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Agreement of self-reported hormone receptor status with cancer registry data in young breast cancer patients

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Abstract

Background—Though breast cancer subtype is a key determinant of treatment choice and prognosis, few studies have assessed breast cancer patients' knowledge of estrogen and progesterone receptor (ER/PR) status.

Methods—Women diagnosed with invasive breast cancer at age 18–64 years in 2007 were recruited from the Pennsylvania Cancer Registry, and mailed a questionnaire that asked respondents to identify their ER/PR status. There were 2191 respondents included in the analysis. Agreement between self-report and cancer registry ER/PR status was assessed using kappa statistic. Logistic regression was used to assess the association of demographic, socioeconomic, and tumor factors with inaccurate self-report of ER/PR status.

Results—Fifty nine percent of respondents reported ER/PR positive status, 15% reported ER/PR negative status, 17% responded 'don't know', and 9% did not respond. Overall, there was 69% agreement between self-report and cancer registry data, and fair agreement as measured by kappa (0.36). After excluding women who didn't know or did not report their ER/PR status, there was 93% agreement, and substantial agreement as measured by kappa (0.76). Women who were older, non-white, less educated, lower income, and had ER/PR negative disease were significantly more likely to inaccurately report their ER/PR status.

Conclusions—Though a significant proportion of women do not know their hormone receptor status, women who reported their ER/PR status were accurate. Our results suggest room for improvement in patient knowledge of tumor subtypes, but also that self-reported ER/PR status may be a useful surrogate when medical record or cancer registry data is unavailable.

Keywords

breast cancer; estrogen receptor; progesterone receptor; agreement; self-report; cancer registry; tumor subtype

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Introduction

Gene expression profiling demonstrates that breast cancer is a heterogeneous disease, with four major subtypes.[1] Breast tumors are commonly classified based on expression of estrogen receptor (ER), progesterone receptor (PR), and human epidermal growth factor receptor 2 (HER2). Immunohistochemical tests for these markers are routinely performed on breast tumors, and results guide targeted treatments. Breast cancer subtypes have unique patterns of occurrence, etiologies, and prognosis,[2, 3] and therefore it is important that epidemiologic studies account for tumor heterogeneity. Furthermore, knowledge of tumor subtype is important for breast cancer patients, as it enables greater involvement in treatment decisions. Patient health knowledge and involvement in decision making has been shown to affect treatment choice, decision satisfaction, adherence to treatment recommendations, quality of life, and health outcomes.[4–13]

Access to data on hormone receptor status in breast cancer research studies is variable. The National Cancer Institute's Surveillance, Epidemiology, and End Results Program (SEER) cancer registries have required reporting of ER/PR status since 2004[14], however the availability and completeness of this information varies across non-SEER registries. Obtaining data from cancer registries or medical records may be prohibitively time consuming and expensive depending on the research question and study design. It is unclear to what extent breast cancer patients are aware of such tumor characteristics and whether self-reported hormone receptor status can be used when data from the cancer registry or medical records are unavailable. To our knowledge only three studies have validated self-reported ER/PR status with estimates of agreement ranging from 40–90%; however, only one of these studies was performed in the U.S.[15–17] Studies of self-reported breast cancer treatment have shown patients to have moderate to high accuracy in reporting breast surgery, chemotherapy, radiotherapy, and hormonal therapy.[18–22] In addition, two studies found self-report of stage at diagnosis to have fair to poor accuracy.[15, 19]

The study objective was to assess patient knowledge of ER/PR status and agreement between self-reported ER/PR status and cancer registry data using a retrospective cohort of breast cancer patients identified through the Pennsylvania Cancer Registry (PCR). Furthermore, we sought to identify subgroups of patients most likely to inaccurately report ER/PR status.

Patients and Methods

Study Population

A total of 4920 women diagnosed with invasive breast cancer at age 18–64 between January 1 and December 31, 2007 were identified from the PCR. Women were mailed an introductory letter explaining the study, followed by a second mailing with a consent form, a study questionnaire, a stamped, addressed return envelope, and an unconditional incentive of five dollars. Non-respondents were sent two additional mailings. Ninety-one women were deceased, 594 had invalid addresses, and 12 were otherwise ineligible (not able to read/speak English, reported not having cancer). Of the 4223 women eligible for the study, 2259 women returned the questionnaire (53%). We further excluded one participant missing age at diagnosis. The institutional review boards of the University of Pennsylvania and the PCR approved the study protocol.

