipt of a routine Pap test. Adherence to mammography screening guidelines was not associated with sociodemographic factors such as education, income, or insurance [9]. The health belief model (HBM) offers one theoretical framework that may explain the observed direct and indirect association between these factors and past mammography utilization among women attending Bonnie's Bus. The HBM posits that six

psychosocial factors could explain the likelihood of an individual engaging in the desired health behavior (adherence to mammography screening guidelines) [11]. These factors include knowledge, beliefs, attitudes, perceptions, cues to action, and self-efficacy regarding the recommended health behavior (receiving a mammogram) and the reduction of the associated disease or health outcome (breast cancer). Previously published studies have reported a positive relationship between perceived risk of breast cancer and mammography utilization, particularly among white women [12, 13]. This is of direct relevance for WV, where 94 % of the population is of white race, in contrast to the 78 % for the USA as a whole [14]. A variety of factors have been shown to mediate the positive relationship between perceived risk of breast cancer and mammography utilization. Among these factors are younger age, having a family history of breast cancer, previous breast biopsy, history of breast problems, greater knowledge of breast cancer, greater anxiety or worry about developing breast cancer, and positive attitudes, such as perceived benefits resulting from mammography [13–15]. Previous research has also established a positive relationship between adherence to mammography screening guidelines and receipt of other early detection services, such as clinical breast exam (CBE) and Pap test. Studies have shown that women who engage in these screening behaviors are more likely to adhere to mammography screening guidelines because they are already knowledgeable about breast cancer early detection, perceive they will benefit from screening mammography, and have already overcome barriers to it [16].

Even though a positive relationship between the various constructs of the HBM and receipt of other early detection services was observed among women attending Bonnie's Bus, an association between perceived risk of breast cancer and mammography utilization was not found [9]. Frequency analysis of survey data gathered from 2009 to 2011 shows that almost a third (32.1 %) (Table 1) of surveyed program recipients indicated a response of "don't know" when asked to estimate whether their individual 5-year risk of developing breast cancer was lower, similar, or higher, compared to other similar women their age. This large proportion of "don't know" regarding risk of breast cancer may be confounding the relationship between perceived risk and mammography utilization observed by other studies. Two prior studies of perceived risk have examined "don't know" responses, albeit rates of "don't know" were lower (3.7–9.5 %) [13, 15]. A study by Waters and colleagues observed that women indicating a "don't know/no response" regarding their perceived risk of breast cancer were more likely to be of racial/ethnic minority, older age, and less educated, suggesting that "don't know" respondents may be a vulnerable population [15]. Therefore, the aim of this study was to determine who are the one third of women responding "don't know" to their perceived 5-year risk of breast cancer and how they differ from women indicating a directional response (lower, similar, or higher) according to constructs of the HBM, including adherence to mammography screening guidelines, perceived 5-year risk of breast cancer, breast cancer knowledge, perceived benefits and barriers to mammography, anxiety about developing breast cancer, risk factors that may be considered cues to action, such as family history of breast cancer, personal history of breast problems, and breast biopsy, as well as receipt of additional women's clinical preventive services, and sociodemographic characteristics. Furthermore, this study aimed to determine how women

who perceive their 5-year risk of breast cancer accurately differ from those who are inaccurate or respond "don't know" among women attending Bonnie's Bus.

Methods

Study Design and Population

This cross-sectional study selected a sample of women 40 years of age and older who participated in Bonnie's Bus Mammography Screening and Preventive Care Survey (BBMSPCS) in the years 2009, 2010, and 2011. Upon arrival for their appointment, women were debriefed as to the purpose and nature of the BBMSPCS and invited to participate. Women choosing to participate in the survey were informed of their rights and required to provide signed consent. Among the 2,576 women who attended Bonnie's Bus in 2009–2011, 1,358 (52.7 %) completed surveys. A comparison of basic demographic and health information collected from all women attending Bonnie's Bus showed that women who did not participate in the BBMSPCS were more likely to be older than 65 years of age, not married or widowed, unemployed, and overweight or morbidly obese. After excluding the second- or third-time survey responses and women younger than 40 years of age, 1,182 responses were included in the final study sample. The methodology, survey, and consent forms were approved by the West Virginia University Institutional Review Board.

Survey Instrument

The structured BBMSPCS questionnaire form is divided into sections that assess demographic information, personal health history, menstrual and reproductive history, family history of cancer, breast cancer risk perceptions, breast cancer knowledge, perceived benefits and barriers to mammography, anxiety about developing breast cancer, women's clinical preventive care, general clinical preventive care, general health status, and health behaviors pertaining to lifestyle. The six-page survey takes about 20 to 25 min to complete and contains a mixture of open-ended, yes/no, and multiple choice questions, as well as statements requiring agree/disagree and Likert scale type responses. Additional information regarding survey structure, development, reliability, and validity has been described elsewhere [9, 10].

