



Published in final edited form as:

*Cancer*. 2015 March 1; 121(5): 724–732. doi:10.1002/cncr.28977.

## Racial/Ethnic Disparities in Knowledge about One's Breast Cancer Characteristics

Rachel A. Freedman, MD,MPH<sup>1</sup>, Elena M. Kouri, PhD<sup>2</sup>, Dee W. West, PhD<sup>3</sup>, and Nancy L. Keating, MD,MPH<sup>2,4</sup>

<sup>1</sup>Department of Medical Oncology, Dana-Farber Cancer Institute, Boston, MA

<sup>2</sup>Harvard Medical School, Department of Health Care Policy, Boston, MA

<sup>3</sup>Cancer Registry of Greater California, Public Health Institute, Sacramento, CA

<sup>4</sup>Division of General Internal Medicine, Department of Medicine, Brigham and Women's Hospital, Boston, MA

### Abstract

**Background**—Understanding tumor characteristics is likely important but little is known about breast cancer patients' knowledge of their disease. We assessed women's knowledge about their tumor characteristics, whether racial/ethnic disparities in knowledge exist, and whether education and health literacy influenced associations.

**Methods**—We surveyed a population-based cohort of women in Northern California with stage 0-III breast cancer diagnosed during 2010-2011 (participation rate=68.5%). Among 500 respondents (222 non-Hispanic white, 142 non-Hispanic black, and 136 Hispanic women), we examined racial/ethnic differences in knowledge about tumor characteristics (estrogen receptor [ER], Human Epidermal Growth Factor Receptor 2 [HER2], stage, grade) and correctness of tumor information (with California Cancer Registry data for confirmation). We used multivariate logistic regression to assess the probability of (a) 'knowing' tumor stage, receptor status, and grade and (b) 'correctly answering' tumor information by race/ethnicity. In sequential models, we examined the impact of education and health literacy on findings.

**Results**—Overall, 32%-82% reported knowing each of the 4 tumor characteristics and 20%-58% correctly reported these characteristics. After adjustment, black and Hispanic women were less likely than white women to know and have correct responses for stage, ER, and HER2 (all  $P < .05$ ). Education and health literacy were significantly associated with knowing and having correct information for some characteristics, but these variables did not eliminate most of the racial/ethnic differences observed.

**Conclusions**—Knowledge about one's breast cancer was generally poor, particularly for minority women. Further study of how this knowledge may impact receipt of care and outcomes is warranted.

---

**Corresponding Author:** Rachel Freedman, MD,MPH, Dana-Farber Cancer Institute, 450 Brookline Avenue, Boston, MA 02215, Ph: 617.632.4587; Fax:617.632.1930, rafreedman@partners.org.

**Financial Disclosures:**none

## Graphical Abstract

**Precis:** Knowledge about one's breast cancer characteristics is generally poor for all patients, and minority, less educated, and older women are the least likely to know and correctly report characteristics.

## Keywords

breast cancer; knowledge; disparities; health literacy; education

---

## INTRODUCTION

Having knowledge about one's health conditions or the risk of developing health conditions can promote healthy behaviors and treatment adherence.<sup>1-3</sup> Better general knowledge about cancer is associated with cancer screening,<sup>4-6</sup> earlier stage at presentation and survival,<sup>7, 8</sup> and enhanced satisfaction with care.<sup>9, 10</sup> Despite these benefits, general cancer knowledge is poor overall,<sup>10-13</sup> and many women with breast cancer want more information from their providers.<sup>14</sup> Prior studies of cancer knowledge have mainly focused on understanding treatment options, rationales, and the associated risks.<sup>10-13, 15</sup> However, for cancer patients, understanding characteristics of one's cancer, such as stage and receptor status, is also likely important. Such tumor-specific knowledge may lead to a better understanding of treatment rationale (e.g., endocrine therapy for hormone receptor-positive tumors), enhanced decision-making, better treatment adherence, and more empowered patients. To our knowledge, prior studies have not examined breast cancer patients' knowledge about their own disease.

Racial disparities in breast cancer treatment and outcomes are pervasive and the reasons for lower rates of guideline-recommended care for racial/ethnic minorities are complex. Racial/ethnic differences in knowledge about one's breast cancer characteristics, if present, could potentially contribute to differences in treatment receipt and adherence. In addition, past studies have suggested that lower health literacy, educational attainment, and income are associated with knowledge about health conditions.<sup>16-19</sup> Because health literacy<sup>20-24</sup> and socioeconomic status<sup>25</sup> are often lower in minority patients, these factors could contribute to suboptimal knowledge for minority patients.

We surveyed a diverse, population-based cohort of women with breast cancer in Northern California to assess differences in knowledge of individual tumor characteristics by race/ethnicity. We also assessed whether differences in educational attainment and health literacy explained any racial/ethnic differences in knowledge.

## METHODS

### Study Population

We identified 1,118 white, black, or Hispanic women who underwent primary surgery for a stage 0-III breast cancer diagnosed during 2010-2011 in Regions 1/8 (San Francisco/Santa Clara) and Region 3 (Sacramento) of the California Cancer Registry (CCR). These areas cover 22 counties and over 9 million residents.<sup>26</sup> The registries (both part of the Surveillance

Epidemiology, and End Results program) uniformly collect information on patient demographics, tumor characteristics, primary treatments, and mortality for all incident cancers in these regions. We obtained study approvals from the CCR, the California Health and Human Services Agency Committee for the Protection of Human Subjects, and the Harvard Medical School Committee on Human Studies.

### Survey Administration and Patient Enrollment

We mailed letters to eligible patients in English and Spanish inviting them to participate voluntarily in a confidential survey about their breast cancer care. The mailing included a postage-paid opt-out card if they preferred not to be contacted and a toll-free number to call to participate or opt-out. Patients who did not opt out but whom we did not reach by phone received a second mailing. At least 6 telephone calls were attempted at different times and on different days. Participants provided verbal consent before the interview began and received a \$20 incentive upon interview completion. Interviews were conducted by trained study staff using computer assisted telephone interview software.

### Survey

Participants were asked about their breast cancer characteristics (Table 1), including tumor stage, grade, and receptors (estrogen receptor [ER], progesterone receptor [PR], Human Epidermal Growth Factor Receptor 2 [HER2]); all questions included the option “don't know”. We also asked about treatments received<sup>27</sup> and collected information on self-reported race/ethnicity, educational attainment,<sup>28</sup> household income,<sup>28</sup> insurance coverage,<sup>28</sup> health literacy,<sup>29</sup> and comorbidity.<sup>28</sup> We performed cognitive testing with 10 patients (in English and Spanish) before the instrument was finalized to ensure feasibility and clarity, resulting in minimal changes to the question sequence only.

