POPULATIONS AT RISK

Race and Family History Assessment for Breast Cancer

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OBJECTIVE: Studies have demonstrated disparities in breast cancer screening between racial and ethnic groups. Knowledge of a woman's family history of breast cancer is important for initiating early screening interventions. The purpose of this study was to determine whether differences exist in the collection of family history information based on patient race.

DESIGN: Cross-sectional patient telephone interview and medical record review.

SETTING: Eleven primary care practices in the Greater Boston area, all associated with Harvard Medical School teaching hospitals.

PARTICIPANTS: One thousand seven hundred fifty-nine women without a prior history of breast cancer who had been seen at least once by their primary care provider during the prior year.

MEASUREMENTS AND MAIN RESULTS: Data were collected on patients regarding self-reported race, family breast cancer history information, and breast cancer screening interventions. Twenty-six percent (462/1,759) of the sample had documentation within their medical record of a family history for breast cancer. On multivariate analysis, after adjusting for patient age, education, number of continuous years in the provider's practice, language, and presentation with a breast complaint, white women were more likely to be asked about a breast cancer family history when compared to nonwhite women (odds ratio, 1.68; 95% confidence interval, 1.21 to 2.35).

CONCLUSIONS: The majority of women seen by primary care providers do not have documentation of a family breast cancer history assessment within their medical record. White women were more likely to have family breast cancer information documented than nonwhites.

KEY WORDS: breast neoplasm; family history; medical interviewing; racial disparities; communication.

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Women with a family history of breast cancer are at increased risk of developing the disease.¹ The prevalence of women with a family history of breast cancer has been estimated to range from 5% to 19%.²⁻⁵ As such, breast cancer family history information has become increasingly

important in breast cancer surveillance strategies in primary care. Clinical guidelines regarding when to initiate breast cancer screening have suggested initiating mammography at earlier ages for women with a family history of breast cancer.⁶⁻⁸ Furthermore, family history is central to algorithms that predict a woman's likelihood of harboring a genetic mutation, and is important in determining women who should consider genetic testing.⁹ Thus, an accurate and complete assessment of a woman's family history of breast cancer is necessary to the delivery of optimal breast cancer preventive care.

Multiple studies have demonstrated racial and ethnic disparities in breast cancer screening and treatment outcomes.¹⁰⁻¹⁶ Efforts to improve breast cancer screening among African-American and Hispanic women have proven successful as mammogram screening rates for minority women have increased significantly.¹⁷⁻¹⁹ While these data are encouraging, they primarily reflect the management of women with an average risk of developing breast cancer. Women considered at higher risk for developing breast cancer than the general population, however, may be candidates for more intensive screening and interventions for primary prevention.²⁰⁻²⁴ Ensuring that all women at high risk for breast cancer have access to effective prophylactic therapies remains a high priority. Recent data suggest that racial disparities might be emerging in the use of *BRCA1/2* testing, with white race being an independent predictor of *BRCA1/2* testing.²⁵

With increasing advances in the fields of genetics and genomics, it is anticipated that the family history assessment in primary care will take on an even greater importance as a risk assessment and decision-making tool.^{26,27} The family history assessment is dependent on good communication between patient and provider. Poor communication has been suggested as an important factor influencing health care disparities.^{28,29} No data exist which have evaluated whether patient factors might influence the collecting of family history information. The purpose of this study was to determine whether race or ethnicity might be associated with the collection of family history information concerning breast cancer.

METHODS

Data Source

The data source for this study was the Ambulatory Medicine Quality Improvement Project (AMQIP). This study included 198 general internist providers affiliated with 11 different practice sites in greater Boston, all associated with Harvard Medical School teaching hospitals. Details of the AMQIP

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methodology have been previously published in detail.³⁰⁻³³ Briefly, patients of providers who agreed to participate were selected if they were between 20 and 75 years of age with at least one visit to their primary care physician (PCP) over the year prior to study enrollment. At each practice site, up to a maximum of 500 eligible patients were randomly selected. Patients were sent an informational letter about the study and mailed an "opt-out" postcard to return if they declined to participate. After the retrieval of the postcard, medical record reviews were conducted. Trained nurse abstractors completed chart reviews of patient electronic medical records on all participants. Information collected from the chart included whether a family history of breast cancer was documented by the provider, prior diagnosis of breast cancer, history of breast complaints, and breast cancer screening tests and their results. Participant information was abstracted from the medical record to 5 years preceding the date of study enrollment.

