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Knowledge and Accuracy of Perceived Personal Risk in Underserved Women Who are at Increased Risk of Breast Cancer

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Abstract

The state of knowledge and personal risk perception among women who are underserved or racial minorities at increased risk of breast cancer (BC) who may be eligible for chemoprevention is limited. The BC knowledge and accuracy of perceived personal risk of a cross-sectional study population of such women residing in the greater Houston Texas area were assessed. The majority had below average knowledge scores and perceived risk inaccurately. The lesser educated were also less knowledgeable. Educational interventions targeted towards this population would enhance their knowledge of BC and empower them to make informed decisions about BC chemoprevention.

Keywords

Knowledge; Accuracy; Perceived personal risk; Underserved women; Breast cancer

Introduction

Chemoprevention therapies with selective estrogen receptor modulators such as tamoxifen and raloxifene has been approved for reducing the risk of breast cancer (BC) in women who are at increased risk outside clinical trial settings [1,2]. These decisions were made based on the findings from multinational studies that showed 32–49% reductions in the risk of invasive BC [3,4]. However, women of low socioeconomic status (SES) and racial/ethnic minorities were underrepresented in these trials. For example, the majority of BCs diagnosed in African-American women (over 50%) and in Latinas (over 60%) are estrogen receptor (ER)-positive [5–7] and, thus, are amenable to chemopreventive interventions; yet, the proportions of racial minority women who were at increased risk of BC in the Breast Cancer Prevention Trial and the Study of Tamoxifen and Raloxifene were 3.5% and 6.5%, respectively [2,4]. Thus, little is known about the factors that influence their decision-making processes with regards to utilizing BC chemoprevention strategies. Consequently, for clinical counseling and other purposes, it is useful to characterize these women separately in terms of their knowledge of risk factors, prevention, and treatments and their perceived personal risk of BC, as this would lay the foundation for future tailored interventions to enhance informed decision making about utilizing chemopreventive strategies. Extensive efforts have been expended to describe the knowledge and perceived

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personal risk of BC in the general population of women (i.e., 40 years of age or older) with regards to the use of mammography for screening [8–11] and in high-risk BC families in terms of the interest, knowledge, or receipt of counseling on genetic risk [12–15] and genetic testing for BRCA I/II genotypes [16–19]. However, research on the knowledge and perceived personal risk of nonhereditary BCs has been predominantly conducted on those of middle relative to other SES [20,21]. The significant correlates of knowledge included an inverse association with age [20] and a direct association with Caucasian race/ethnicity [15,20]. With regards to perceived personal risk, the picture is unclear. One group reported only a 32% accuracy of perceived vs. objectively determined risk in their population [20]. Meanwhile, another group reported that women of average risk could more accurately perceive their risk (i.e., 72%) than those of high risk (i.e., 43.1%) when perceived vs. objectively determined risk status were compared [21]. In women of average risk, Asian Pacific Islanders and younger women tended to inaccurately perceive their BC risk. In the high-risk group, African Americans were more likely to inaccurately perceive their risk than were Caucasians [21]. Furthermore, women who tended to overestimate their risks had a family history of BC, were nulliparous, had frequent exposures to the media, tended to be younger, and had more knowledge of BC risk factors than their counterparts [21]. The limitations in these studies included the fact that women of low SES or of racial/ethnic minority backgrounds were underrepresented [20,21]; one group focused only on age-related differences and used numeric values to assess perceived risk—a method that increases respondent errors [20,22]; another group assessed the objective BC risk with the older version of the Gail model, which is known to underestimate the risk of racial minorities [23–25]. Thus, little is known about the state of the knowledge and perceived personal risk of BC in women who may be eligible for chemoprevention therapies, are underserved, and of racial/ethnic minority backgrounds. It is well documented that lack of knowledge and poor personal risk perception which are usually mediated by low SES, limited access to health care services, cultural barriers such as misconceptions about BC risk factors, prevention, and treatments, or the fear of being diagnosed with the disease predispose to the underutilization of prevention services such as clinical breast examination, mammographic screening, or genetic testing [26,27]. These events predispose to the observed disparities in BC health outcomes in these women. Thus, I hypothesized that the level of knowledge of BC risk factors, prevention and treatments strategies, and perceived personal risk of women who are medically underserved, of racial/ethnic minority backgrounds, and may be eligible for chemoprevention therapies will vary according to their SES, sociodemographic, lifestyle, health care access, and selected clinical characteristics. In this report, I describe the association of socio-demographic, SES, lifestyle, health care access, and selected clinical characteristics with the knowledge of BC prevention and treatment strategies and the accuracy of personal risk perception.