### Response Rates

Among the 1,118 patients (Figure 1), 231 refused participation, 317 could not be reached, 68 were deceased/too ill, and 502 women were surveyed. Two of these 502 women self-identified as Asian and were excluded. The response rate (using American Association for Public Opinion Research [AAPOR] methods) was 47.8%; the participation rate among those for whom we had contact information was 68.5%. White women were less likely to have no contact information (15%) compared with black (25%) and Hispanic (23%) women. However, after exclusion of those without contact information (n=227), respondents (n=502) (vs. non-respondents [n=389]) were similar with regard to race/ethnicity and tumor characteristics, although respondents were younger (mean age=58 vs. 64;p<.0001). Seventy of 136 Hispanic women were interviewed in Spanish.

### Variables of Interest

We examined whether participants reported ‘knowing’ their breast cancer characteristics (ER/HER2/grade/stage) as well as the ‘correctness’ of participant-reported breast cancer characteristics using CCR data. ‘Knowing’ tumor characteristics was defined as providing an answer (correct or incorrect) to specific questions about the characteristics (Table 1) versus responding “I don't know”. Answers were considered ‘correct’ if a participant's

answer matched the tumor characteristic according to the CCR or if the CCR result was “unknown,” “not performed,” or missing. Women who reported having stage IV disease (N=12) were considered to correctly report stage because their cancer (originally diagnosed as stage 0-III) may have recurred.

### Independent Variables

Independent variables of interest included race/ethnicity, educational attainment, and health literacy.<sup>29</sup> We assessed health literacy using three questions:<sup>29</sup> (1) “How confident are you filling out medical forms,” (2) “How often do you have problems learning about your medical condition?,” and (3) “How often do you have someone help you read hospital materials?” Responses used a 5-item Likert scale. After reversing responses for the first item, we assigned each of these answers a score of 1-5 (lowest number consistent with the most confidence/fewest problems) and calculated the mean of the three scores as a summary variable. One participant did not answer question (2) above; we used the mean of her two other responses. Control variables were categorized as in Table 2 and included age, marital status, insurance status at diagnosis, and number of comorbidities. We also collected household income (Table 1) but because this variable was highly correlated with education, we did not include it in adjusted analyses.

### Statistical Analysis

We used the  $\chi^2$  and Kruskal-Wallis tests to assess differences in baseline characteristics by race/ethnicity and the  $\chi^2$  test to assess associations between race/ethnicity and ‘knowing’ and ‘correctly answering’ questions. We then performed a series of logistic regression models to examine the probability of (a) ‘knowing’ and (b) ‘correctly answering’ questions about stage, grade, ER, and HER2. For each tumor characteristic endpoint, we performed three models. First, we included race/ethnicity, adjusting for age, marital status, insurance, and comorbidity (i.e. base model). We next repeated models also including education, followed by a model which also included health literacy. We also performed ordinal logistic regression models for the summed outcomes of (a) knowing more characteristics (0-4) and (b) correctly answering questions (0-4).

Because grade, HER2 status, and other tumor features are less emphasized in the setting of noninvasive disease, we repeated all analyses after excluding patients with stage 0 cancers (N=86). Results were similar and are not presented.

In an exploratory analysis, we examined whether women with ER or PR-positive disease (according to CCR data) who reported knowing or having correct ER status were more likely to report taking hormonal treatment than women who reported they did not know or answered incorrectly.

## RESULTS

Characteristics of the cohort by race/ethnicity are shown in Table 2. In general, Hispanic participants were younger than other groups and white and Hispanic patients were more likely married. Hispanic women had lower educational attainment and lower household

incomes compared with black and white women and were less likely to be insured at diagnosis.

Overall, 55% reported knowing ER status, 33% reported knowing HER2 status, 82% reported knowing stage, 32% reported knowing grade, and 14% reported knowing all four characteristics; 14% reported knowing no characteristics. Approximately 56% reported correct ER, 58% reported correct HER2, 57% reported correct stage, 20% reported correct grade, and 8% had all four questions correct. In general, minority participants were less likely to report knowing or answering questions correctly for multiple tumor characteristics, including stage and receptors (Figure 2).

In adjusted analyses (Table 3), the results of the base models revealed racial/ethnic differences for all outcomes, with exception of knowing and having correct grade and correct HER2 status, with black and Hispanic (vs. white) women having consistently lower odds of knowing and correctly answering questions. When education was added to models, the findings for black women did not significantly change across all outcomes examined. However, for Hispanic women, odds ratios for several models changed by >20%, with findings becoming non-significant in both stage models and in the correct HER2 model (Table 3). Adding health literacy in the final models did not change results for black women but narrowed differences for Hispanic (vs. white) women in models for both ER variables, knowing HER2, knowing more answers, and having more answers correct. In addition, older age (particularly age >70 vs. age <50) was consistently associated with less knowledge and correctness with exception of the grade models. Less education and lower reported health literacy were also associated with various outcomes (Table 4).

Approximately 80% of the 336 women with ER or PR-positive disease per CCR data reported taking hormonal therapy; knowing and correctly reporting ER status was associated with hormonal therapy use. Rates of self-reported treatment were 86% among women who knew versus 71% among women who did not know their ER status. Similarly, among women who reported ER-positivity correctly, 88% reported taking hormonal therapy versus 69% of those answering ER incorrectly ( $p<.05$  for both).

## DISCUSSION

In this large, diverse, population-based cohort of breast cancer patients, we observed low rates of knowing and correctly reporting tumor information, with minority patients less likely than white patients to have information about their cancers. Lower educational attainment and lower health literacy were also associated with less knowledge about one's cancer. Nevertheless, differences in education and health literacy did not eliminate most of the observed differences for minority participants.

Our results dramatically illustrate the lack of understanding many patients have about their cancers and have identified a critical need for improved patient education and provider awareness of this issue. Although many factors contribute to disparities in care and outcomes, improving knowledge about one's tumor characteristics is a mutable factor that is likely amenable to educational interventions. Improving patients' understanding about why a

particular treatment is important for her *individual* situation (i.e. hormonal therapy because she has ER-positive disease or trastuzumab because she has HER2-positive disease) may lead to more informed decisions and better adherence to treatment plans. In addition, complementary interventions focusing on providers and how they transmit information to patients is essential to improved communication and comprehension of one's disease. Past studies have illustrated the tendency of minority patients to ask fewer questions and to participate less actively in care than white patients, with more reliance on providers for treatment recommendations.<sup>30-32</sup> Because of differences in patient needs, providers may need to tailor the way they transmit information to patients about their disease. In addition to cultural competency training, additional work is needed to understand how physicians can best assess patients' specific information needs and knowledge base and most effectively communicate information to them.

