ORIGINAL ARTICLE

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Women's Knowledge and Attitudes about Genetic Testing for Breast Cancer Susceptibility

OBJECTIVE. To assess female primary care patients' knowledge about breast cancer genetics and attitudes toward genetic testing.

DESIGN. Self-administered survey.

PARTICIPANTS. A convenience sample of 91 female patients awaiting appointments at a large primary care clinic of Group Health Cooperative in Seattle, Washington.

RESULTS. Forty-seven percent of women had read or heard almost nothing about genetic susceptibility testing, and most did not know the answers to questions that assessed knowledge about breast cancer genetics. Eighty-one percent "somewhat" or "strongly" agreed that testing should be offered to everyone; women who had heard or read about genetic testing for breast cancer were more likely to agree that genetic testing should be offered only to people who have a reason to think that they have an altered gene. When asked whether they planned to have genetic testing for breast cancer, many women said "probably or definitely yes" (71% would do so if insurance covered the cost; 44% would do so even if they had to pay out-of-pocket).

CONCLUSIONS. Although most women knew little about genetic testing, many expressed interest in being tested and believed that it should be offered to everyone. Primary care providers may be asked to educate women about cancer genetics and appropriate use of susceptibility testing.

BRCA1 and *BRCA2* are genetic mutations responsible for approximately 5% to 10% of cases of breast cancer and ovarian cancer.[1] Testing for these mutations has recently become more widely available and is being promoted by for-profit laboratories, which are marketing the test directly to women. Members of families with multiple cases of breast and ovarian cancer or early-onset breast cancer are the most likely carriers of the *BRCA1* and *BRCA2* genetic mutations and are the most appropriate candidates for genetic testing.[2–4] Interest in genetic testing for breast cancer susceptibility among these high-risk women has been sizable.[5–7]

Potential demand for testing may be greatest, however, among women for whom testing is least appropriate. Health care systems must be prepared to address the demand for genetic counseling services not only among women at high risk for carrying genetic mutations but also among women who are at average risk. Health care organizations are developing screening algorithms and guidelines for appropriate testing but may not provide general patient education about these guidelines (e.g., about appropriate identification of high-risk individuals) or about the risks, benefits, and limitations of testing.

We report the results of an opinion survey about genetic testing for breast cancer that was conducted among female primary care patients. We assessed awareness of the availability of testing for genetic susceptibility for breast cancer, knowledge about breast cancer genetics, and attitudes toward genetic testing.

The abstract of this paper is available at ecp.acponline.org.

Edited by Lisa Schwartz, MD, MS

Methods

Design

The respondents were women awaiting medical appointments at a large primary care clinic of Group Health Cooperative of Puget Sound, a staff-model HMO in western Washington State. For 2 days, a research assistant sequentially approached all women waiting to be seen at the clinic and asked them to complete an anonymous questionnaire. Women were offered a certificate for a coffee beverage as thanks for completing the survey.

Ninety-one of 95 women who were approached agreed to participate (response rate, 96%); 2 women could not consent because they did not speak English, and 2 women declined to participate. Characteristics of the participants are shown in **Table 1**.

Measures

In addition to demographic information, the survey included questions on perceived breast cancer risk, breast cancer worries, mammography, breast self-examination in the past year, and experience with other kinds of genetic tests (e.g., amniocentesis and testing for Tay-Sachs disease). Patients were asked two knowledge questions about breast cancer genetics that were taken from a core set of instruments developed by the National Center for Human Genome Research Cancer Studies Consortium and have been used in previous research.[8,9] Patients were then asked two questions concerning their beliefs about how much access women should have to *BRCA1* testing and two questions about their own intention to be tested. Patients were also asked about their preferred method for learning more about testing for genetic susceptibility to breast cancer. The survey took 5 to 10 minutes to complete.

Results

As shown in **Table 2**, the survey respondents did not have an exaggerated sense of breast cancer risk. Only 6% of the women thought that their risk was much higher than average, and only 8% had thought often or a lot in the past month about their own chance of developing the disease.

Knowledge about Genetic Testing

About half of the women reported that they had read or heard almost nothing about genetic testing for breast cancer. Only one woman reported that she had read or heard a lot about genetic testing for breast cancer. More than half answered "do not know" to the two questions that assessed knowledge about breast cancer genetics. As shown in **Figure 1**, most of the women who answered a true/false question gave the correct response to the two questions.