Measures

Dependent Variables—The main outcomes of interest in this study were perceived 5-year breast cancer risk and accuracy of perceived risk compared to actual 5-year risk. Perceived 5-year risk was assessed with the question "In your opinion, how do you compare your risk of developing breast cancer in the next 5 years to that of any woman of your age in the general population?" The options were "lower," "similar," "higher," or "don't know." To determine accuracy, each woman's actual 5-year risk of breast cancer was computed using the Gail model 2 of projected individualized breast cancer risk [17, 18]. This model estimates 5-year risk utilizing relative risks (RR) associated with age, family history of breast cancer, age at menarche, age at first childbirth, history of biopsy, and biopsy results. Women with an estimated 5-year risk of breast cancer of 1.66 % are considered to be at high risk. After calculating the estimated 5-year risk of breast cancer for women without any missing information for the RR measures, objective 5-year risk was cross-tabulated with

perceived 5-year risk to categorize women who accurately or inaccurately perceived their 5-year level of breast cancer risk. Women who responded "don't know" to their level of perceived risk were omitted from this cross-tabulation and retained their own category.

Independent Measures—Breast cancer knowledge was assessed by asking participants to respond with "agree," "disagree," or "don't know" to six statements about breast cancer. The six statements, with their correct answers following in parentheses, are as follows: (1) "The risk of breast cancer is greater in younger women than in older women" (disagree). (2) "Women with close relatives with breast cancer have higher risk of breast cancer" (agree). (3) "A woman currently using birth control pills has a slightly greater risk of breast cancer as compared to a woman not using them" (agree). (4) "Obesity (being very heavy) is not a risk factor for breast cancer" (disagree). (5) "Mammography screening can detect breast lumps early" (agree). (6) "One breast screening mammogram is enough to ensure that you will not get breast cancer" (disagree). Correct responses were totaled for each woman, with a possible score of 6 out of 6 correct. Responses of "don't know" were scored as incorrect. For analysis, averaged scores were categorized as "2," "2–4," and "4–6."

Perceived benefits and barriers to mammography were assessed by asking participants to choose their level of agreement with eight statements about mammography using a Likert scale of 1-7, where "1" equals "strongly disagree" and "7" equals "strongly agree." Four of the statements, which pertained to the benefits of mammography, are as follows: (1) "Having mammography screening would reassure me that everything was OK." (2) "Having mammography screening would make me feel that I am doing something positive about my risk of breast cancer." (3) "Having mammography screening would reduce my chances of dying of breast cancer." (4) "Having mammography screening would make me feel less anxious about breast cancer." Four of the statements pertaining to barriers to mammography are as follows: (1) "Having mammography screening would be painful." (2) "Having mammography screening would be a difficult experience for me." (3) "Having mammography screening would make me worry unnecessarily." (4) "Having mammography screening would make me worry about the effects of radiation." A principal component analysis (PCA) with Varimax rotation with Kaiser normalization was employed to identify common constructs using IBM SPSS Statistics Version 21.0 for Windows (SPSS, Inc., 2009, Chicago, IL). Bartlett's test of sphericity (P<0.001) and the Kaiser-Meyer-Olkin measure of sampling adequacy (0.777) suggested good matrix factorability. The rotated component extraction identified two components with eigenvalues >1.0, explaining 63.25 % of the variance. Responses to the four positive and four negative statements were averaged to provide each respondent to construct a single measure of perceived benefits and barriers to mammography. Cronbach's alpha (0.852 and 0.733, respectively) suggested satisfactory internal consistency for the positive and negative subscales. For analysis, averaged scores were categorized as "1-4," "4-5," and "5-7."

Anxiety about developing breast cancer was measured by having women choose their level of agreement (not at all, sometimes, often, or a lot) with four statements that were as follows: (1) "During the past one week including today, how often have you thought about your own chances of developing breast cancer?" (2) "During the past one week, including this time, how often have thoughts about your chances of breast cancer affected your

mood?" (3) "During the past one week, how often have our thoughts about your chances of getting breast cancer affected your ability to perform your daily activities?" (4) "During the past one week, how concerned were about getting cancer?" The response categories (not at all, sometimes, often, or a lot) were assigned numerical values (0, 1, 2, or 3, respectively), and the four responses were averaged to create a single measure of anxiety. Cronbach's alpha (0.959) suggested a high internal consistency for this subscale. Averaged scores were dichotomized as "1" (less anxiety) and "1–3" (more anxiety).