In exploratory analyses, we observed that knowledge about ER is associated with hormonal therapy for women with ER/PR-positive cancers, an important finding given the high rates of treatment non-adherence.<sup>33</sup> Although prior knowledge intervention studies have focused on general treatment and cancer knowledge, this work suggests that cancer information, often in the form of decision aids, may increase general breast cancer knowledge<sup>15, 34, 35</sup> and that a better understanding of general treatment benefits is associated with higher treatment rates.<sup>11, 13, 36</sup> A qualitative study of 49 black breast cancer patients found that many lacked knowledge about their diagnoses and treatments, and those with a better understanding more often adhered to treatments.<sup>37</sup> This study, other qualitative work,<sup>10</sup> and our exploratory findings about the receipt of hormonal therapy support a hypothesis that improved general knowledge as well improved understanding of one's tumor characteristics and the reasons for *personalized* treatment recommendations may improve adherence and ultimately, outcomes. In addition, improved knowledge about one's own disease may impact a woman's trust, communication, confidence, and satisfaction with her treatment team.

Our findings of lower knowledge and correctness associated with worse health literacy and lower educational attainment were consistent with other evidence that low health literacy is associated with poor knowledge about health conditions.<sup>16, 18, 19, 38</sup> Despite literacy and knowledge being distinct entities, a connection between literacy and cancer knowledge likely exists because of the potential challenges in gaining knowledge in the setting of lower health literacy. We also observed lower odds of knowledge and correctness for older patients, who may be more likely to prioritize other comorbidities, have memory loss, or participate in care less actively, possibly because of involvement of caregivers or because of poor health literacy.<sup>20, 39-41</sup>

To our knowledge, this is the first study to examine women's knowledge about their own disease characteristics. We surveyed a large number of women in their primary language and collected health literacy and socioeconomic information. However, the study has several limitations. First, our definitions of correctness relied on the accuracy of registry data and we did not have access to medical records. Nevertheless, prior studies have shown relatively accurate tumor stage reporting in registries compared with medical records, particularly for early-stage cancers.<sup>42</sup> To avoid misclassification of women who reported information about their tumors when CCR data were not available, we considered answers correct whenever



registry data were missing/unknown for that characteristic. Overall, for the 396 women in our study who reported their stage (0-III), 69% matched the staging provided by the CCR. Second, our health literacy measure, although previously validated,<sup>29</sup> was a brief screening measure only, selected to minimize patient burden. Third, although population-based, this study included women in Northern California only. Fourth, we cannot rule out non-response bias, although responders did not differ from non-responders by race/ethnicity and tumor characteristics. Moreover, because we surveyed women up to three years after their breast cancer diagnosis, it is possible that recall bias contributed to the lack of knowledge for some women. However, one would expect that knowledge about one's tumor characteristics would remain stable over time, particularly for those with ER-positive or HER2-positive disease, for whom prolonged treatments are often recommended.

In summary, our findings underscore the major deficits in women's knowledge about their cancers, with minority patients less likely than white women to know and report accurate information about their tumor characteristics. These observations highlight the need to better educate our patients about their tumors and to further examine how knowledge about one's cancer may contribute to receipt of care, adherence, and ultimately, outcomes.

## Acknowledgements

We acknowledge Ana Guerra for assistance with interviews and Huichuan Lii for her programming expertise.

**Funding:** Komen for the Cure Foundation

**Data:** The collection of cancer incidence data used in this study was supported by the California Department of Public Health as part of the statewide cancer reporting program mandated by California Health and Safety Code Section 103885; the National Cancer Institute's Surveillance, Epidemiology and End Results Program under contract HHSN261201000140C awarded to the Cancer Prevention Institute of California, contract HHSN261201000035C awarded to the University of Southern California, and contract HHSN261201000034C awarded to the Public Health Institute; and the Centers for Disease Control and Prevention's National Program of Cancer Registries, under agreement U58DP003862-01 awarded to the California Department of Public Health. The ideas and opinions expressed herein are those of the author(s) and endorsement by the State of California, Department of Public Health the National Cancer Institute, and the Centers for Disease Control and Prevention or their Contractors and Subcontractors is not intended nor should be inferred.