After medical record review, eligible patients were then contacted by telephone and interviewed. Patients were excluded from participating in the telephone interview if they spoke a language other than English or Spanish, were hard of hearing, too ill to participate, had an inaccurate telephone number, or had died prior to telephone contact. Telephone interviews were conducted between August 1996 and September 1997. The telephone interview included questions regarding patient sociodemographic factors and satisfaction with their health care. For the purposes of this study, only women who had both completed the interview and responded to the race/ethnicity questions were included in the analysis. The study was approved by the institutional review board at each site.

Analytic Variables

The primary variable of interest was whether a woman had her family history of breast cancer recorded. Family history of breast cancer was divided into patients with a positive family history of breast cancer recorded within the medical record, women with a negative family history of breast cancer recorded within the medical record, and women with no documentation within the medical record. The family history variable was abstracted from the medical record as a dichotomous variable with no information recorded regarding the degree of kinship or number of affected relatives.

Independent variables of interest included patient age and whether the patient had presented with a specific breast complaint such as breast pain or a self-identified lump. The race variable was derived from patient self-report and included white, African-American, Hispanic of both white and African-American descent, and other. Race was then dichotomized into white and nonwhite. Language was dichotomized into English as primary language or other. Education was dichotomized into patients with any formal education leading up to and including high school and patients that had at least some college-level education or beyond. The continuity-of-care variable was categorized as patients with less than 3 years of continuous care from a provider and patients with 3 or more years with their provider. Data were missing in no more than 1% of all analyzed covariates. Observations with missing data were not included within the regression model, resulting in 98% of all observations being modeled.

Data Analysis

Categorical variables were compared using the χ^2 test. Descriptive statistics were compared using Student's *t* test for parametric data and Wilcoxon rank order sum for nonparametric data. For comparison of proportions among the 3 primary groups, we used the Cochran-Armitage test for trend. For each individual covariate, an unadjusted regression model was calculated and an odds ratio estimated. We then used generalized estimating equations to control for intraphysician correlation.³⁴ All models were constructed initially including variables of clinical significance. After constructing and evaluating the model, other confounding variables were included within the final model. All statistical calculations were performed using SAS v8.2 statistical software (SAS Institute, Cary, NC).

RESULTS

Medical records were reviewed for 4,857 patients. After excluding male patients ($N=1,912$), women with a personal history of breast cancer ($N=35$), and women who had not seen their PCP in over a year ($N=8$), the study sample included 2,858 women. Thirty-eight percent of these women did not complete the survey instrument. Table 1 compares patient characteristics between survey responders and survey nonresponders. More survey responders had a family history of breast cancer recorded within their charts than nonresponders (15% vs 12%; $P=.02$). Survey responders were also more likely to have had a clinical breast exam performed as well as mammography screening performed over the past 5 years when compared to nonrespondents. Forty-four patients (2%) declined to identify their race and were excluded from the analysis. The final study sample included 1,759 women.

The mean age of the study sample was 47.6 years (Table 2). Seventy-two percent of the sample identified themselves as white, 13% as African-American, 12% as Hispanic, and 4% as "other." The education level was high in the sample, with 73% of the women having some college education, completed college, or postgraduate education. Fifty-two percent of the sample had seen their primary care provider for 3 or more years of continuous care and 7% of the sample had presented with a

Table 1. Characteristics of Female Survey Respondents Versus Nonrespondents

Characteristic	Respondents (N=1,803)	Nonrespondents (N=1,099)	P value
Mean age, y	48	46	.02
Family history of breast cancer	15	12	.02
recorded in charts, %			
Presented with a breast complaint, %	7	6	.24
Clinical breast exam performed, %	67	63	.02
History of abnormal mammogram, %	11	9	.17
Mammogram screening performed over the last 5 years, %	52	44	< .0001
Three or more years continuous care with PCP, %	52	49	.12

PCP, primary care physician.