Risk factors and cues to action were family history (having a first-degree relative with breast cancer) (yes or no), previous breast biopsy (yes or no), personal history of breast problems (yes or no), age at menarche (11, 12–13, or 14 years), and age at first childbirth (<20, 20–24, 25–29, 30 years, or nulliparous). Breast biopsy results that were found to be atypical hyperplasia were used in the calculation of actual 5-year risk but were not included in the analysis due to a small proportion (1.02 %) of women who had atypical hyperplasia.

Measures of women's clinical preventive behaviors were time since last mammogram, CBE, and Pap test (1 year, 1–2 years, 2 years, or never), and having seen an OB/GYN in the past year (yes or no). Sociodemographic characteristics examined were age (40–49, 50–59, 60–69, and 70 years), race (white or non-white), marital status (married or not married), annual family income (<\$10,000, \$10,000–\$25,000, \$25,000–\$50,000, or >\$50,000), highest level of education (< high school, high school/GED, or > high school), and type of insurance (private, state, Medicare, Medicaid, other, or uninsured).

Statistical Analysis

Chi-square tests, Mantel-Haenszel chi-square test of location shift using modified ridit scores, and the Mantel-Haenszel chi-square test of general association (depending on whether the independent measure was dichotomous, nominal, or ordinal) were used to compare significant group differences between independent and dependent measures. Dependent measures were type of response to perceived 5-year risk of breast cancer (directional (lower, similar, and higher) vs. "don't know") and accuracy of perceived 5-year risk (accurate vs. inaccurate vs. "don't know"), with significance set at *P*<0.05. A Bonferroni adjusted probability level, *P*<0.0025, was used to correct for type I error associated with multiple comparisons (0.05/20). Cramer's V statistic was used to measure the strength of association between independent and dependent measures. Categories for time since last mammogram, Pap test, and CBE were collapsed to 1 year, 1–2 years, or 2 years/never due to small cell sizes. Findings are presented in Tables 1, 2, and 3. All analysis was conducted using SAS version 9.2 software (SAS Institute Inc., Cary, NC).

Results

Sample Description

Characteristics of women aged 40 years and older who attended Bonnie's Bus Mobile Mammography Screening Program in years 2009–2011 are presented in Table 1.

"Don't Know" Perceived Risk

Following the Bonferroni correction, a greater proportion of women who responded "don't know" to their perceived 5-year risk of breast cancer were of lower annual income (P<0.001), less educated (P<0.001), insured by Medicare or uninsured (P<0.001), and less knowledgeable about breast cancer (P<0.001), compared to women who indicated a directional response (lower, similar, and higher) (Table 2).

Accuracy of Perceived Risk

Following the Bonferroni correction, a greater proportion of women who accurately perceived their 5-year risk of breast cancer had a low/average objective 5-year risk, compared to women who were inaccurate or responded "don't know" (P<0.001); had a higher annual income compared to women who responded "don't know" (P<0.001); were less educated than women who were inaccurate but more educated than women who responded "don't know" (P<0.001); were insured privately and less through Medicaid compared to women who responded "don't know" (P<0.001); had never had a breast biopsy compared to women who were inaccurate or responded "don't know" (P<0.001); had no family history of breast cancer compared to women who were inaccurate or responded "don't know" (P<0.001); had no personal history of breast problems compared to women who were inaccurate (P<0.001); had a younger age at childbirth with less of them being nulliparous than women who were inaccurate or responded "don't know" (P<0.001); and were more knowledgeable about breast cancer than women who responded "don't know" (P<0.001); and were more knowledgeable about breast cancer than women who responded "don't know" (P<0.001) (Table 3).

Discussion

The purpose of this study was to determine who the women who responded "don't know" regarding their perceived 5-year risk of breast cancer were and what contributes to the accuracy of perceived risk among this Appalachian sample of women attending a mobile mammography program. Women indicating a response of "don't know" were less educated, of lower income, more frequently insured by Medicare or uninsured, and less knowledgeable about breast cancer, compared to women who indicated a directional response (lower, similar, and higher). These findings are consistent with those reported by Waters and colleagues who identified women indicating a "don't know" response to their perceived risk of breast cancer as being a vulnerable population characterized by racial/ethnic minority status and low levels of education [15]. Recent research by Waters and colleagues confirmed that these associations between "don't know" responses and sociodemographic disparities extend to risk perceptions for other types of cancer [19]. In addition to vulnerable sociodemographic characteristics, findings from this study show that women who "don't know" their risk are less knowledgeable about breast cancer. It is not surprising that women responding "don't know" to their level of perceived risk would be characterized by both low levels of education and breast cancer knowledge, as the association between level of education and breast cancer knowledge has been established [20]. Regardless of accuracy, women who are more knowledgeable about breast cancer may be more confident to estimate their level of risk. Moreover, knowledge about health conditions, otherwise known as health literacy, has become an important mechanism to empower patients to communicate with

their health care providers, take an active role in their health, and make informed health care decisions [21, 22].