Survey questionnaire

The survey questionnaire elicited information on socio-demographic characteristics, family history of cancer, tumor characteristics, and treatment. Women were asked, "Was your

cancer estrogen (ER) or progesterone (PR) receptor positive?" and possible responses were "no", "yes", or "don't know."

ER/PR status

The PCR abstracted results of Estrogen Receptor and Progesterone Receptor Assays from medical records. Assays performed prior to treatment were preferentially abstracted. If assay results prior to treatment were unavailable, results following treatment were utilized. If multiple assays were performed with discordant results, the tumor was classified as hormone receptor positive if any test was positive. ER/PR status was recorded in the registry in the following manner: positive/elevated, negative/normal, borderline/undetermined, test not done, test ordered but results not in chart, and unknown.[14] The PCR received Gold Certification from the North American Association of Central Cancer Registries (NAACR) for data quality and completeness.

Statistical analysis

For comparison with questionnaire data, ER and PR status from the registry were categorized: ER and/or PR positive and ER and PR negative. For analysis, women with unknown/missing ER/PR status from the registry were excluded (N=67), resulting in an analytic population of 2191. Concordance between self-reported and cancer registry data on ER/PR status was compared using percent agreement and Cohen's kappa statistic. Multivariate logistic regression was used to assess predictors of discordant self-report of ER/PR status compared to cancer registry data. First, we included inaccurate, and don't know/missing self-report as discordant. We then excluded women who answered "don't know" or were missing ER/PR status and repeated logistic regression. All analyses were performed using STATA IC version 12 (College Station, TX).

Results

Characteristics of the 2191 respondents are shown in Table 1. There was no difference in mean age between respondents (52.1 ± 8.1) and non-respondents (52.1 ± 8.1). Respondents were less likely to be non-white race than non-respondents (8% vs. 15%, as reported to cancer registry). Respondents were more likely to have localized stage disease (65% vs. 61%) and less likely to have distant stage disease (2% vs. 4%) than non-respondents. In the full cancer registry population of 18–64 year olds diagnosed with invasive breast cancer in 2007, 76% were ER/PR positive, 19% were ER/PR negative, and 5% had unknown status. Respondents were significantly more likely to have ER/PR positive disease and less likely to have missing ER/PR status than non-respondents.

Among respondents, the median age at cancer diagnosis was 53 years, and they completed the questionnaire a median of three years following diagnosis (95% CI 2–5 years). Sixty-five percent of respondents had local, 32% had regional, and 2% had distant stage disease. The majority of the study population were white (90%) and employed (55%). Most respondents had college (43%) or graduate school (21%) education, and 38% reported annual household income over $70,000.

Based on cancer registry data, 81% of participants had ER/PR positive disease and 19% had ER/PR negative disease. Per self-report, 59% reported ER/PR positive cancer, 15% ER/PR negative, 17% responded "don't know", and 9% did not respond. Among the 573 women who did not know or were missing ER/PR status, the distribution of cancer registry receptor status was similar to the distribution among respondents, with 78% having positive and 22% having negative ER/PR status.

Table 2 displays the agreement of self-reported and cancer registry ER/PR status. Overall, there was 69% agreement, and there was fair agreement as measured by kappa (agreement corrected for chance, κ=0.36). After excluding women who did not know their receptor status or did not respond to the question, the percent agreement was 93% and there was substantial agreement as measured by kappa (κ=0.76).