Materials and Methods

This cross-sectional study utilized the data from the Acceptance of Breast Cancer Chemoprevention Therapy (ABCCPT) project, whose goal was to determine the barriers and enhancing factors to accepting chemoprevention therapies among racial minorities and medically underserved women who were at increased risk of BC. The study was conducted at the Baylor College of Medicine and its affiliated health establishments (i.e., The Ben Taub General Hospital and the Lyndon B. Johnson General Hospital) in Houston, Texas from 2005 to 2007. These establishments cater to indigent patients who have mainly public health insurance.

Selection of Participants

All participants were defined as being at increased risk of BC in that they had to be either 60 years or older or 35 to 59 years with multiple risk factors including a family history in single or multiple first-degree relatives (FDRs), multiple breast biopsies, a history of atypical ductal or lobular hyperplasia, nulliparity, late first live birth (35 years or older), early menarche (<12 years of age), and/or late menopause [28,29]. Thus, participants who were 60 years or older without additional risk factors were considered to be eligible. For participants who were 35 to 59 years of age, the minimum numbers of additional risk factors were one for 50–59 years, two for 40–49 years, and three for 35–39 years. Thus, the younger participants needed to have more risk factors to be eligible. This method is consistent with current nonmathematical risk assessment models [28,29]. Women who had been diagnosed with BC, received chemoprevention therapies counseling and/or the therapies, those with psychiatric disorders, the terminally ill, Asian and other racial/ethnic groups (i.e., due to their small population), and nonresidents of the Houston, Texas area were excluded. The objectives of this study were to describe the factors associated with the knowledge of BC prevention and treatments (n=254) and perceived personal risk of BC (n=249) in a subset of the ABCCPT study participants. The ABCCPT project was approved by the Institutional Review Boards of the Baylor College of Medicine and its affiliated institutions. Participants were selected from those who visited these establishments for breast care and gave their written informed consents prior to participating in the study.

Variables and Measurements

Data were collected by trained bilingual (i.e., in English and Spanish) telephone interviewers using the Breast Cancer Risk Reduction Health Belief scale, a 45-item instrument that was developed based on the constructs of the Health Belief Model (HBM) [30] and validated with communality estimates ranging from 0.50 to 0.75 and retest reliability of r=0.85 [31]. The HBM construct “perceived susceptibility” was used to assess the accuracy of the participants’ perceived personal risk of BC. This was done using a five-point Likert-style item (i.e., “Compared to other women my age, my chances of getting BC are: much lower, a little lower, about the same, a little higher, or much higher”). Subsequently, it was dichotomized into above average vs. average or lower than average risk perception. Other self-reported variables included sociodemographic characteristics such as age; educational attainment; annual household income before taxes; race/ethnicity; marital status; employment status; health insurance status; having a regular personal physician; clinical characteristics such as the use of hormone replacement therapy (HRT); the number of mammogram received in the past 5 years prior to the interview date; a family history of BC in a FDR; and lifestyle characteristics such as cigarette smoking and weekly alcohol intake. The Breast Cancer Knowledge Test and validated by Veath in 1993 had 16 items with a “true” or “false” response option that assessed the participant’s knowledge of the risk factors, symptoms, signs, diagnosis, and treatment strategies [32]. Minor revisions were made to improve readability, and it was then reassessed to ascertain its internal consistency reliability prior to its use in the study. The performance on the knowledge test was classified in terms of the average (mode) scores (i.e., 66.7% or higher or <66.7%), a cut-point that is commensurate with previous findings in other study populations with similar socioeconomic and demographic characteristics [32,33].