Table 2. Characteristics Associated with the Documentation of the Family History Interview for Breast Cancer Within the Medical Record

Characteristic	Total Sample (N=1,759) (%)	Documentation of Family History of Breast Cancer (n=462) (%)	No Documentation of Family History Interview (n=1,297) (%)	P Value
Mean age, y	47.6	47.2	47.8	.43
Ethnicity				
White	1,258 (72)	389 (84)	869 (67)	< .0001
African American	220 (13)	31 (7)	189 (15)	
Hispanic	209 (12)	26 (6)	183 (14)	
Other	72 (4)	16 (3)	56 (4)	
Education level				
High school or less	461 (27)	129 (28)	332 (26)	.42
College or postgraduate education	1,275 (73)	332 (72)	943 (74)	
English as primary language	1,533 (88)	432 (94)	1,101 (85)	< .0001
Three or more years of continuous care with PCP	919 (52)	247 (54)	672 (52)	
Presented to PCP with breast complaint	120 (7)	33 (7)	87 (7)	.77

PCP, primary care physician.

prior breast complaint. The median number of patients seen per provider was 7 (interquartile range of 2 to 14).

Twenty-six percent (462/1,759) of the sample had documentation within their medical record that the family history interview for breast cancer had been obtained. Thirty-one percent of white women had documentation of a family breast cancer history assessment compared to 15% of nonwhite women ($P<.0001$). A positive family breast cancer history was documented for 18% of white women and 8% of nonwhite women, and a negative family history for 13% of white women and 6% of nonwhite women ($P<.0001$ for both). Patients with documentation of a family breast cancer history assessment were more likely to be white and more likely to identify English as their primary language than patients not asked about their family history of breast cancer (84% vs 67%, and 94% vs 85%, respectively; $P<.0001$ for both). There were no differences seen in educational level, years of continuous care with the PCP, presenting with a breast complaint, or age between the two groups (Table 2).

A positive family history interview for breast cancer was recorded in 58% (269/462) of patients with documentation of their family history of breast cancer (Table 3). Patients with a positive family history of breast cancer were more likely to have a clinical breast exam performed (73% vs 49% vs 69%; $P<.0001$) and be taught self-examination skills (42% vs 15% vs 35%; $P<.0001$) than patients with either a negative family history of breast cancer or no family history documented within their chart, respectively. Patients with a positive family history were also more likely to have had mammography screening performed over the prior 5 years (65% vs 35% vs

52%; $P<.0001$) when compared to women with no family history of breast cancer or women who had no documentation of their family history, respectively. These trends remained significant even after adjusting for patient age, race, education level, language, years seen by their provider, and presenting with a breast complaint.

Forty-one percent (726/1,759) of the sample included women under 40 years of age. Twenty-seven percent of the women under 40 had a family history of breast cancer interview recorded within their medical record. In women under 40, 32% of white women underwent the family history interview for breast cancer compared to 13% of African-American, 14% of Hispanic, and 24% of women categorized as "other" ($P=.0002$). For women 40 years or older, 30% of white women had their family breast cancer interview documented compared to 15% of African Americans, 11% of Hispanics, and 19% of women categorized as "other" ($P<.0001$).

On univariate analysis, (Table 4) only white race (odds ratio [OR], 2.62; 95% confidence interval [CI], 1.99 to 3.46) and English as a primary language (OR, 2.57; 95% CI, 1.71 to 3.86) were significantly associated with documentation of a family breast cancer history interview. Education level was not associated with this information being recorded (OR, 0.91, 95% CI, 0.71 to 1.15).

On multivariate analysis, after adjusting for patient age, number of years in continuous care with their provider, education, language, and presenting with a breast complaint, white race was a significant predictor of medical record documentation of a family breast cancer history (OR, 1.68, 95% CI, 1.21 to 2.35).