Table 3 shows the results of multivariate logistic regression of predictors of discordant self-report of ER/PR status among women with complete registry data. Age, education, race, income, and cancer registry receptor status were significantly associated with discordant self-report of ER/PR status. Women aged 51–64 had 60% increased odds of discordance compared to women age 40 or younger (OR=1.61, 95% CI 1.10–2.37, p=0.015). Women with high school education had more than twice the odds of discordance as women with higher education (OR=2.60, 95% CI 2.11–3.21, p<0.001), non-white women had more than three times the odds of discordance compared to white women (OR=3.12, 95% CI 2.26–4.31, p<0.001), and low income women had nearly three times the odds of discordance compared to high income women (<$30,000 vs. >$70,000 OR=2.89, 95% CI 2.18–3.82, p<0.001). Finally, women with ER/PR negative disease per the cancer registry had 60% increased odds of mis-reporting their ER/PR status compared to women with ER/PR positive disease (OR=1.62, 95% CI 1.27–2.06, p<0.001).

We repeated logistic regression focusing on women who reported their ER/PR status. As in the full analysis, non-white race was associated with discordance (OR=2.55, 95% CI 1.38–4.69, p=0.003), as was ER/PR negative status (OR=2.66, 95% CI 1.76–4.02, p<0.001). In this subgroup, distant stage at diagnosis was associated with discordant self-report (OR=2.72, 95% CI 1.06–6.97, p=0.037). The odds ratio for education was elevated, and nearly statistically significant (OR=1.49, 95% CI 0.97–2.28, p=0.070). Age and household income were not significant after excluding those who didn't know or were missing ER/PR status.

Discussion

Our study found fair agreement between self-report of breast cancer ER/PR status and cancer registry data, although over a quarter of respondents did not know or did not report their ER/PR status. Older age at diagnosis, less education, non-white race, lower household income, and ER/PR negative disease were associated with incomplete or inaccurate self-report of hormone receptor status. Three quarters of women responded that their ER/PR status was positive or negative, and in this group there was substantial agreement between self-report and cancer registry data. These results suggest that while some women do not know their hormone receptor status, those who do report it tend to be accurate.

We observed more accurate self-report of hormone receptor status than two prior studies. An Australian study of 1684 breast cancer patients found 52% agreement between self-report and the Victorian Cancer Registry an average of 10 months following diagnosis.[17] Similar to our results, age and education were associated with inability to correctly report hormone receptor status. A study of 480 breast cancer patients recruited from a hospital cancer registry in Minnesota found 58% agreement for ER status and 39% agreement for PR status, and age was associated with accuracy of self-report.[15] However, this study included women with ductal carcinoma in situ, and receptor status was not routinely tested in these patients. Both studies enrolled patients of all ages, and the younger age of our cohort may partly explain the greater accuracy of self-report observed. A third validation study among nearly 5000 women in the Shanghai Breast Cancer Survival Study found excellent agreement (Kappa=0.91) between patient responses and medical record information on ER/

PR status.[16] The authors note that patients received a written summary of their diagnosis and lab results, which may have improved patient recall.

It is not surprising that race, education, and income were associated with inaccurate self-report of ER/PR status, as these factors have been identified as determinants of knowledge of breast cancer prognosis and treatment.[8, 9, 23] Numerous studies have highlighted that minority women experience poorer quality physician-patient communication and less involvement in decision making, which may reduce quality of care and contribute to disparities in outcomes.[5, 8, 10, 24–26] In addition, women with ER/PR negative cancer, which is more frequent among African American women and has poorer prognosis than ER/PR positive cancer, were more likely to misreport their tumor receptor status. Receptor status may not be discussed as frequently with ER/PR negative patients, since they do not receive hormonal therapy. Given that ER/PR status has important implications for treatment decisions, developing strategies to improve patient awareness and understanding of tumor subtype is warranted, particularly among minority women and women with low education and income.

Strengths of the study include its large sample size of young breast cancer patients, information on socioeconomic factors, and use of cancer registry data as the gold standard. The PCR received NAACR Gold Certification for 2007 data, the highest standard for data quality and completeness. However, it is possible that some discordance is due to errors or omissions in registry data rather than inaccurate self-report.

A limitation of the study was the modest response rate to the mailed questionnaire. Non-respondents were more likely to be non-white, have advanced disease, and have ER/PR negative disease than respondents. Also, the written questionnaire may have yielded respondents with higher literacy and education than non-respondents, though we cannot assess this directly since these factors are not collected by the cancer registry. These issues may have resulted in an overestimate of the accuracy of self-reported ER/PR status. In addition, the study was performed in PA and may not generalize to other locations. Finally, given the wording of the questionnaire, we could not assess agreement for ER or PR status separately.