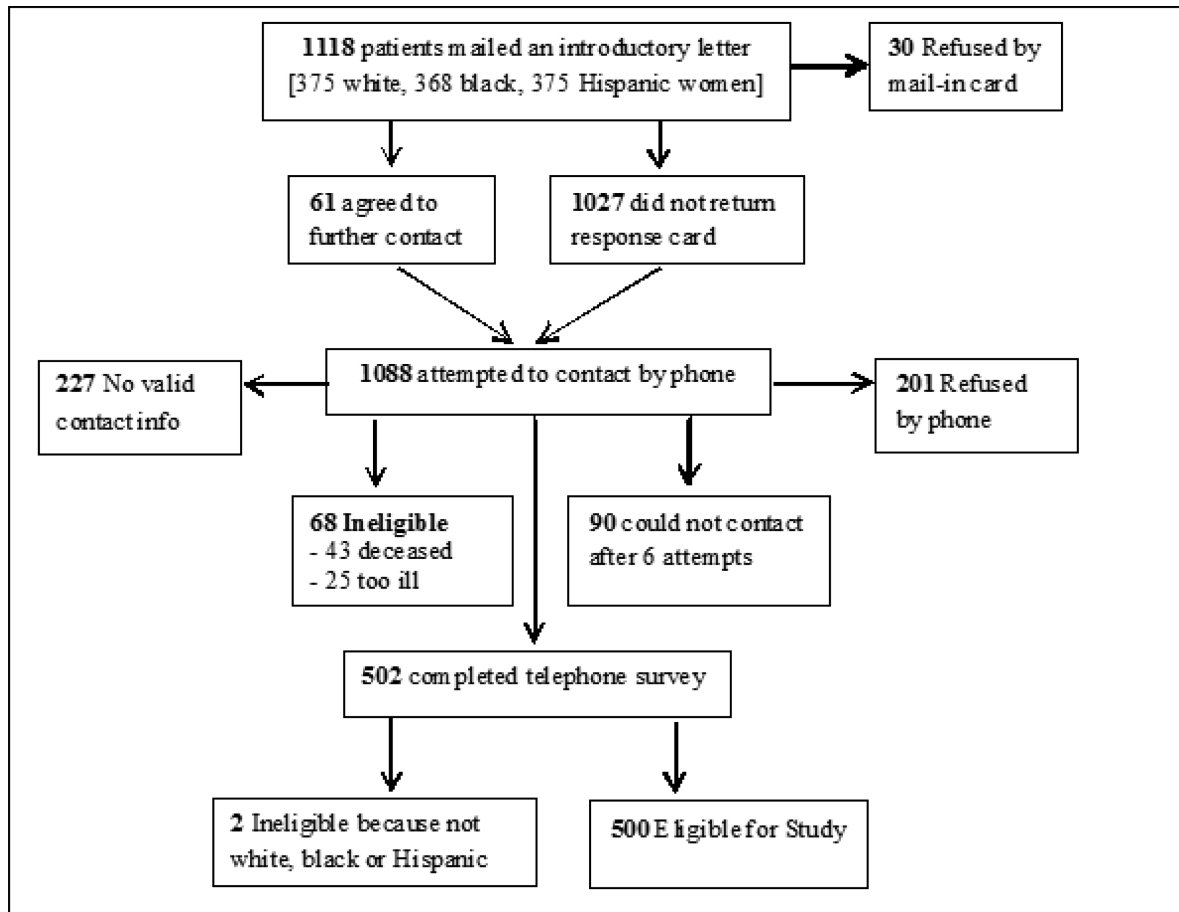
## REFERENCES

1. Brooks SE, Gordon NJ, Keller SJ, Thomas SK, Chen TT, Moses G. Association of knowledge, anxiety, and fear with adherence to follow up for colposcopy. *J Low Genit Tract Dis.* 2002; 6:17–22. [PubMed: 17050987]
2. Pearlman DN, Clark MA, Rakowski W, Ehrich B. Screening for breast and cervical cancers: the importance of knowledge and perceived cancer survivability. *Women Health.* 1999; 28:93–112. [PubMed: 10378347]
3. Alm-Roijer C, Fridlund B, Stagmo M, Erhardt L. Knowing your risk factors for coronary heart disease improves adherence to advice on lifestyle changes and medication. *J Cardiovasc Nurs.* 2006; 21:E24–31. [PubMed: 16966907]
4. Boling W, Laufman L, Lynch GR, Weinberg AD. Increasing mammography screening through inpatient education. *J Cancer Educ.* 2005; 20:247–250. [PubMed: 16497138]
5. Kessler TA. Increasing mammography and cervical cancer knowledge and screening behaviors with an educational program. *Oncol Nurs Forum.* 2012; 39:61–68. [PubMed: 22201656]
6. Sabatino SA, Lawrence B, Elder R, et al. Effectiveness of interventions to increase screening for breast, cervical, and colorectal cancers: nine updated systematic reviews for the guide to community preventive services. *Am J Prev Med.* 2012; 43:97–118. [PubMed: 22704754]

7. Goodwin JS, Samet JM, Hunt WC. Determinants of survival in older cancer patients. *J Natl Cancer Inst.* 1996; 88:1031–1038. [PubMed: 8683633]
8. Samet JM, Hunt WC, Goodwin JS. Determinants of cancer stage. A population-based study of elderly New Mexicans. *Cancer.* 1990; 66:1302–1307. [PubMed: 2400979]
9. Street RL Jr, Voigt B. Patient participation in deciding breast cancer treatment and subsequent quality of life. *Med Decis Making.* 1997; 17:298–306. [PubMed: 9219190]
10. Fagerlin A, Lakhani I, Lantz PM, et al. An informed decision? Breast cancer patients and their knowledge about treatment. *Patient Educ Couns.* 2006; 64:303–312. [PubMed: 16860523]
11. Chen JY, Diamant AL, Thind A, Maly RC. Determinants of breast cancer knowledge among newly diagnosed, low-income, medically underserved women with breast cancer. *Cancer.* 2008; 112:1153–1161. [PubMed: 18189306]
12. Lukwago SN, Kreuter MW, Holt CL, Steger-May K, Bucholtz DC, Skinner CS. Sociocultural correlates of breast cancer knowledge and screening in urban African American women. *Am J Public Health.* 2003; 93:1271–1274. [PubMed: 12893610]
13. Bickell NA, Weidmann J, Fei K, Lin JJ, Leventhal H. Underuse of breast cancer adjuvant treatment: patient knowledge, beliefs, and medical mistrust. *J Clin Oncol.* 2009; 27:5160–5167. [PubMed: 19770368]
14. von Friederichs-Fitzwater MM, Denyse T. The unmet needs of African-American women with breast cancer. *Advances in Breast Cancer Research.* 2012; 1:1–6.
15. Whelan T, Levine M, Willan A, et al. Effect of a decision aid on knowledge and treatment decision making for breast cancer surgery: a randomized trial. *Jama.* 2004; 292:435–441. [PubMed: 15280341]
16. Lindau ST, Tomori C, Lyons T, Langseth L, Bennett CL, Garcia P. The association of health literacy with cervical cancer prevention knowledge and health behaviors in a multiethnic cohort of women. *Am J Obstet Gynecol.* 2002; 186:938–943. [PubMed: 12015518]
17. Williams MV, Baker DW, Parker RM, Nurss JR. Relationship of functional health literacy to patients' knowledge of their chronic disease. A study of patients with hypertension and diabetes. *Arch Intern Med.* 1998; 158:166–172. [PubMed: 9448555]
18. Gazmararian JA, Williams MV, Peel J, Baker DW. Health literacy and knowledge of chronic disease. *Patient Educ Couns.* 2003; 51:267–275. [PubMed: 14630383]
19. Wilkinson AV, Vasudevan V, Honn SE, Spitz MR, Chamberlain RM. Sociodemographic characteristics, health beliefs, and the accuracy of cancer knowledge. *J Cancer Educ.* 2009; 24:58–64. [PubMed: 19259867]
20. Williams MV, Parker RM, Baker DW, et al. Inadequate functional health literacy among patients at two public hospitals. *Jama.* 1995; 274:1677–1682. [PubMed: 7474271]
21. Baker DW, Parker RM, Williams MV, Clark WS. Health literacy and the risk of hospital admission. *J Gen Intern Med.* 1998; 13:791–798. [PubMed: 9844076]
22. Kirsch, I.; Jungeblut, A.; Jenkins, L.; Kolstad, A. *A First Look at the Results of the National Adult Literacy Survey.* National Center for Education, US Dept of Education; Washington, DC: 1993. *Adult Literacy in America..*
23. Sudore RL, Mehta KM, Simonsick EM, et al. Limited literacy in older people and disparities in health and healthcare access. *J Am Geriatr Soc.* 2006; 54:770–776. [PubMed: 16696742]
24. Institute for Education Sciences. [August 29, 2012] report: The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy. (<http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2006483>)
25. United States Census Bureau. [June 10, 2014] <http://www.census.gov/main/www/cen2000.html>
26. California Cancer Resistry. [May 9, 2014] [www.cancer-rates.info/ca/](http://www.cancer-rates.info/ca/)
27. Phillips KA, Milne RL, Buys S, et al. Agreement between self-reported breast cancer treatment and medical records in a population-based Breast Cancer Family Registry. *J Clin Oncol.* 2005; 23:4679–4686. [PubMed: 15851764]
28. Ayanian JZ, Chrischilles EA, Fletcher RH, et al. Understanding cancer treatment and outcomes: the Cancer Care Outcomes Research and Surveillance Consortium. *J Clin Oncol.* 2004; 22:2992–2996. [PubMed: 15284250]