Statistical Analysis

Descriptive statistics were generated for continuous (i.e., mode, mean, standard deviations [SD], and associated p values) and categorical variables (i.e., numbers, percentages, chi-square statistics with p values, Cochran–Armitage trend tests with corresponding p values). Based on significant p values (i.e., $p \leq 0.05$) for chi-square estimates, univariate and multivariate logistic regression logistic regression models were fitted to determine the

natural log odds of having an average or higher test score or perceiving one's risk to be above average relative to the reverse, then crude or adjusted odds ratios (OR) with 95% confidence intervals (CI) were generated, respectively (see Table 1). The Hosmer and Lemeshow Goodness-of-Fit Test [35] was conducted to assess how well each model fitted together, and appropriate chi-square statistics and *p* values were generated. Following the preliminary results and in order to gain a better understanding of the role of educational attainment as a significant correlate of knowledge in this population, I cross-tabulated the former by the latter and generated chi-square statistics and *p* values. Similarly, I also explored the potential association between the knowledge of BC and perceived personal risk by cross-tabulating perceived personal risk by knowledge test scores. With a sample size of 254 at a significance level of 5% in a two-tailed test, I achieved a statistical power of 80% to detect differences of at least 20% between comparison groups. The response rate for this subset of the population was 74.1%.

All statistical tests were two-sided, and a *p* value of 0.05 or less was considered significant. The Statistical Analysis Software version 9.1 (SAS, Cary NC) was used for all analyses. The National Cancer Institute provided the funds for the ABCCPT project, but were not directly involved in the design, conduct, and reporting of this study.

Results

Participants

The mean age of participants was 61 years (SD=11.9). Educational attainment was low (i.e., 66.4% had a high school education or less), most reported an annual household income of < $20,000 (59.7%), most had only public health insurance (79.3%), and most were married (59.5%). With respect to racial/ethnic backgrounds, Caucasians accounted for 31.7%, Hispanics 28.9%, and African Americans 39.4%. In all, the knowledge of the participants about BC prevention and treatments was low with only 39% of the women being relatively more knowledgeable (i.e., 66.7% or higher test scores). Similarly, only 42% accurately perceived their risk (i.e., perceived themselves to be at above average risk) of BC.

Unadjusted Correlates of Knowledge or Perceived Personal Risk

From the chi-square analyses, being relatively more knowledgeable was directly associated with having a college education, having an annual household income of $30,000 or more, being of Caucasian race/ethnicity, or being married. Other characteristics directly associated with being more knowledgeable were being employed, having a private health insurance, being a current user of HRT, being a former smoker, and having at least five mammograms in the past 5 years. Women who perceived their risk of BC accurately were more likely to have attended college, to be of Caucasian race/ethnicity, and to have a family history of BC in at least one FDR when compared to their counterparts. Univariate logistic regression analyses showed that the odds of being more knowledgeable were 60% lower in women who were 70 years or more (with those <50 years as the referent group). When compared to those with a college education, those with elementary and high school education were 90% and 80% of the times less knowledgeable, respectively (i.e., had <66.7% in the knowledge test). Relative to those with annual household incomes of $30,000 or more, those with < $20,000 or $20,000–$29,000 were 90% of the times less knowledgeable. With respect to employment status, homemakers or retirees were 60% of the time relatively less knowledgeable than those who were employed. When compared to those with private insurance, those with Medicare/Medicaid and those with Medicaid only were 90% and 100% of the time less knowledgeable, respectively. On the other hand, relative to singles, married women were 2.3 times more knowledgeable. Compared to women who reported never using HRT, current users were 6.5 times more knowledgeable than the never used

group, former smokers were twice more knowledgeable than the never smoked group, and women who reported the receipt of five or more mammograms in the past 5 years were 1.8 times more knowledgeable than their counterparts. With respect to the accuracy of perceived susceptibility to BC, Hispanics were 50% of the time less likely to accurately perceive their risk of BC when compared to Caucasians. Relative to their respective referent groups (see Table 1), former smokers were two times, women with a family history in at least one FDR were over two times, and those who had average or higher knowledge test scores were 1.7 times more likely to accurately perceive their risk of BC, respectively. However, these were not statistically significant after multivariate-adjusted analyses.

The Correlates of the Knowledge of Breast Cancer Risk Factors, Prevention, and Treatment Strategies

Upon multivariate-adjusted analyses, only the association of educational attainment with knowledge scores was statistically significant. With respect to perceived personal risk of BC, women with elementary school education were 60% of the time less likely to accurately perceive their risk relative to those who had a college education. The Hosmer and Lemeshow Goodness-of-Fit Tests for each of the models were not significant (i.e., p=0.63 and p=0.28 for the knowledge test scores and the perceived personal BC risk models, respectively), indicating that the model was accurately fitted.