Similarly, women who responded "don't know" in their 5-year risk of breast cancer were of lower income, less educated, more often insured through Medicaid or uninsured, and less knowledgeable about breast cancer than women who accurately perceived their risk of breast cancer, suggesting that these may be associated with not only their confidence to estimate their risk, but also the accuracy of their risk perception. However, women who inaccurately perceived their 5-year risk of breast cancer were of higher risk, more educated, had more breast biopsies, family history of breast cancer, personal history of breast problems, and had their first child at an older age or were nulliparous, compared to women who accurately perceived their breast cancer risk. Given that women who bear their first child at an older age or are nulliparous tend to be more highly educated and of higher income, and perhaps more knowledgeable about breast cancer, it stands to reason that these women of advanced maternal age or nulliparity are more likely to recognize themselves as having risk factors, but may overestimate the magnitude of the impact on their individual risk of breast cancer [23]. A similar overestimation of risk may be occurring among women who report a personal history of breast biopsies and breast problems.

The large proportion of women attending Bonnie's Bus who "don't know" their level of breast cancer risk are of lower socioeconomic status and less knowledgeable about breast cancer. For this reason, this vulnerable population of women may be ambivalent or unmotivated to seek recommended routine mammography screening. Moreover, the majority of women do not accurately perceive their level of risk and more importantly the vast majority of women at high risk do not recognize their level of risk. Therefore, increasing their level of breast cancer knowledge could empower them to take the initiative to make informed choices for breast cancer screening and other preventive health measures. Individuals who are more activated, or empowered, have been shown to engage in better preventive health, healthy lifestyle behaviors, and consequently have better health outcomes [24]. Interventions for patient empowerment that have been led by community health centers and primary care physicians have both been found to be successful [25, 26]. Given that many of the women attending Bonnie's Bus are from rural and medically underserved areas where primary care providers and local health clinics are the main sources of health care, these settings may be ideal for implementing interventions to increase patient education and empowerment. Interventions for patient education could improve the accuracy of breast cancer risk perception and empower women to initiate a dialogue with their physician about an appropriate age to initiate screening and the appropriate screening interval (annual vs. biennial) for their needs and preferences.

Strengths and Limitations

The current study possesses several strengths. This study provides new insights regarding vulnerable characteristics of women who "don't know" their perceived 5-year level of risk for breast cancer and what factors contribute to accuracy of perceived risk, and how these characteristics and perceptions may be associated with patient empowerment for seeking preventive health care services, such as mammography screening, after access barriers have

been removed. Additionally, this study was conducted using primary data collected from an understudied population. However, this study may be limited by the inherent bias that comes from self-reported data, and it is uncertain how responses from the 47.3 % of women attending Bonnie's Bus who did not participate in the survey would have affected study findings. Findings from this study may not be generalizable to populations of women who are more racially and ethnically diverse, reside in urban areas, more affluent, and attend stationary mammography facilities.

Conclusions

Although mobile mammography services help eliminate barriers to access among rural and medically underserved women, it does not insure appropriate utilization of services that may be influenced by women's perceptions of breast cancer risk and breast cancer knowledge. Empowering patients through community health center and physician-led educational interventions may allow for patients to make appropriate and informed choices regarding their preventive health. Future research is needed to identify methods of engaging community health center and physician participation in such interventions, as well as, effective methods of disseminating knowledge about breast cancer risk and mammography screening. Moreover, breast cancer awareness campaigns and media should strive to use images of women of an appropriately older age in their internet and print material.

Acknowledgments

The study authors acknowledge the partial financial funding by AHRQ Grant no. 1R24H5018622-01, the Claude Worthington Benedum Foundation, and by the Susan G. Komen for the Cure[®]. The authors would also like to thank the following contributors for their valued efforts: Dee Headley, Barbara Menear, Amy Mayhugh, Gary Osborne, James Taylor, Gina Short, Emily Bucher, and Deena Young.