TABLE 1
Characteristics of Respondents ($n = 91$)

CHARACTERISTIC	RESPONDENTS, %
Age, yr	
18–39	41%
40–49	18%
50–69	26%
≥70	15%
Education	
High school or less	17%
Some college or technical school	35%
College graduate or more	48%
Race	
White	84%
Asian	10%
Other	6%
Total annual household income	
<$35,000	41%
$35,000–$50,000	25%
>$50,000	34%
Experience with breast cancer and genetic testing	
Family history of breast cancer before age 50 years	6%
Breast self-examination in past year	89%
Mammography within past 2 years (women >50 years)	97%
Amniocentesis or chorionic villus sampling	11%
Testing for Tay-Sachs or other inherited diseases	4%

Attitudes toward Testing

Attitudes toward access to testing are shown in **Figure 2**. More than three quarters of respondents reported believing that once genetic testing is available, it should be offered to everyone. Women who had heard or read about genetic testing for breast cancer susceptibility were twice as likely as women who had not to believe that genetic testing should be offered only to people who have a reason to think that they have an altered gene (63% vs. 33%). Seventy-one percent of respondents

TABLE 2

Perceptions of Breast Cancer Risk (*n* = 91)

SURVEY QUESTION AND RESPONSE	RESPONDENTS, %
In your opinion, compared to other women your age, what are your chances of getting breast cancer?	
Much lower	14%
A little lower	22%
About the same	47%
A little higher	11%
Much higher	6%
During the past month, how often have you thought about your own chances of developing breast cancer?	
Never or rarely	47%
Sometimes	45%
Often	7%
A lot	1%
During the past month, how often have thoughts about your chances of getting breast cancer affected your mood?	
Never or rarely	83%
Sometimes	17%
Often	0%
A lot	0%

said that they plan to obtain genetic testing for breast cancer if their health insurance covers it (23% answered "definitely yes," and 48% answered "probably yes"). Forty-four percent reported that they plan to obtain testing even if they have to pay for it themselves (9% answered "definitely yes," and 35% answered "probably yes").

Interest in Educational Programs

Ninety-six percent of respondents reported that they would be interested in learning more about genetic testing for breast cancer susceptibility if the managed care organization developed education programs. Respondents clearly preferred education obtained through discussions with their primary care providers (67%) and through informational booklets (63%) over discussions with a health educator (25%), group classes (28%), or an informational video (30%; multiple response options available).

Discussion

Our findings suggest that despite increasing media attention, almost half of the women visiting a primary care clinic had read or heard almost nothing about genetic testing for breast cancer susceptibility. Not surprisingly, most women did not have accurate information about breast cancer genetics; for example, only 40% knew that a woman who does not have an altered *BRCA1* gene can still get breast cancer. Although few women gave incorrect answers, most responded that they did not know the answer.

Despite limited knowledge about genetic testing, most women believed that genetic testing for breast cancer susceptibility should be offered to everyone, and many women said that they plan to undergo such testing themselves. Women who were more informed about genetic susceptibility testing were more likely to believe that genetic testing should be offered only to people who have reason to think that they have an altered gene.

This short opinion survey has some limitations. We asked women about their beliefs and intentions regarding genetic testing in isolation from their other health concerns and beliefs about their HMO. It is not clear from this survey the priority that women place on discussing genetic testing in relation to other topics

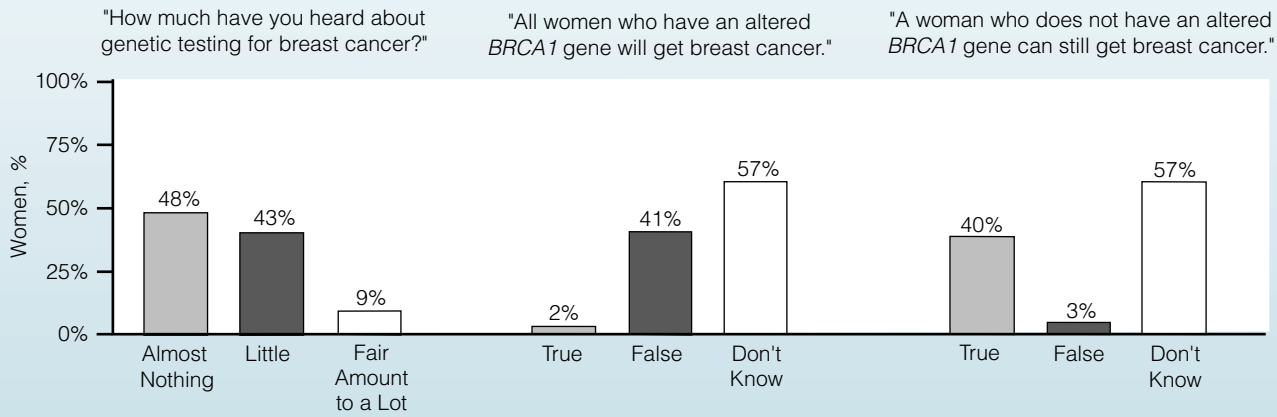

FIGURE 1. Women's knowledge about genetic testing for breast cancer.