29. Chew LD, Griffin JM, Partin MR, et al. Validation of screening questions for limited health literacy in a large VA outpatient population. *J Gen Intern Med.* 2008; 23:561–566. [PubMed: 18335281]
30. Gordon HS, Street RL Jr, Sharf BF, Soucek J. Racial differences in doctors' information-giving and patients' participation. *Cancer.* 2006; 107:1313–1320. [PubMed: 16909424]
31. Hack TF, Degner LF, Parker PA, Team SC. The communication goals and needs of cancer patients: a review. *Psychooncology.* 2005; 14:831–845. [PubMed: 16200519]
32. Kreling B, Figueiredo MI, Sheppard VL, Mandelblatt JS. A qualitative study of factors affecting chemotherapy use in older women with breast cancer: barriers, promoters, and implications for intervention. *Psychooncology.* 2006; 15:1065–1076. [PubMed: 16598833]
33. Hershman DL, Kushi LH, Shao T, et al. Early discontinuation and nonadherence to adjuvant hormonal therapy in a cohort of 8,769 early-stage breast cancer patients. *J Clin Oncol.* 2010; 28:4120–4128. [PubMed: 20585090]
34. Whelan T, Sawka C, Levine M, et al. Helping patients make informed choices: a randomized trial of a decision aid for adjuvant chemotherapy in lymph node-negative breast cancer. *J Natl Cancer Inst.* 2003; 95:581–587. [PubMed: 12697850]
35. Waljee JF, Rogers MA, Alderman AK. Decision aids and breast cancer: do they influence choice for surgery and knowledge of treatment options? *J Clin Oncol.* 2007; 25:1067–1073. [PubMed: 17369570]
36. Livaudais JC, Franco R, Fei K, Bickell NA. Breast cancer treatment decision-making: are we asking too much of patients? *J Gen Intern Med.* 2013; 28:630–636. [PubMed: 23229908]
37. Sheppard VB, Adams IF, Lamdan R, Taylor KL. The role of patient-provider communication for black women making decisions about breast cancer treatment. *Psychooncology.* 2010
38. Williams MV, Baker DW, Honig EG, Lee TM, Nowlan A. Inadequate literacy is a barrier to asthma knowledge and self-care. *Chest.* 1998; 114:1008–1015. [PubMed: 9792569]
39. Amalraj S, Starkweather C, Nguyen C, Naeim A. Health literacy, communication, and treatment decision-making in older cancer patients. *Oncology (Williston Park).* 2009; 23:369–375. [PubMed: 19476267]
40. Lewis M, Pearson V, Corcoran-Perry S, Narayan S. Decision making by elderly patients with cancer and their caregivers. *Cancer Nurs.* 1997; 20:389–397. [PubMed: 9409060]
41. Chouliara Z, Kearney N, Stott D, Molassiotis A, Miller M. Perceptions of older people with cancer of information, decision making and treatment: a systematic review of selected literature. *Ann Oncol.* 2004; 15:1596–1602. [PubMed: 15520059]
42. Malin JL, Kahn KL, Adams J, Kwan L, Laouri M, Ganz PA. Validity of cancer registry data for measuring the quality of breast cancer care. *J Natl Cancer Inst.* 2002; 94:835–844. [PubMed: 12048271]



**Figure 1.**

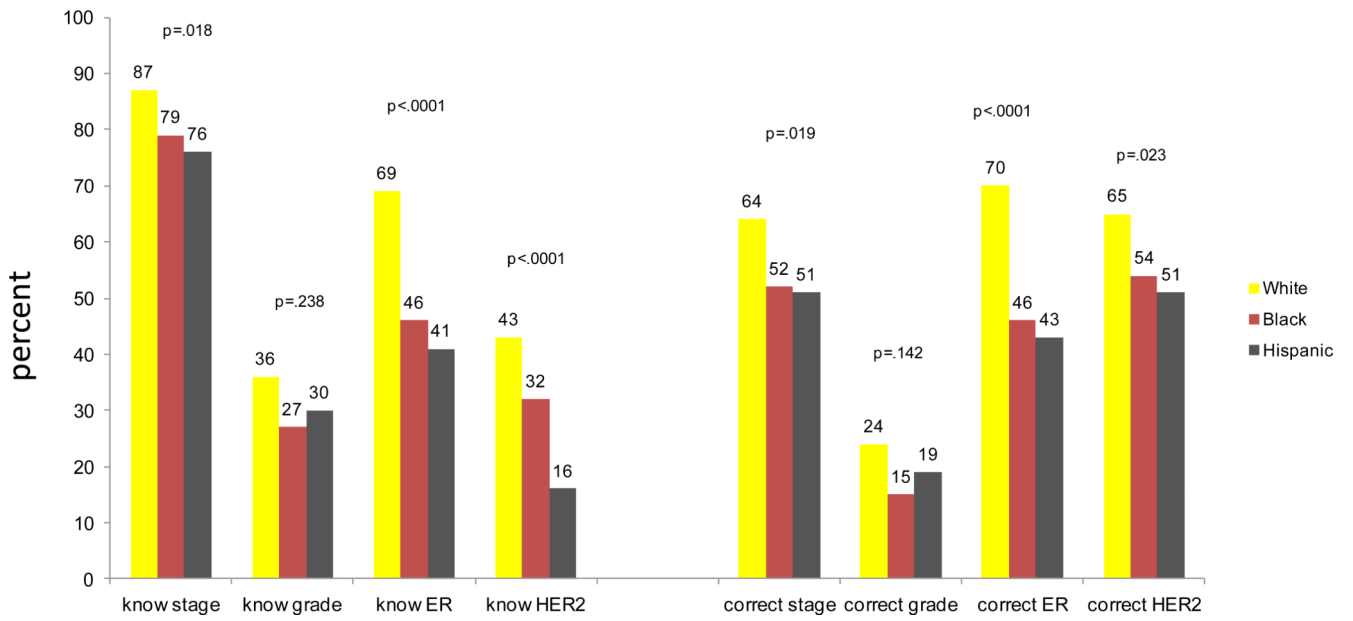
Schema for participant enrollment

American Association for Public Opinion Research Response Rate= $502/(1118-68)=47.8\%$ ;

refusal rate= $231/(1118-68)=22\%$ ; Participation rate among women contacted= $502/$