References

- 1. Howlader, N.; Noone, AM.; Krapcho, M., et al. SEER cancer statistics review, 1975–2009 (Vintage 2009 populations). National Cancer Institute; Bethesda: 2012. http://seer.cancer.gov/csr/1975_2009_pops09/ [Accessed 03 Apr 2013]
- Schonberg MA, Marcantonio ER, Ngo L, Li D, Silliman RA, McCarthy EP. Causes of death and relative survival of older women after a breast cancer diagnosis. J Clin Oncol. 2011; 29(12):1570– 1577. [PubMed: 21402602]
- American Cancer Society. Breast cancer facts & figures 2011–2012. American Cancer Society;
 Atlanta: 2012. http://www.cancer.org/research/cancerfactsfigures/breastcancerfactsfigures/
 [Accessed 03 Apr 2013]
- 4. Kaiser State Health Facts. Percent of women age 40 and older who report having had a mammogram within the last two years, 2010. Kaiser Family Foundation; Menlo Park: 2013. http://statehealthfacts.org [Accessed 03 Apr 2013]
- 5. Miller JW, King JB, Joseph DA, Richardson LC. Breast cancer screening among adult women—behavioral risk factor surveillance system, United States, 2010. MMWR Morb Mortal Wkly Rep. 2010; 61(Suppl):46–50.
- 6. Lengerich EJ, Tucker TC, Powell RK, et al. Cancer incidence in Kentucky, Pennsylvania, and West Virginia: disparities in Appalachia. J Rural Health. 2005; 21:39–47. [PubMed: 15667008]
- 7. Blackley D, Behringer B, Zheng S. Cancer mortality rates in Appalachia: descriptive epidemiology and an approach to explaining differences in outcomes. J Community Health. 2012; 37(4):804–813. [PubMed: 22101638]

8. Roth R, Newhouse R, Robinson B, Faulkner S, Remick SC. Bonnie's Bus—cancer disparities in West Virginia, philanthropy and opportunities to build lasting partnerships. W V Med J. 2009; 105(Spec):68–72. [PubMed: 19999270]

- 9. Vyas A, Madhavan S, LeMasters T, et al. Factors influencing adherence to mammography screening guidelines in Appalachian women participating in a mobile mammography program. J Community Health. 2012; 37(3):632–646. [PubMed: 22033614]
- Atkins E, Madhavan S, Lemasters T, Vyas A, Gainor SJ, Remick S. Are obese women more likely to participate in a mobile mammography program? J Community Health. 2013; 38(2):338–348.
 [PubMed: 23054419]
- 11. Rosenstock I. Historical origins of the health belief model. Health Educ Monogr. 1974; 2:4.
- 12. Gross CP, Filardo G, Singh HS, Freedman AN, Farrell MH. The relation between projected breast cancer risk, perceived risk, and mammography use. J Gen Intern Med. 2006; 21:158–164. [PubMed: 16390511]
- Katapodi MC, Lee KA, Facione NC, Dodd MJ. Predictors of perceived breast cancer risk and the relation between perceived risk and breast cancer screening: a meta-analytic review. Prev Med. 2004; 38:388–402. [PubMed: 15020172]
- 14. U.S. Census Bureau. State and county quickfacts. U.S. Department of Commerce; Washington: 2013. http://quickfacts.census.gov/qfd/states/54000.html [Accessed 13 Jan 2014]
- 15. Waters EA, Klein WMP, Moser RP, et al. Correlates of unrealistic risk beliefs in a nationally representative sample. J Behav Med. 2011; 34(3):225–235. [PubMed: 21110077]
- Schueler KM, Chu PW, Smith-Bindman R. Factors associated with mammography utilization: a systematic quantitative review of the literature. J Womens Health (Larchmt). 2008; 17(9):1477– 1498. [PubMed: 18954237]
- Costantino JP, Gail MH, Pee D, et al. Validation studies for models projecting the risk of invasive and total breast cancer incidence. J Natl Cancer Inst. 1999; 91(18):1541–1548. [PubMed: 10491430]
- Fisher B, Costantino JP, Wickerham DL, et al. Tamoxifen for prevention of breast cancer: report of the National Surgical Adjuvant Breast and Bowel Project P-1 study. J Natl Cancer Inst. 1998; 90:1371–1388. [PubMed: 9747868]
- Waters EA, Hay JL, Orom H, Kiviniemi MT, Drake BF. "Don't know" responses to risk perception measures: implications for underserved populations. Med Decis Making. 2013; 33(2):271–281.
 [PubMed: 23468476]
- 20. Cyrus-David MS. Knowledge and accuracy of perceived risk in underserved women who are at increased risk of breast cancer. J Cancer Educ. 2010; 25:617–623. [PubMed: 20229073]
- Camerini L, Schulz PJ, Nakamoto K. Differential effects of health knowledge and health empowerment over patients' self-management and health outcomes: a cross-sectional evaluation. Patient Educ Couns. 2012; 89(2):337–344. [PubMed: 22959333]
- 22. Schulz PJ, Nakamoto K. Health literacy and patient empowerment in health communication: the importance of separating conjoined twins. Patient Educ Couns. 2013; 90(1):4–11. [PubMed: 23063359]
- Bayrampour H, Heaman M. Comparison of demographic and obstetric characteristics of Canadian primiparous women of advanced maternal age and younger age. J Obstet Gynaecol Can. 2011; 33(8):820–829. [PubMed: 21846437]
- 24. Greene J, Hibbard JH. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. J Gen Intern Med. 2012; 27(5):520–526. [PubMed: 22127797]
- Deen D, Wei-Hsin L, Rothstein D, Santana L, Gold MR. Asking questions: the effect of a brief intervention in community health centers on patient activation. Patient Educ Couns. 2011; 84(2): 257–260. [PubMed: 20800414]
- 26. Parchman ML, Zeber JE, Palmer RF. Participatory decision making, patient activation, medication adherence, and intermediate clinical outcomes in type 2 diabetes: a STARNet study. Ann Fam Med. 2010; 8(5):410–417. [PubMed: 20843882]