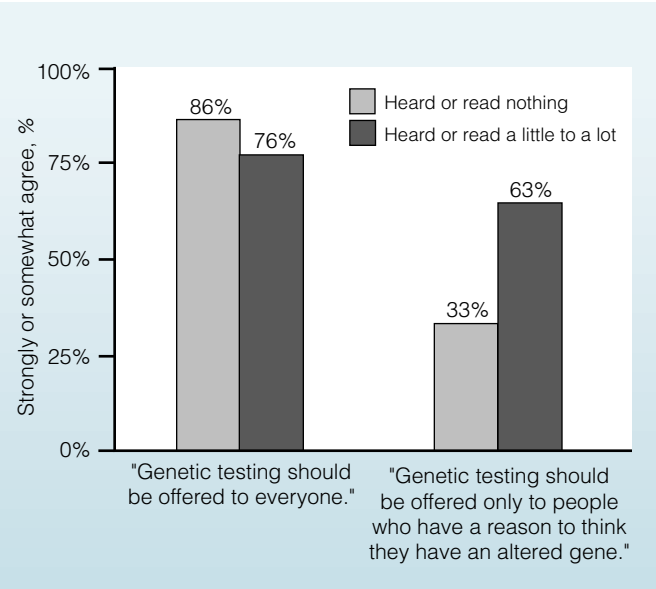

FIGURE 2. Attitudes toward genetic testing for breast cancer stratified by whether women had read or heard about such testing.

they may want to discuss with their providers (e.g., acute problems, such as menopausal symptoms, or lifestyle behavior changes). It is also not clear whether women's interest in testing and their belief that testing should be offered to everyone reflects a specific interest in genetic testing for breast cancer or a belief that HMOs should not limit a patient's access to testing in general. The fact that women know little about testing for breast cancer susceptibility but believe it should be offered to everyone may also reflect an implicit assumption that diagnostic testing of any kind is valuable. Other limitations of this study are related to the small size of the convenience sample and the limited variability in income, race or ethnicity, and education of the respondents.

Providing written information for primary care providers to deliver to women who request such information may be an efficient way to educate women about the benefits, limitations, and consequences of testing and may reduce requests for testing by women at average risk. Although interest in testing among primarily average-risk women in our sample seemed high, only 3 of 91 women had actually discussed testing with their physician. Previous studies have shown that even among higher-risk women (i.e., relatives of patients with breast and ovarian cancer), interest in testing is substantially higher than actual requests for testing. [5, 7] Only about 60% of high-risk women for whom testing was recommended actually pursued testing after undergoing education and counseling. [9, 10]

Education to inform women about the risks and benefits of genetic susceptibility testing currently occurs in pretest counseling sessions in genetic testing clinics. Actual testing for breast cancer susceptibility, accompanied by such pretest counseling, is typically recommended only for a small subset of the population seen by primary care providers (e.g., patients with strong family histories of breast and ovarian cancer).[3] Despite widespread media attention about new breast cancer genetic findings, most health care consumers do not have key information that is important to decision making. Even the highly educated women in our study had little knowledge of the facts of breast cancer inheritance; less well-educated women probably have even less knowledge.

Primary care visits present a potential opportunity for delivering information about genetic testing for breast cancer susceptibility to interested women. In our setting, women older than 18 years of age make an average of three to four primary care visits a year. The results of this opinion survey show a high level of interest in breast cancer genetics among average-risk women who are unlikely to be seen in specialty (i.e., oncology) practices. Women in this study told us that they would prefer to learn more about genetic testing by discussing these issues with their health care providers and by reading written information. Further studies are needed to examine the effectiveness of such primary care–based intervention strategies for patient education.

Take-Home Points

- **Genetic testing for breast cancer susceptibility is becoming widely available and is being promoted by for-profit laboratories.**
- **Half of the women surveyed in our primary care clinic had heard almost nothing about genetic testing and did not know the answers to basic questions about breast cancer genetics.**
- **Despite a lack of knowledge about breast cancer genetic testing, most thought that all women should be offered testing.**
- **Almost all of the survey respondents were interested in learning more about cancer genetics and testing.**

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