$(1118-68-317)=68.5\%$

**a. Proportion of participants who reported knowing and having correct information for each characteristic (n=500)\***



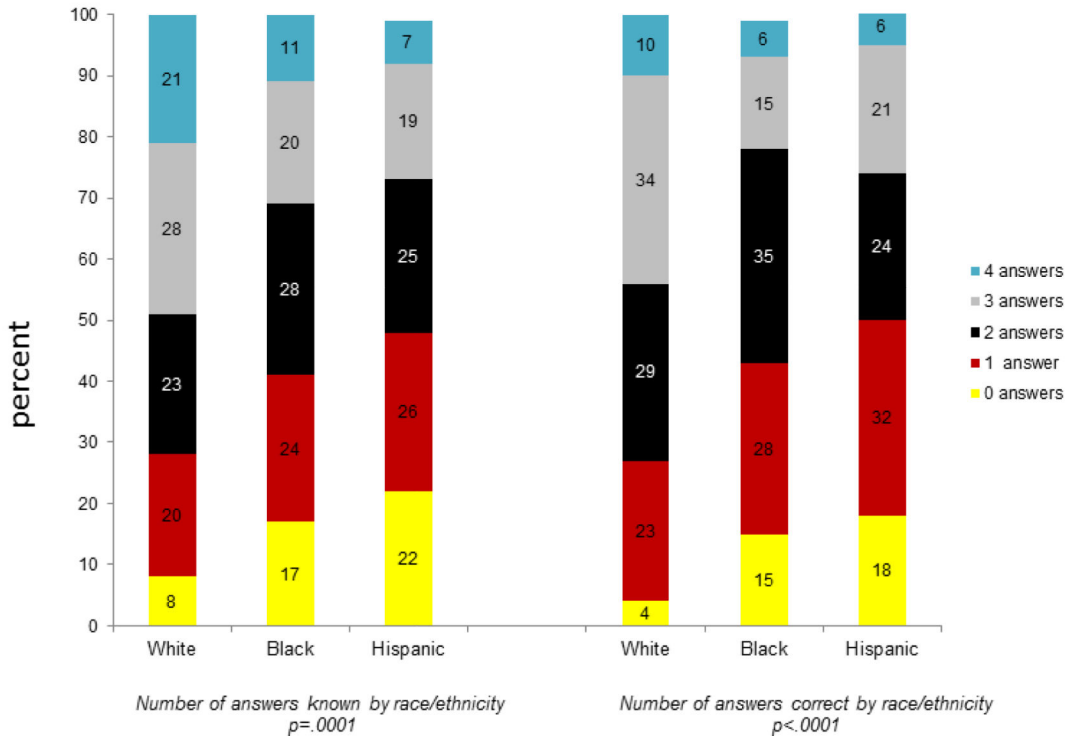
Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

**b. Proportion of participants with total of 0, 1, 2, 3, or 4 tumor characteristics known or correct by race/ethnicity, unadjusted (n=500)\***



**Figure 2.**

Figure 2a demonstrates the proportion of patients who reporting knowing (4 left bars) or correctly answering (4 right bars) information about their tumor stage, grade, ER status, and HER2 status for women who are white (yellow bars), black (red bars), or Hispanic (black bars). Figure 2b demonstrates the summed number of tumor characteristics known (3 left bars) or correctly reported (3 right bars) by race/ethnicity. The proportion of individuals knowing or correctly reporting 0 of the 4 characteristics is shown in yellow, 1 known/correct is shown in red, 2 known/correct in black, 3 known/correct in gray, and 4 (all) known/correct in blue.

Abbreviations: ER=estrogen receptor, HER2=Human Epidermal Growth Factor Receptor 2

\*p-values using chi-square tests

**Table 1**Survey questions about breast cancer knowledge<sup>a</sup>

What was the stage of your breast cancer? Was it 0, 1, 2, 3, or 4?
What was the grade of your cancer? Was it...
<input type="radio"/> Low grade, well differentiated, or grade 1
<input type="radio"/> Intermediate grade, moderately differentiated, or grade 2
<input type="radio"/> High grade, poorly differentiated, or grade 3
Was your cancer subtype HER2-positive, also called Human Epidermal Growth Factor Receptor 2-positive?
<input type="radio"/> Yes
<input type="radio"/> No
Was your breast cancer estrogen receptor-positive?
<input type="radio"/> Yes
<input type="radio"/> No

<sup>a</sup>Patients could answer "I don't know" for any of the above questions

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

**Table 2**

Participant characteristics by race/ethnicity for surveyed women (n=500)<sup>a</sup>

Characteristic	Overall N=500	Non-Hispanic White N=222	Non-Hispanic Black N=142	Hispanic N=136	<i>b</i> p-value
<b>Age at diagnosis, N(%)</b>					.004
<50	129 (26)	45 (20)	32 (23)	52 (38)	
50-59	153 (31)	67 (30)	48 (34)	38 (28)	
60-69	114 (23)	63 (28)	29 (20)	22 (16)	
>70	104 (21)	47 (21)	33 (23)	24 (18)	
<b>Marital status, N(%)</b>					<.0001
Married	280 (56)	149 (67)	46 (32)	85 (63)	
Not married/unknown	220 (44)	73 (33)	96 (68)	51 (38)	
<b>Number of comorbid conditions, N(%)</b>					.919
0	201 (40)	89 (40)	56 (39)	56 (41)	
1	182 (36)	84 (38)	49 (35)	49 (36)	
2+	117 (23)	49 (22)	37 (26)	31 (23)	
<b>Educational attainment, N(%)</b>					<.0001
Some high school or less	57 (11)	6 (3)	8 (6)	43 (32)	
High school diploma	108 (22)	45 (20)	27 (19)	36 (27)	
Some college	157 (31)	70 (32)	56 (39)	31 (23)	
College graduate	178 (36)	101 (46)	51 (36)	26 (19)	
<b>Annual household income (\$), N(%)</b>					<.0001
20,000	100 (20)	23 (10)	34 (24)	43 (32)	
20-39,000	92 (18)	30 (14)	34 (24)	28 (21)	
40-59,000	76 (15)	36 (16)	23 (16)	17 (13)	
60,000	182 (36)	109 (49)	36 (25)	37 (27)	
Unknown	50 (10)	24 (11)	15 (11)	11 (8)	
<b>Insurance at diagnosis, N(%)</b>					.0004
None	28 (6)	3 (1)	10 (7)	15 (11)	