Table 1

Characteristics of women attending the Bonnie Wells Wilson Mobile Mammography Program (Bonnie's Bus Mammography Screening and Preventive Care Survey 2009–2011)

	Number	Percent
All	1,182	100.00
Perceived 5-year risk of breast	cancer	
Lower	343	29.02
Similar	335	28.34
Higher	89	7.53
Don't know	379	32.06
Missing	36	3.05
Objective 5-year risk of breast	cancer	
1.66 % (high risk)	404	34.18
<1.66 % (low/average risk)	628	53.13
Missing	150	12.69
Accuracy of 5-year perceived ri	isk	
Accurate	433	36.63
Inaccurate	257	21.74
Don't know	379	32.06
Missing	113	9.56
Age		
40–49	370	31.30
50–59	466	39.42
60–69	286	24.20
70	56	4.74
Missing	4	0.34
Race		
White	1,105	93.49
Non-white	38	3.21
Missing	39	3.30
Married		
Yes	704	59.56
No	393	33.25
Missing	85	7.19
Annual family income		
<\$10,000	209	17.68
\$10,000-\$25,000	475	40.19
\$25,000-\$50,000	238	20.14
>\$50,000	132	11.17
Missing	128	10.83
Highest level of education com	pleted	
< High school	129	10.91

	Number	Percent
High school or GED	579	48.98
> High school	426	36.04
Missing	48	4.06
Type of insurance		
Private	205	17.34
State	118	9.98
Medicare	110	9.31
Medicaid	46	3.89
Other	73	6.18
Uninsured	507	42.89
Missing	123	10.41
Time since last mammogram		
1 year	140	11.84
1–2 years	427	36.13
>2 years/never	565	47.80
Missing	50	4.23
Time since last clinical breast	exam	
1 year	509	43.06
1–2 years	361	30.54
>2 years/never	249	21.06
Missing	63	5.33
Time since last Pap test		
1 year	422	35.70
1–2 years	355	30.03
>2 years/never	344	29.10
Missing	61	5.16
Seen OB/GYN in past year		
Yes	359	30.37
No	621	52.54
Missing	202	17.09
Had a breast biopsy		
Yes	200	16.92
No	956	80.88
Missing	26	2.20
Family history of breast cance	r	
Yes	190	16.07
No	923	78.09
Missing	69	5.84
Personal history of breast prob	alems	
	111111111111111111111111111111111111111	
Yes	140	11.84
Yes No		11.84 87.23

	Number	Percent
Age at menarche		
11	290	24.53
12–13	591	50.00
14	269	22.76
Missing	32	2.71
Age at first childbirth		
19	470	39.76
20–23	351	29.70
24–29	196	16.58
30	59	4.99
Nulliparous	85	7.19
Missing	21	1.78
Breast cancer knowledge		
Less (<2)	119	10.07
Some (2–4)	297	25.13
More (4–6)	682	57.70
Missing	84	7.11
Anxiety about breast cancer		
Less (<1)	944	79.86
More (1–3)	64	5.41
Missing	174	14.72
Perceived mammography ben	efits	
Less (1-4)	60	5.08
Some (4–5)	69	5.84
More (5–7)	988	83.59
Missing	65	5.50
Perceived mammography bar	riers	
Less (1-4)	895	75.72
Some (4–5)	118	9.98
More (5–7)	106	8.97
Missing	63	5.33

