

Too Many Referrals of Low-Risk Women for *BRCA1/2* Genetic Services by Family Physicians

Della Brown White,¹ Vence L. Bonham,¹ Jean Jenkins,²
Nancy Stevens,³ and Colleen M. McBride¹

¹Social and Behavioral Research Branch and ²Office of the Director, National Human Genome Research Institute, NIH, Bethesda, Maryland; and ³University of Washington School of Medicine, Seattle, Washington

Abstract

The increasing availability and public awareness of *BRCA1/2* genetic testing will increase women's self-referrals to genetic services. The objective of this study was to examine whether patient characteristics influence the referral decisions of family physicians when a patient requests *BRCA1/2* genetic testing. Family physicians ($n = 284$) completed a Web-based survey in 2006 to assess their attitudes and practices related to the use of genetics in their clinical practice. Using a $2 \times 2 \times 2$ factorial design, we tested the effects of a hypothetical patient's race, level of worry, and insurance status on the decisions of family physicians to refer her for *BRCA1/2* testing. The patient was not appropriate for referral based on U.S. Preventive Services Task Force guidelines. No patient characteristics were associated with the family physicians' referral decisions.

Although referral was not indicated, only 8% did not refer to genetic services; 92% referred for genetic services, and 50% referred to genetic counseling. Family physicians regarded it unlikely that the patient carried a mutation, but 65% of family physicians believed that if they refused to refer for genetic services it would harm their relationship with the patient. Despite scarce and costly genetic services, family physicians were likely to inappropriately refer a low-risk patient who requested *BRCA1/2* testing. The implications of this inappropriate referral on women's screening behavior, genetic services, and health care costs are unknown. Clinicians and patients could benefit from education about the appropriate use of genetic services so that both are more comfortable with a decision against referral. (Cancer Epidemiol Biomarkers Prev 2008;17(11):2980-6)

Introduction

The integration of genomics into clinical practice is forecast to have important benefits for health care delivery and health outcomes (1). *BRCA1* and *BRCA2* (*BRCA1/2*) testing for familial breast and ovarian cancer is an example of the kinds of testing that will be available clinically. Carriers of *BRCA1/2* mutations are at substantially increased risk of breast and ovarian cancer. However, the distribution of *BRCA1/2* mutations in the general population is very low, estimated at 1 in 300 to 500 (2). Additionally, hereditary breast cancers account for about 5% to 10% of all breast cancer cases, with *BRCA1/2* mutations only contributing to a small fraction of these cases (3). One study reported that within an average general practitioner's caseload of 1,700 patients, only 140 patients would be estimated to have a family history of breast, colorectal, or breast/ovarian cancer, and 10 of these patients would be considered appropriate for referral to genetic counseling based on well-defined risk criteria (4).

Direct-to-consumer marketing of *BRCA1/2* testing and the tendency among American women to overestimate their risks of breast cancer (5) create consumer demand

as women "self refer" to primary care clinicians and request genetic testing (6-9). Traditionally, genetic testing is provided in the context of appropriate genetic counseling or education, yet clinical genetic services in the U.S. remain relatively scarce (10-12). The low prevalence of *BRCA1/2* mutations means that in the majority of self-referral situations, primary care clinicians will be in the position of having to dissuade low-risk women from *BRCA1/2* counseling and testing. This will put considerable pressure on clinicians to make appropriate referrals.

Inappropriate referral to *BRCA1/2* testing also could have significant implications for health care costs and service delivery. The results of Myriad Genetics Laboratories' direct-to-consumer marketing campaign for BRACAnalysis led to a 240% increase in the number of referrals to genetic services within managed care settings (6, 7), creating delays in patient access to these services (6). At \$3,000 per test in the United States, *BRCA* testing and supportive genetic counseling is a significant expenditure of resources (13).

Moreover, the patient-clinician conversations required to clarify why a patient is or is not appropriate for genetic service referral may increase visit time in ways that do not directly benefit patient care. This may be particularly true in circumstances in which women present with heightened worry and misperceptions about the factors that contribute to their risk. Insurance status also may further complicate these conversations when women with health care insurance believe that they have the right to services even if they are not appropriate.

Received 12/8/07; revised 6/17/08; accepted 8/5/08.

Grant support: Intramural Research Program of the National Human Genome Research Institute, NIH.