Characteristic	Overall N=500	Non-Hispanic White N=222	Non-Hispanic Black N=142	Hispanic N=136	<i>b</i> p-value
Insured	472 (94)	219 (99)	132 (93)	121 (89)	
<b>Mean health literacy (lower=better literacy) (standard deviation)</b>	<b>1.78 (1.04)</b>	<b>1.48 (.77)</b>	<b>1.65 (.95)</b>	<b>2.38 (1.25)</b>	<b>&lt;.0001</b>

<sup>a</sup>Totals may not equal 100% because of rounding

<sup>b</sup>Using Chi-square test for categorical variables and Kruskal-Wallis test for the health literacy score

**Table 3**

Adjusted odds ratios [OR] (95% confidence interval) for race/ethnicity in sequential models for knowing and having correct tumor information (n=500)

Model <sup>a</sup>	Race/ethnicity (all ORs are vs. white women) <sup>b</sup>	
	Black	Hispanic
<i>'Knows' characteristic</i>		
<b>Know stage</b>		
Base model	<b>0.47 (0.25-0.89)</b>	<b>0.37 (0.20-0.68)</b>
+Education	<b>0.49 (0.25-0.93)</b>	0.70 (0.34-1.43)
+Health Literacy	<b>0.51 (0.26-0.98)</b>	0.94 (0.44-2.01)
<b>Know grade</b>		
Base model	0.65 (0.40-1.05)	0.79 (0.49-1.27)
+Education	0.64 (0.39-1.05)	0.96 (0.57-1.60)
+Health Literacy	0.65 (0.39-1.06)	1.03 (0.61-1.75)
<b>Know ER</b>		
Base model	<b>0.37 (0.23-0.60)</b>	<b>0.24 (0.15-0.40)</b>
+Education	<b>0.36 (0.22-0.60)</b>	<b>0.46 (0.26-0.81)</b>
+Health Literacy	<b>0.37 (0.22-0.62)</b>	<b>0.54 (0.30-0.95)</b>
<b>Know HER2</b>		
Base model	<b>0.70 (0.42-1.19)</b>	<b>0.15 (0.08-0.28)</b>
+Education	<b>0.69 (0.40-1.18)</b>	<b>0.20 (0.11-0.39)</b>
+Health Literacy	<b>0.69 (0.40-1.19)</b>	<b>0.23 (0.12-0.45)</b>
<b>Know more characteristics<sup>c</sup></b>		
Base model	<b>0.50 (0.33-0.75)</b>	<b>0.30 (0.20-0.46)</b>
+Education	<b>0.48 (0.32-0.72)</b>	<b>0.47 (0.31-0.73)</b>
+Health Literacy	<b>0.48 (0.32-0.73)</b>	<b>0.54 (0.35-0.85)</b>
<i>Correctly reports characteristic</i>		
<b>Correct stage</b>		
Base model	<b>0.57 (0.36-0.91)</b>	<b>0.56 (0.35-0.89)</b>
+Education	<b>0.58 (0.36-0.93)</b>	0.74 (0.44-1.22)
+Health Literacy	<b>0.59 (0.37-0.95)</b>	0.82 (0.49-1.37)
<b>Correct grade</b>		
Base model	0.60 (0.33-1.07)	0.69 (0.40-1.20)
+Education	0.61 (0.34-1.10)	0.83 (0.46-1.51)
+Health Literacy	0.62 (0.34-1.11)	0.92 (0.51-1.69)
<b>Correct ER</b>		

Model <sup>a</sup>	Race/ethnicity (all ORs are vs. white women) <sup>b</sup>	
	Black	Hispanic
Base model	<b>0.38 (0.24-0.62)</b>	<b>0.27 (0.17-0.44)</b>
+Education	<b>0.38 (0.23-0.62)</b>	<b>0.51 (0.30-0.88)</b>
+Health Literacy	<b>0.39 (0.24-0.64)</b>	<b>0.55 (0.32-0.97)</b>
<b>Correct HER2</b>		
Base model	0.71 (0.44-1.13)	<b>0.52 (0.33-0.83)</b>
+Education	0.72 (0.45-1.14)	0.63 (0.38-1.04)
+Health Literacy	0.72 (0.45-1.15)	0.65 (0.38-1.08)
<b>More characteristics correct<sup>c</sup></b>		
Base model	<b>0.42 (0.28-0.64)</b>	<b>0.34 (0.23-0.51)</b>
+Education	<b>0.42 (0.28-0.63)</b>	<b>0.54 (0.35-0.83)</b>
+Health Literacy	<b>0.42 (0.28-0.63)</b>	<b>0.60 (0.38-0.94)</b>

<sup>a</sup>Using logistic regression; base models include race/ethnicity, insurance, comorbidity, and marital status.

<sup>b</sup>Bolded results reflect p<.05

<sup>c</sup>Using ordinal logistic regression after summing responses

**Table 4**

Full adjusted models (odds ratio, 95% confidence interval) for knowing and having correct tumor information (n=500)