Interactions between Race/Ethnicity and Knowledge

There was a significant interaction between race/ethnicity and educational attainment (p<0.001), in that Caucasians were more likely to have attended college (54.8% vs. 7.1% vs. 38.1% for Caucasians, Hispanics, and African Americans, respectively). African Americans were more likely to have only a high school education (51.9% vs. 19.8% vs. 28.3% for African Americans, Hispanics, and Caucasians, respectively). Finally, Hispanics were more likely to have only elementary school education (76.3% vs. 18.6% vs. 5.1% for Hispanics, African Americans, and Caucasians, respectively). There was also a significant association between perceived personal risk of BC and knowledge tests scores (p=0.05), in that women who accurately perceived their risk of BC were more knowledgeable (46.2%) than their counterparts (33.9%; p for trend=0.05, OR=1.7, 95% CI= 1.01–2.81). While this direction of association remained, it was no longer statistically significant when other covariates were included in the model (see Table 1).

Discussion

The goal of the study was to assess the association of sociodemographic variables, SES, lifestyle, health care access, and selected clinical characteristics with the knowledge of BC prevention and treatment strategies and with perceived personal risk. After controlling for potential confounding factors, educational attainment was significantly associated with being more knowledgeable. The findings are consistent with studies in other populations where being college educated was shown to be crucial to having an adequate knowledge of BC prevention and treatment strategies [36,37]. These findings suggested that having more education (such as being a college graduate) enables one to acquire and assimilate information on BC risk factors [37–39]. This view is buttressed by the finding that Hispanic participants who mostly had elementary education were the least knowledgeable (i.e., only 15% had average or higher test scores). With respect to perceived personal risk, I did not find a significant correlate of the accuracy of perceived personal risk in this study population. While a positive association of family history of BC in at least one FDR with accurate personal risk perception has been reported by some investigators [10,40,41], this has not been the case with others. For example, Lipkus et al. in 1999 reported a confounded association of having a family history of BC with perceived personal risk. Further

assessments of these reports suggested that the differences in the literacy levels of women in the respective study populations may have played a significant role with regards to these findings [10,40,41]. A positive family history was a significant predictor of accurate risk perception in study populations that comprised mainly of middle or higher SES women who may have been more knowledgeable of BC risk factors. Meanwhile, the reverse was the case in the study population that comprised mainly of participants who were underserved, of low SES, and had limited knowledge of BC risk factors. Furthermore, as was reported by Daly et al. in 1996, known BC risk factors, such as those used in the selection criteria for chemoprevention trials and in this study, correlated poorly with perceived personal risk, as most women are not aware of these characteristics [42]. It appears that a good education empowers one to know more about BC, but how this knowledge would affect one's personal risk perception is further influenced by other factors such as types of risk factors assessed, the method of assessment, or cultural factors [17,22,40–43].

The strengths of the study include the focus on a new and emerging population of underserved, low SES, and racial minority women who are at increased risk of ER-positive BC, which is amenable to chemoprevention therapies. This is of utmost importance since these women bear a disproportionate burden of the deaths from BC and largely understudied especially with respect to their knowledge and perceived personal risk of BC, as it pertains to their decision-making processes with respect to the use of BC risk assessment, chemoprevention therapies counseling, or the therapies. Furthermore, the findings are consistent with the literature (see above), psychosocially plausible in that studies in other populations have demonstrated that there is a clear relationships between limited knowledge of BC risk factors and prevention strategies and utilization of preventive services [40,44]. The use of a stringent criterion to select the participants ensured that they were not only at increased risk, but may be eligible for chemopreventive interventions [28,29]. Finally, it is unlikely that these findings are due to chance in view of the significant *p* values, narrow CI, and the adjustments I made for other covariates. Albeit, the study had certain limitations, for instance, the cross-sectional design limited the assessments to a specific point in time, while the level of knowledge or risk perception may change over time. Furthermore, the selection criteria was based on the current knowledge of BC risk factors, which is limited especially for racial minorities, as such some potentially eligible women may have been excluded. Data on nonresponders were not obtained, as this was particularly difficult in a largely indigent and frequently mobile population. However, the fact that the findings of this study are consistent with large longitudinal studies gives it credence [6,7]. These results should be generalizable to underserved or racial minority women at increased risk of BC.