Requests for reprints: Della Brown White, Social and Behavioral Research Branch, National Human Genome Research Institute, NIH, 31 Center Drive, Building 31, Room B1B54G, Bethesda, MD 20892-2073. Phone: 301-443-2617; Fax: 301-480-3108. E-mail: whitede@mail.nih.gov

Copyright © 2008 American Association for Cancer Research.

doi:10.1158/1055-9965.EPI-07-2879

Biases such as underreferral of minority women to *BRCA1/2* services also could occur in ways that exacerbate existing racial/ethnic disparities in health delivery (14-17). Patient characteristics such as age, race, and gender have been noted as reasons for patients not receiving clinically recommended services (16). Evidence to date suggests, however, that patient demands for clinical services (18, 19), including cancer susceptibility testing (20, 21), are likely to be granted even when deemed inappropriate by the physician (19, 22). The reasons for these patterns of inappropriate referral have included physician concerns about patient satisfaction and fears of malpractice (23).

To this end, the U.S. Preventive Services Task Force (USPSTF) published guidelines in late 2005 to assist clinicians in determining which patients are appropriate for referral to genetic counseling and testing for *BRCA1/2* mutations (24). These guidelines recommend against routine referrals of low-risk women to *BRCA1/2* genetic services. Whereas clinicians have indicated favorable attitudes toward practice guidelines (25), concerns have been raised that guidelines can be too rigid and impractical to incorporate and interfere with physician autonomy (26-28). Further, clinicians may have difficulty applying the USPSTF referral guidelines because they have low levels of confidence in their ability to calculate breast cancer risk and related counseling (4, 29, 30). Physicians also lack confidence in their ability to discuss mammography screening and to decide whether a patient should be referred for genetic counseling (4, 30).

Family physicians who provide the majority of primary care in the United States (31) will be fielding the majority of self-referral for *BRCA1/2* testing. Thus, the adherence of family physicians to USPSTF guidelines has significant implications for the effect of self-referral on genetic services and breast cancer screening more generally. The competence of family physicians in considering women's concerns about breast cancer has broader implications for cancer control. For example, inappropriate referral could influence women's adherence to screening guidelines if they misunderstand indications from their doctors that they are unlikely to have increased familial risk.

This report describes the results of an experiment where family physicians, through a Web-based survey, were presented with a hypothetical patient named "Terry" who requests genetic testing but is not appropriate for referral based on USPSTF guidelines. The experiment also tested whether varying Terry's personal characteristics influenced the decisions of family physicians for *BRCA1/2* testing.

Materials and Methods

Study Design. A cross-sectional $2 \times 2 \times 2$ factorial design was used. All family physicians viewed a hypothetical patient named Terry who presents for her annual exam and requests genetic testing for breast cancer. The vignette describes Terry's request as being prompted by her sister's recent diagnosis of breast cancer at age 53 years and provided a description of Terry, including her age, health status, family history of cancer, ethnicity (not Ashkenazi Jewish), and results of

the previous year's mammography results. Physicians were randomized to see one of eight variations of the vignette based on the three experimental factors: (a) level of worry (high versus not high), (b) insurance status (insured versus not insured), and (c) race (black versus white as indicated by the picture provided with the vignette; see Fig. 1). In each vignette, Terry was not appropriate for referral to *BRCA1/2* genetic services based on the USPSTF guidelines (24); the estimated prevalence of *BRCA1/2* mutations in women with the same health history as Terry is 2.8% and 2.9% for Terry's sister (32).

After reading the vignette, physicians were asked a series of questions that included their decision regarding whether or not to refer Terry to genetic services. For these questions, physicians were not allowed to scroll back to the page with the patient description. Participants who completed the follow-up survey were entered into a lottery to receive one of six iPods. The study procedures were approved by the Institutional Review Boards of the National Human Genome Research Institute and the American Academy of Family Physicians.

Sample. The sample for this report was drawn from a longitudinal survey of members of the American Academy of Family Physicians (AAFP) conducted to evaluate the AAFP's Annual Clinical Focus on Genomics in January 2005. First, a random stratified sample of 10,000 AAFP members was drawn such that half of the sample had completed residency less than 15 years ago; a total of 1,035 family physicians completed this Web-based survey (10% response rate). Compared with the AAFP membership as a whole, family physicians who completed the first survey were significantly more likely to be working in teaching hospitals compared with the AAFP membership as a whole (18% versus 9%, respectively). At the end of this survey, family physicians who completed the survey were asked to provide personal identifiers that would enable them to be recontacted for a similar survey a year hence.