Characteristic	KNOW CHARACTERISTIC					CORRECT CHARACTERISTIC				
	Stage <sup>a</sup>	Grade <sup>a</sup>	ER <sup>a</sup>	HER2 <sup>a</sup>	More variables (0-4) <sup>b</sup>	Stage <sup>a</sup>	Grade <sup>a</sup>	ER <sup>a</sup>	HER2 <sup>a</sup>	More variables (0-4) <sup>b</sup>
<b>Overall N (%)</b>	<b>N=408 (82%)</b>	<b>N=159 (32%)</b>	<b>N=274 (55%)</b>	<b>N=163 (33%)</b>	<b>N=72 for all 4 (14%)</b>	<b>N=285 (57%)</b>	<b>N=101 (20%)</b>	<b>N=278 (56%)</b>	<b>N=291 (58%)</b>	<b>N=38 for all 4 (8%)</b>
<b>Race/ethnicity</b>										
White	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Black	<b>0.51 (0.26-0.98)</b>	0.65 (0.39-1.06)	<b>0.37 (0.22-0.62)</b>	<b>0.69 (0.40-1.19)</b>	<b>0.48 (0.32-0.73)</b>	<b>0.59 (0.37-0.95)</b>	0.62 (0.34-1.11)	<b>0.39 (0.24-0.64)</b>	0.65 (0.38-1.08)	<b>0.42 (0.28-0.63)</b>
Hispanic	0.94 (0.44-2.01)	1.03 (0.61-1.75)	<b>0.54 (0.30-0.95)</b>	<b>0.23 (0.12-0.45)</b>	<b>0.54 (0.35-0.85)</b>	0.82 (0.49-1.37)	0.92 (0.51-1.69)	<b>0.55 (0.32-0.97)</b>	0.72 (0.45-1.15)	<b>0.60 (0.38-0.94)</b>
<b>Age</b>										
<50	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
50-59	0.72 (0.31-1.67)	0.98 (0.59-1.63)	<b>0.42 (0.24-0.76)</b>	<b>0.31 (0.18-0.55)</b>	<b>0.54 (0.35-0.83)</b>	1.28 (0.77-2.14)	0.84 (0.48-1.49)	<b>0.45 (0.26-0.80)</b>	<b>0.51 (0.30-0.87)</b>	<b>0.63 (0.41-0.97)</b>
60-69	<b>0.41 (0.17-0.98)</b>	0.94 (0.54-1.65)	<b>0.40 (0.21-0.75)</b>	<b>0.16 (0.08-0.30)</b>	<b>0.37 (0.23-0.60)</b>	0.58 (0.34-1.01)	0.62 (0.32-1.20)	<b>0.48 (0.26-0.89)</b>	<b>0.38 (0.22-0.68)</b>	<b>0.36 (0.22-0.58)</b>
>70	<b>0.09 (0.04-0.20)</b>	0.61 (0.32-1.15)	<b>0.17 (0.09-0.34)</b>	<b>0.05 (0.02-0.13)</b>	<b>0.13 (0.08-0.22)</b>	<b>0.49 (0.27-0.88)</b>	0.74 (0.36-1.51)	<b>0.27 (0.14-0.53)</b>	<b>0.26 (0.14-0.47)</b>	<b>0.23 (0.14-0.40)</b>
<b>Marital status</b>										
Married	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Not married	1.62 (0.89-2.93)	1.32 (0.86-2.02)	0.88 (0.56-1.38)	<b>0.51 (0.31-0.83)</b>	0.92 (0.64-1.31)	1.26 (0.83-1.91)	0.89 (0.54-1.47)	0.78 (0.51-1.21)	0.76 (0.50-1.14)	0.88 (0.62-1.26)
<b>Comorbidity</b>										
0	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
1	0.75 (0.41-1.37)	1.02 (0.66-1.58)	0.81 (0.50-1.30)	0.89 (0.54-1.47)	0.86 (0.60-1.24)	0.82 (0.53-1.26)	1.22 (0.74-2.00)	0.83 (0.52-1.31)	1.30 (0.85-2.01)	1.07 (0.74-1.54)
2+	1.96 (0.92-4.15)	0.90 (0.53-1.54)	0.67 (0.38-1.17)	1.13 (0.61-2.08)	1.03 (0.66-1.59)	0.85 (0.51-1.40)	0.76 (0.39-1.46)	0.67 (0.39-1.16)	<b>1.74 (1.04-2.92)</b>	1.05 (0.68-1.63)
<b>Educational attainment</b>										
Some HS or less	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
HS diploma	<b>2.49 (1.05-5.92)</b>	1.01 (0.43-2.37)	<b>4.88 (1.65-14.41)</b>	1.26 (0.35-4.51)	<b>2.04 (1.05-3.97)</b>	1.35 (0.64-2.86)	1.29 (0.47-3.59)	<b>7.17 (2.47-20.84)</b>	1.90 (0.90-4.02)	<b>2.96 (1.53-5.73)</b>
Some college	<b>2.84 (1.12-7.19)</b>	1.54 (0.66-3.60)	<b>9.72 (3.27-28.84)</b>	3.10 (0.91-10.57)	<b>4.11 (2.08-8.13)</b>	1.51 (0.70-3.23)	1.24 (0.44-3.50)	<b>12.69 (4.32-37.34)</b>	1.78 (0.83-3.83)	<b>3.78 (1.91-7.44)</b>
College degree	<b>3.34 (1.27-8.82)</b>	1.43 (0.60-3.37)	<b>12.54 (4.17-37.70)</b>	1.98 (0.57-6.79)	<b>3.65 (1.83-7.30)</b>	1.91 (0.88-4.16)	1.43 (0.51-4.08)	<b>13.80 (4.64-41.08)</b>	1.79 (0.82-3.91)	<b>4.63 (2.32-9.27)</b>
<b>Insurance at diagnosis</b>										

Characteristic	KNOW CHARACTERISTIC						CORRECT CHARACTERISTIC					
	Stage <sup>a</sup>	Grade <sup>a</sup>	ER <sup>a</sup>	HER2 <sup>a</sup>	More variables (0-4) <sup>b</sup>		Stage <sup>a</sup>	Grade <sup>a</sup>	ER <sup>a</sup>	HER2 <sup>a</sup>	More variables (0-4) <sup>b</sup>	
<b>Overall N (%)</b>	<b>N=408 (82%)</b>	<b>N=159 (32%)</b>	<b>N=274 (55%)</b>	<b>N=163 (33%)</b>	<b>N=72 for all 4 (14%)</b>		<b>N=285 (57%)</b>	<b>N=101 (20%)</b>	<b>N=278 (56%)</b>	<b>N=291 (58%)</b>	<b>N=38 for all 4 (8%)</b>	
Insured	1.00	1.00	1.00	1.00	1.00		1.00	1.00	1.00	1.00	1.00	
None	0.51 (0.18-1.43)	0.64 (0.24-1.72)	0.85 (0.30, 2.39)	0.60 (0.18-2.05)	0.66 (0.31-1.39)		0.43 (0.18-1.03)	1.33 (0.48-3.66)	0.65 (0.24-1.79)	<b>0.38 (0.16-0.92)</b>	<b>0.43 (0.20-0.91)</b>	
<b>Health Literacy (Average, continuous)</b>	<b>0.61 (0.47-0.80)</b>	0.82 (0.64-1.05)	<b>0.66 (0.51-0.85)</b>	<b>0.57 (0.41-0.80)</b>	<b>0.64 (0.53-0.77)</b>		<b>0.79 (0.64, 0.98)</b>	0.77 (0.57-1.04)	0.82 (0.64-1.04)	0.93 (0.75, 1.16)	<b>0.76 (0.63-0.92)</b>	

Bolded results are significant with p<.05

Abbreviations: ER=estrogen receptor, HER2=Human epidermal growth factor receptor 2, HS=high school

<sup>a</sup>Using multivariable logistic regression, adjusting for variables in the table

<sup>b</sup>Using ordinal logistic regression for the probability of having more answers known/correct, adjusting for variables in the table