Adequate knowledge of BC risk factors and prevention strategies have been associated with the increased use of mammography [41], the knowledge of genetic testing prerequisites [14], and interest in [12] or attendance of genetic counseling clinics [13]. It is, therefore, appropriate to infer that, except in the instances where the patients are resistant [16,45], educating medically underserved women who are at increased risk of BC on the risk factors, prevention, and treatment strategies would increase their knowledge of BC in general. This would in turn enable them to make informed decisions about the receipt of BC risk assessment, counseling on chemoprevention therapies, or the actual therapies. These findings suggest the need for tailored educational interventions that target the under-served women in general and those at increased risk of BC in particular.

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Table 1

Results of univariate and multivariate logistic regression analyses

Patients' characteristics	Crude OR	95% CI	Adjusted OR[a]	95% CI
Percent knowledge scores				
Age (years)				
<50	1.0		1.0	
50–59	1.1	0.5–2.3	0.9	0.2–3.2
60–69	1.0	0.5–1.9	1.2	0.3–4.1
≥70	0.4	0.2–1.0	0.4	0.1–2.0
Education				
College	1.0		1.0	
Elementary	0.1	0.1–0.3[b]	0.3	0.1–1.6
High school	0.2	0.1–0.4[b]	0.3	0.1–0.9[b]
Annual income				
$≥30,000	1.0		1.0	
<$20,000	0.1	0.0–0.2[b]	0.3	0.1–1.2
$20,000–$29,000	0.1	0.1–0.4[b]	0.3	0.1–1.9
Race/ethnicity				
Caucasian	1.0		1.0	
Hispanic	0.1	0.1–0.2[b]	0.4	0.1–1.7
African American	0.2	0.1–0.3[b]	0.5	0.2–1.3
Marital status				
Single	1.0		1.0	
Married	2.3	1.4–3.9[b]	1.6	0.6–4.4
Employment status				
Employed	1.0		1.0	
Homemaker/volunteer	0.4	0.2–0.9[b]	2.0	0.2–16.1
Retired	0.4	0.2–0.8[b]	0.8	0.1–4.3
Unemployed/unable to work	0.5	0.3–1.1	1.4	0.3–7.0
Health insurance				
Private insurance	1.0		1.0	
Medicare/Medicaid	0.1	0.0–0.3[b]	0.5	0.10–2.9
Medicaid only	0.0	0.0–0.1[b]	0.4	0.07–2.4
HRT use				
Never	1.0		1.0	
Former	1.6	0.9–2.9	1.5	0.6–3.7
Current	6.5	2.7–15.6[b]	2.0	0.5–7.7
Smoking				
Never	1.0		1.0	
Former	2.0	1.1–3.7[b]	2.3	0.8–6.8

Patients' characteristics	Crude OR	95% CI	Adjusted OR[a]	95% CI
Current	0.5	0.2–1.1	0.4	0.1–1.6
Number of mammograms in the past 5 years				
<5	1.0		1.0	
5 or more	1.8	1.1–3.1[b]	1.4	0.5–3.6
Perceived personal risk of BC				
Age (years)				
<50	1.0		1.0	
50–59	0.9	0.5–1.9	0.9	0.4–2.0
60–69	1.1	0.5–2.1	1.0	0.4–2.1
≥70	1.0	0.4–2.2	0.7	0.3–1.8
Education				
College	1.0		1.0	
Elementary	0.4	0.2–0.7[b]	0.5	0.2–1.2
High school	0.6	0.3–1.1	0.6	0.3–1.3
Race/ethnicity				
Caucasian	1.0		1.0	
Hispanic	0.5	0.2–0.9[b]	1.0	0.3–2.5
African American	1.2	0.7–2.2	1.6	0.8–3.4
Smoking				
Never	1.0		1.0	
Former	2.0	1.1–3.5[b]	1.7	0.9–3.3
Current	1.3	0.6–2.6	1.1	0.5–2.5
Knowledge scores (%)				
Less than average	1.0		1.0	
Average or higher	1.7	1.0–2.8[b]	1.2	0.6–2.4
Family history of BC in FDRs				
No	1.0		1.0	
Yes	2.1	1.1–4.0[b]	1.8	0.9–3.5

CI confidence intervals, *OR* odds ratios, *HRT* hormone replacement therapy, *BC* breast cancer, *FDR* first-degree relative

[a] Adjusted for all other covariates

[b] Statistically significant