Author Manuscript

Author Manuscript

Table 2

(Bonnie's Bus Mammography

	5-year per	5-year perceived relative risk of breast cancer	ive risl	s of breast	cancer		
	Directional response	response	Don'	Don't Know	P value	Cramer's V	
	N	%	N	%			
All	191	100.00	379	100.00			
Objective 5-year risk of breast cancer					0.135	0.047	
1.66 % (high risk)	282	40.87	118	35.98			
<1.66 % (low/average risk)	408	59.13	210	64.02			
Age					0.089	0.076	
40-49	238	31.11	122	32.36			
50–59	322	42.09	132	35.01			
69-09	174	22.75	102	27.06			
70	31	4.05	21	5.57			
Race					0.512	0.020	
White	721	96.52	355	97.26			
Non-white	26	3.48	10	2.74			
Married					0.325	0.030	
Yes	469	65.05	215	61.96			
No	252	34.95	132	38.04			
Annual family income					<0.001*	0.177	
<\$10,000	1111	15.86	87	26.77			
\$10,000-\$25,000	310	44.29	155	47.69			
\$25,000-\$50,000	171	24.43	63	19.38			
>\$50,000	108	15.43	20	6.15			
Highest level of education completed					<0.001*	0.220	
< High school	09	8.08	29	18.66			
High school or GED	355	47.78	205	57.10			
> High school	328	44.15	87	24.23			
Type of insurance					<0.001*	0.179	

	J-year pero	5-year perceived relative risk of breast cancer	ive risk	of breast	cancer	
	Directional response	response	Don't	Don't Know	P value	Cramer's V
	N	%	N	%		
Private	156	22.58	43	12.76		
State	92	13.31	25	7.42		
Medicare	21	3.04	46	13.65		
Medicaid	09	89.8	22	6.53		
Other	42	80.9	28	8.31		
Uninsured	320	46.31	173	51.34		
Time since last mammogram					0.094	0.065
1 year	68	11.87	49	13.42		
1–2 years	299	39.87	121	33.15		
>2 years/never	362	48.27	195	53.42		
Time since last clinical breast exam					0.706	0.025
1 year	338	45.37	164	45.56		
1–2 years	245	32.89	111	30.83		
>2 years/never	162	21.74	85	23.61		
Time since last Pap test					0.671	0.027
1 year	281	37.62	133	36.84		
1–2 years	243	32.53	111	30.75		
>2 years/never	223	29.85	117	32.41		
Seen OB/GYN in past year					0.754	0.010
Yes	240	36.53	105	35.47		
No	417	63.47	191	64.53		
Had a breast biopsy					0.038	0.062
Yes	146	19.11	53	14.13		
No	618	80.89	322	85.87		
Family history of breast cancer					0.687	0.012
Yes	124	16.80	49	17.78		
No	614	83.20	296	82.22		
Personal history of breast problems					0.049	0.058
Yes	102	13.40	35	9.36		

	5-year per	5-year perceived relative risk of breast cancer	ive risk	of breast	cancer	
	Directions	Directional response	Don'	Don't Know	P value	Cramer's V
	N	%	N	%		
No	659	86.60	339	90.64		
Age at menarche					0.350	0.043
11	182	24.23	100	27.40		
12–13	386	51.40	188	51.51		
14	183	24.37	77	21.10		
Age at first childbirth					0.341	0.063
<20	292	38.62	164	44.44		
20–24	232	18.12	106	28.73		
24–29	137	5.16	53	14.36		
30	39	5.16	18	4.88		
Nulliparous	99	7.41	28	7.59		
Breast cancer knowledge					<0.001*	0.201
Less (2)	51	7.11	99	18.54		
Some (2–4)	179	24.97	110	30.90		
More (4–6)	487	67.92	180	50.56		
Anxiety about breast cancer					0.525	0.020
Less (1)	618	94.35	308	93.33		
More (1–3)	37	5.65	22	6.67		
Perceived mammography benefits					0.047	0.075
Less (1-4)	31	4.22	27	7.52		
Some (4–5)	42	5.71	25	96.9		
More (5-7)	662	90.07	307	85.52		
Perceived mammography barriers					0.024	0.083
Less (1-4)	297	81.00	283	78.39		
Some (4–5)	82	11.13	32	8.86		
More $(5-7)$	58	7.87	46	12.74		

 * Significant after Bonferroni adjustment (P<0.0025)

Author Manuscript

Table 3

Accuracy of perceived 5-year risk of breast cancer among women attending the Bonnie Wells Wilson Mobile Mammography Program (Bonnie's Bus Mammography Screening and Preventive Care Survey 2009-2011)