Table 3. Association of Family History Status with Visit Characteristics

Characteristic	Total Sample (N=1,759) (%)	Negative Family History of Breast Cancer (n=193) (%)	No Documentation of Family History Interview (n=1,297) (%)	Positive Family History of Breast Cancer (n=269) (%)	P Value*
Clinical breast exam performed	1,171 (67)	95 (49)	880 (69)	196 (73)	< .0001
Taught patient self-exam	592 (34)	29 (15)	451 (35)	112 (42)	< .0001
Mammogram screening performed over the last 5 years	911 (52)	66 (35)	671 (52)	174 (65)	< .0001

*Cochran-Armitage test for trend.

Table 4. Association of Race with Provider Documenting Either a Positive or Negative Family History of Breast Cancer

Characteristic	Univariate OR (95% CI)	P Value	Adjusted OR (95% CI)*	P Value
Race, white	2.62 (1.99 to 3.46)	<.001	1.68 (1.21 to 2.35)	.002
Patient age	1.00 (0.99 to 1.01)	.42	1.00 (0.99 to 1.01)	.66
Education	0.91 (0.71 to 1.15)	.42	1.13 (0.76 to 1.22)	.75
Years in practice	1.08 (0.87 to 1.33)	.46	1.13 (0.84 to 1.38)	.56
English	2.57 (1.71 to 3.86)	<.0001	1.24 (0.90 to 2.07)	.14
Breast complaint	1.07 (0.70 to 1.61)	.77	1.22 (0.82 to 1.76)	.35

*Model is adjusted for age, race, education, number of years that patient has been continuously followed within the practice, language, and presenting with a specific breast complaint as well as intraprovider correlation.

OR, odds ratio; CI, confidence interval.

DISCUSSION

The family history assessment is an important aspect of high-quality breast cancer care. Our results would suggest that in primary care, a little over a quarter of women have documentation of a family history interview for breast cancer within their medical charts. These findings represent a substantial barrier to high-quality breast cancer control in primary care and could have important implications for the identification and management of women at high risk for breast cancer. Furthermore, white women appear to be more likely than nonwhite women to have had this information recorded. This disparity remained even after adjusting for education, age, language, and presenting to a provider with a specific breast complaint, such as pain or a self-detected lump. Less than 1 in 7 of African-American and Hispanic women under 40 years of age, a group in which the early identification of risk status could influence screening practice behavior, had documentation concerning familial breast cancer.

The lack of documentation of the family breast cancer history within the medical record could suggest that primary care providers are infrequently inquiring about familial breast cancer with their patients. We are unable to determine from this study whether this information was collected and not documented or not inquired about altogether. However, our findings support those of Acheson et al., who determined in an observational study of primary care providers that family history information was collected in 24% of all encounters.³⁵ In our study the overall rate of documentation of family history information was 26%. Of note, our sample included only individuals who had participated in the telephone interview. Respondents were more likely to have had family history information recorded within their medical record than nonrespondents and as such our overall rate of documentation might represent an overestimation of actual documentation practices if the nonrespondents have a similar prevalence of familial breast cancer.

Continued disparities in the family history assessment could result in high-risk minority women being less likely to be identified early and offered genetic counseling or testing, earlier screening interventions, or preventive therapies. Guidelines recently released from the American Cancer Society have suggested initiating breast cancer screening interventions at age 30 for woman at increased risk for breast cancer.⁸ Much work has gone into reducing delays in mammography screening for minority women and screening disparities have significantly improved.²⁹ Yet, while differences in breast cancer screening improve for average-risk minority women, it is im-

portant that screening disparities be identified and eliminated for high-risk women.