In conclusion, our results show fair agreement between self-report and cancer registry data on ER/PR status. A significant proportion of breast cancer patients do not know the ER/PR status of their cancer, and women who are older, non-white, and lower socioeconomic status are less likely to accurately report this information. Conversely, among respondents who reported their ER/PR status, most were accurate, suggesting that many women are well informed about this tumor characteristic and retain this knowledge for a significant amount of time following cancer diagnosis. Depending on the purposes of the study and the characteristics of patients enrolled, self-report may be an acceptable source of information on hormone receptor status when medical records or cancer registry data is unavailable.

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Abbreviations

ER	estrogen receptor
PR	progesterone receptor
PCR	Pennsylvania Cancer Registry

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Table 1

Characteristics of Respondents Diagnosed with Breast Cancer at age 18–65 in Pennsylvania in 2007 (N=2191)

	N	%
Age at Diagnosis		
40 and under	195	9%
41 to 50	681	31%
51 to 60	939	43%
61 to 64	376	17%
Stage at Diagnosis		
Local	1418	65%
Regional	702	32%
Distant	48	2%
Unstaged/Unknown	23	1%
White	1975	90%
Employed	1206	55%
Educational attainment		
High School or Less	785	36%
College (2 or 4 year)	934	43%
Graduate School	451	21%
Missing	21	1%
Annual household income		
<$ 30,000	444	20%
$ 30 001 to $ 70 000	763	35%
> $ 70 000	840	38%
Missing	144	7%
Cancer Registry ER/PR status		
Positive	1780	81%
Negative	411	19%
Self-reported ER/PR status		
Positive	1297	59%
Negative	321	15%
Don't know	381	17%
Missing	192	9%
Among women who don't know/missing self-report	N=573	
Cancer Registry ER/PR status		
Positive	446	78%
Negative	127	22%

Table 2

Agreement between Self-reported ER/PR status and Cancer Registry data

	Cancer Registry ER/PR status	
Self-reported ER/PR status	**Positive**	**Negative**
Positive	1257	40
Negative	77	244
Don't know/Missing	446	127
	Total population (N=2191)	Excluding Don't know/Missing Self-reported ER/PR status (N=1618)
Percent Agreement	69%	93%
kappa	0.36	0.76

Table 3

Multivariate Logistic Regression Analysis of Discordant Self-report of Hormone Receptor Status compared with the cancer registry

	Total (N=2191)*			Among women who reported positive or negative status (N=1618)†;		
	OR	**95% CI**	**p-value**	**OR**	**95% CI**	**p-value**
Age at Diagnosis						
41–50 vs. ≤40	1.18	0.79–1.76	0.425	0.78	0.40–1.52	0.466
51–64 vs. ≤40	1.61	1.10–2.37	0.015	1.09	0.59–2.03	0.787
Stage at Diagnosis						
Regional vs. Local	1.00	0.81–1.24	0.979	1.15	0.76–1.74	0.509
Distant vs. Local	1.15	0.59–2.22	0.689	2.72	1.06–6.97	0.037
Unstaged/Unknown vs. Local	1.70	0.70–4.16	0.245	---		
Education						
High School vs. Higher education	2.60	2.11–3.21	<0.001	1.49	0.97–2.28	0.070
Race						
Non-white vs. white	3.12	2.26–4.31	<0.001	2.55	1.38–4.69	0.003
Household Income						
30–70K vs. >70K	1.31	1.02–1.68	0.032	0.85	0.54–1.32	0.459
<30K vs. >70K	2.89	2.18–3.82	<0.001	0.87	0.48–1.59	0.650
Hormone receptor status (registry)						
ER/PR negative vs. positive	1.62	1.27–2.06	<0.001	2.66	1.76–4.02	<0.001

*Discordant N=690 vs. Concordant N=1501

†Excludes don't know/missing self-report, Discordant N=117 vs. Concordant N=1501