	o-yea	r perceive	ed relai	5-year perceived relative risk of breast cancer	ı oreas	t cancer		
	Accurate	rate	Inacc	Inaccurate	Don'	Don't know	P value	Cramer's V
	N	%	N	%	N	%		
All	433	100.00	257	100.00	379	100.00		
Objective 5-year risk of breast cancer							<0.001 *	0.628
1.66 % (high risk)	53	12.24	229	89.11	118	35.98		
<1.66 % (low/average risk)	380	87.76	28	10.89	210	64.02		
Age							0.336	0.079
40-49	129	29.79	06	35.02	122	32.36		
50–59	179	41.34	113	43.97	132	35.01		
69-09	106	24.48	48	18.68	102	27.06		
70	19	4.39	9	2.33	51	5.57		
Race							0.202	0.056
White	412	97.63	241	95.26	355	97.26		
Non-white	10	2.37	12	4.74	10	2.74		
Married							0.344	0.046
Yes	264	64.86	166	92.79	215	61.69		
No	143	35.14	62	32.24	132	38.04		
Annual family income							<0.001*	0.138
<\$10,000	09	15.23	37	15.29	87	26.77		
\$10,000-\$25,000	172	43.65	103	42.56	155	47.69		
\$25,000-\$50,000	76	24.62	65	26.86	63	19.38		
>\$50,000	99	16.50	37	15.29	20	6.15		
Highest level of education completed							<0.001*	0.178
< High school	28	6.65	25	9.88	29	18.66		
High school or GED	221	52.49	66	39.13	205	57.10		
> High school	172	40.86	129	50.99	87	24.23		
Type of incline							*	0.100

	, y Ca	122		Trail perceived relative fish of breast cancer		707		
	Accurate	ate	Inaccurate	urate	Don't	Don't know	${\it P}$ value	Cramer's V
	N	%	N	%	N	%		
Private	98	21.83	59	25.54	43	12.76		
State	52	13.20	30	12.99	25	7.42		
Medicare	35	8.88	17	7.36	46	6.53		
Medicaid	6	2.28	10	4.33	22	13.65		
Other	27	6.85	13	5.63	28	8.31		
Uninsured	185	46.95	102	44.16	173	51.34		
Time since last mammogram							0.189	0.054
1 year	4	10.45	32	12.55	49	13.42		
1–2 years	170	40.38	103	40.39	121	33.15		
>2 years/never	207	49.17	120	47.06	195	53.42		
Time since last clinical breast exam							0.692	0.033
1 year	191	45.15	112	44.80	164	45.56		
1–2 years	145	34.28	77	30.80	1111	30.83		
>2 years/never	87	20.57	61	24.40	85	23.61		
Time since last Pap test							0.853	0.026
1 year	158	37.80	26	38.04	133	36.84		
1-2 years	133	31.82	98	33.73	111	30.75		
>2 years/never	127	30.38	72	28.24	1117	32.41		
Seen OB/GYN in past year							0.707	0.028
Yes	131	35.79	98	38.74	105	35.47		
No	235	64.21	136	61.26	191	64.53		
Had a breast biopsy							<0.001*	0.207
Yes	41	9.47	73	28.63	53	14.13		
No	329	90.53	182	71.37	322	85.87		
Family history of breast cancer							<0.001*	0.186
Yes	43	9.93	71	27.63	64	17.78		
No	390	90.07	186	72.37	296	82.22		
Personal history of breast problems							<0.001*	0.136
Yes	35	8.10	47	18.58	35	9.36		

	5-year	5-year perceived relative risk of breast cancer	ed relati	ive risk o	f breast	cancer		
	Accurate	ate	Inaccurate	urate	Don't	Don't know	P value	Cramer's V
	N	%	N	%	N	%		
No	397	91.90	206	81.42	339	90.64		
Age at menarche							0.009	0.080
11	92	21.25	92	29.57	100	27.40		
12–13	217	50.12	133	51.75	188	51.51		
14	124	28.64	48	18.68	77	21.10		
Age at first childbirth							<0.001*	0.261
<20	204	47.11	99	21.79	164	44.44		
20–24	162	37.41	55	21.40	106	28.73		
25–29	47	10.85	82	31.91	53	14.36		
30	9	1.39	32	12.45	18	4.88		
Nulliparous	14	3.23	32	12.45	28	7.59		
Breast cancer knowledge							<0.001*	0.147
Less (<2)	27	6.57	16	6.78	99	18.54		
Some (2–4)	103	25.06	49	27.12	110	30.90		
More (4–6)	281	68.37	156	66.10	180	50.56		
Anxiety about breast cancer							0.770	0.024
Less (<1)	358	94.21	200	94.79	308	93.33		
More (1–3)	22	5.79	11	5.21	22	6.67		
Perceived mammography benefits							0.080	0.061
Less (1–4)	18	4.31	∞	3.28	27	7.52		
Some (4–5)	22	5.26	15	6.15	25	96.9		
More $(5-7)$	378	90.43	221	90.57	307	85.52		
Perceived mammography barriers							0.190	0.081
Less (1-4)	345	81.56	197	81.40	283	78.39		
Some (4–5)	41	69.6	33	13.64	32	8.86		
More $(5-7)$	37	8.75	12	4.96	46	12.74		

 * Significant after Bonferroni adjustment (P<0.0025)