A total of 694 of the 1,035 family physicians (67%) agreed to be recontacted via e-mail to complete the follow-up survey. E-mails were sent to inform these family physicians that they could log onto a Web site, review brief consent information, and complete a follow-up survey between May 8, 2006, and June 2, 2006. Two e-mail reminders went to each participant; one at 7 days after the broadcast e-mail, and the other at 14 days after the broadcast e-mail. The final sample included the 284 physicians (27% response rate) who completed questions related to the referral of Terry to genetic services. This sample size enables us to detect the effects of the experimental manipulation that are in the small to medium range of standardized effect sizes with 80% power at the $P < 0.05$ level of significance (33). Analyses were conducted in the fall of 2006.

Measures and Survey Items

Demographics and Practice Characteristics. Gender and time out of residency were obtained from AAFP membership records. Self-identified race and practice characteristics (including approach to work, teaching/training environment, urban setting or not, the proportion of non-white residents, and residents living in poverty) were assessed in the initial Web-based survey.

AAFP Phase 2 Survey

Please read the following chart and clinical scenario below and answer the questions that follow.

PATIENT: Terry Jones

GENDER: Female

AGE: 47 years old


HEALTH STATUS: Excellent

FAMILY HISTORY: Maternal aunt diagnosed with lung cancer at age 59. No other family history of cancer.

ETHNICITY: Not Ashkenazi Jewish

TREATMENT: Last year had a routine mammography that was unremarkable.

Terry presents today for her annual exam and tells you about her sister's recent diagnosis of breast cancer at age 53. She tells you that she is very worried about her own risk for breast cancer and that she has read recently about a test for the breast cancer gene. Terry also tells you that she has checked and knows that her insurance will cover genetic testing for breast cancer. She asks you to refer her for genetic testing because her sister's diagnosis makes her feel very anxious about whether she and her daughters may be at higher than average risk for getting breast cancer.



In response to Terry's request for referral to genetic testing, you have several genetic service options to choose from. The next set of questions are going to ask you about your attitudes about referring Terry to either genetic testing, genetic counseling, a combination of the two genetic services or other genetic services.

Figure 1. Example of Web page used to present the hypothetical scenarios to physicians. This experimental description of Terry is of black race, insured, and with high level of worry.

Referral Decision. Family physicians were asked the following question: "How likely are you to refer Terry to the following services considering the circumstances described?" (Neither genetic testing nor genetic counseling, both genetic testing and genetic counseling, genetic testing as she requests, genetic counseling, or other)."

Attitudes about the Referral Decision. Family physicians were asked two questions: (a) "How sure are you that your decision about this referral is the best clinical decision?" and (b) "How sure are you that your decision about this referral is an optimal use of genetic services?" For each question family physicians rated their responses on a scale of 1 (not at all sure) to 7 (extremely sure).

Factors Important in Referral Decision. Family physicians were asked to rate the importance of patient characteristics (e.g., Terry's race, age, sister's age at diagnosis) in their referral decision on a scale of 1 (not at all important) to 7 (extremely important). Family physicians were also asked the extent to which they agreed or disagreed with the following: "If you refuse to refer Terry for genetic counseling or testing, it will harm your relationship with her." Family physicians rated their agreement using a 5-point Likert scale (strongly disagree, disagree, neither agree nor disagree, agree, strongly agree). Family physicians' opinions about Terry's level of risk of breast cancer were assessed with the following two questions: (a) "What do you think is the likelihood that Terry has a genetic mutation that

increases her risk for breast cancer?" and (b) "How would you rate Terry's level of breast cancer risk?" Family physicians responded on a scale of 1 (very low) to 7 (very high).

Value of Referral to Genetic Services. Family physicians were asked a series of questions to assess their opinions on the value of referring Terry to genetic counseling (e.g., "Terry could get needed reassurance from your referral for genetic counseling even if she isn't appropriate for testing") and for genetic testing (e.g., "There's no harm in referring Terry for genetic testing even if she isn't really appropriate for testing"). Family physicians rated their responses using a 5-point Likert scale (strongly disagree, disagree, neither agree nor disagree, agree, strongly agree).

Statistical Analyses. Means and proportions were computed to describe the distribution of survey items. Contingency tables were used to examine the bivariate relationships among the three experimental factors: (a) level of worry (high versus not high), (b) insurance status (insured versus not insured), and (c) race (black picture versus white picture) and outcome variable of interest (i.e., family physician's referral decision). Multivariable polytomous logistic regression models were used to test the association of the three experimental dichotomous factors on family physician's referral decision. Throughout this report $P < 0.05$ is used as the criterion for statistical significance.