Most risk factors for breast cancer have a similar prevalence among white and African-American women,³⁶ but reports have been conflicting regarding the prevalence of a positive family history of breast cancer among whites and African Americans.³⁶⁻³⁹ In studies that have included only women without a personal history of breast cancer, the prevalence rates of African-American women reporting a family history of breast cancer in a first-degree relative have ranged from 4.5% to 4.7% compared with 6.5% to 6.6% for white women.^{36,37}

Transmission of family history information requires communication between both the patient and the provider and thus several possible mechanisms might explain our findings. The average length of a primary care visit in the United States is slightly over 16 minutes⁴⁰ and taking a family history can require a significant time commitment.³⁵ Providers might have little time available to ask an individual about their family history. One survey of 291 general practitioners in England found that only 48% routinely asked women whether they had family members with breast cancer.⁴¹ In another large observational study of over 4,000 patient visits, family history information was only collected one fourth of the time.³⁵ Because incident rates for breast cancer are higher for white women than minority women,^{42,43} providers might be less likely to inquire about a family history of breast cancer in minority women, believing it to be less relevant. Yet race-specific incidence rates for breast cancer vary with age, with African Americans actually having higher incident rates for breast cancer than white women under 45 years of age.⁴⁴⁻⁴⁶ Furthermore, African-American women are more likely to diagnose at a more advanced stage of the disease than white women.^{29,43} Younger women who have not yet begun routine cancer screening would be a group in which the early identification of high-risk individuals might be particularly useful.

Another provider-related factor associated with this disparity might be related to knowledge deficiencies regarding the utility of family history in minority women. Several studies have suggested that primary care providers are unclear of the appropriate indications for referral to genetic services.⁴⁷⁻⁵⁰ This, coupled with the fact that much of the literature evaluating *BRCA* testing⁵¹ and breast cancer risk modeling^{52,53} has included predominately white women, might also contribute to a provider being less likely to perceive family history as being important in minority women. In a recent study by Armstrong et al., white, non-Ashkenazi women were over 4 times as likely to be referred for genetic counseling for *BRCA1/2* testing than

nonwhite women,²⁵ even though several studies have identified *BRCA* mutations in African-American women.^{54,55}

Even if a provider does not ask a woman about her family history, the patient might volunteer this information. Some data suggest that a provider is 6.6 times more likely to solicit a family history of breast cancer from a patient than the patient is to voluntarily mention it.⁵⁶ In fact, women only spontaneously mentioned their family history in 0.5% of primary care consultations. Regardless, patient factors might influence whether a woman is likely to volunteer information about her family history of breast cancer to a provider, which could influence this information's inclusion within the medical record; however, this is unlikely to explain the differences in documentation rates seen within our study.

The study has several limitations. First, the AMQIP study was conducted in the mid-1990s, when *BRCA* testing was conducted only in research settings. Efforts to promote newly discovered genetic knowledge in primary care have been introduced. If knowledge factors contributed to this disparity, these interventions might have since served to reduce these differences. Second, the AMQIP chart review methodology only evaluated family history as a dichotomous variable. A family history of breast cancer in a patient's mother at age 80 is significantly different from a family history that includes two first-degree relatives developing the disease before 45 years of age. Thus, although women with a family history of breast cancer documented within their chart had the highest rates of mammography screening, it is not possible to determine whether this rate of screening was clinically appropriate. Third, although we eliminated women with personal diagnoses of breast cancer, we did not adjust our analysis for comorbid conditions, which could potentially influence documentation rates. Fourth, family history of breast cancer was based on patients' self-report. However, several studies have confirmed that patient self-report of a family history of breast cancer is accurate.⁵⁷⁻⁶⁰

Finally, we had limited information regarding provider demographics and were unable to adjust our analysis based on these factors. Emerging literature has suggested that concordance between patient and provider gender and/or race might have an important impact on communication.^{61,62} This study is unable to comment on whether or not patient and provider concordance might influence documentation of a family breast cancer interview.

In conclusion, our results suggest that only one fourth of women have information regarding whether any of their family members have been diagnosed with breast cancer recorded within their medical record. White women were more likely to have this information documented, even after adjusting for patient education and age. This study represents 11 practices in a single urban location and more studies will be necessary to confirm whether this disparity exists in other health care settings or with other cancer types. If these findings remain consistent, patients and providers must be educated in order to ensure that minority women at high risk for breast cancer are identified and managed appropriately. Community-based programs aimed at raising women's awareness about the importance of knowing their family breast health history and initiating discussion with their primary care provider about familial risks would likely improve the collection of family breast cancer information.

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