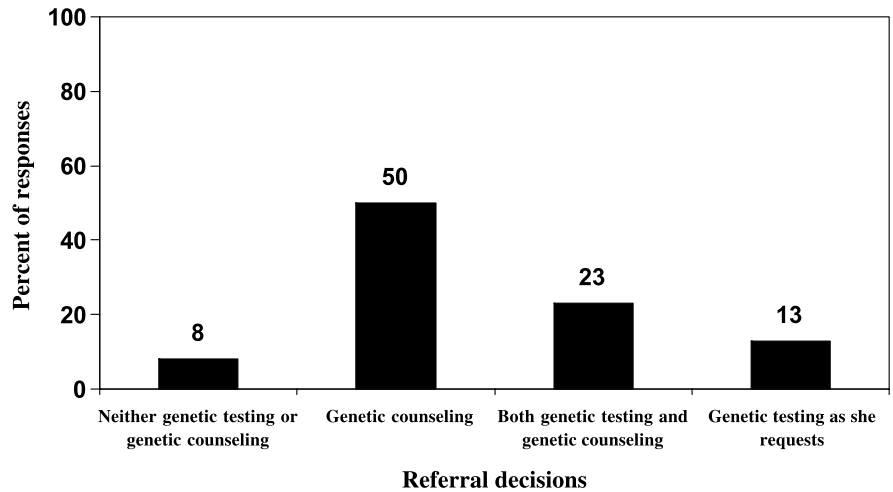


Figure 2. Family physicians' decisions to refer Terry to genetic services.

Results

Sample Characteristics. Family physicians who completed the follow-up survey were predominantly non-Hispanic white physicians (87%) and male (71%); most practiced in urban areas (65%), half were more than 15 years out of residency, and one third were currently working in a teaching or training environment. About half reported practicing in a clinic where more than 15% were minority patients, and 43% practiced in a clinic where more than 10% of residents lived in poverty. Family physicians who completed the first and second surveys were demographically similar (e.g., male: 67% and 71%, respectively; preferred innovative practice: 61% and 66%, respectively; and practiced in a teaching environment: 30% and 35%, respectively).

Experiment Outcomes. The referral decisions of family physicians were not associated with Terry's level of worry ($P = 0.89$), insurance status ($P = 0.99$), or race ($P = 0.65$). Although Terry was not appropriate for referral to *BRCA1/2* genetic services, only 8% of family physicians made a decision against referral (see Fig. 2). Thus, 92% of family physicians made a referral decision inconsistent with the USPSTF guidelines. Half reported they would refer Terry for genetic counseling only, 23% said they would refer her to both genetic testing and counseling, 13% would refer Terry directly to genetic testing as requested, and 6% of participants noted they would make a decision other than those presented, such as asking to have Terry's sister tested for *BRCA1/2*.

Manipulation checks on the experimental factors showed that family physicians accurately recalled the details of Terry's age, race, and emotional status. Fifty nine percent of family physicians accurately recalled that Terry's age was below 50 years, 94% of family physicians who saw a white Terry identified her race as white, and 70% who saw a black Terry indicated that she was black. Family physicians who saw the High Worry Terry rated her as significantly more nervous ($P < 0.001$) and afraid ($P < 0.001$), than those for whom Terry presented without mention of worry.

Explanations for Non-Guideline Recommended Referral Decisions. To better understand the factors that

might underlie the referral decisions of the 260 family physicians who indicated a decision inconsistent with referral guidelines, we explored the family physicians' beliefs about the appropriateness of their referral decision (see Table 1). Family physicians perceived Terry's risk of breast cancer to be moderate (mean, 4.2; SD, 1.1); but regarded her risk of having a genetic mutation as relatively low (mean, 2.8; SD, 1.4). Family physicians reported being relatively sure that their referral decision was the best clinical decision (mean, 4.8; SD, 1.4) and an optimal use of genetic services (mean, 4.5; SD, 1.5). Family physicians rated Terry's level of emotional distress (mean, 5.5; SD, 1.2; scale 1-7) and her sister's age at diagnosis (mean 5.1; SD, 1.5; scale 1-7) as important factors in their referral decision. Terry's race (mean, 3.2; SD, 1.7) and insurance status (mean, 3.4; SD, 1.9) were less important factors in their decision.

Table 1. Beliefs about the appropriateness of referral decision among physicians who reported non-guideline recommended referral decisions for Terry ($n = 260$)

Item	Mean (SD)
Beliefs about Terry's level of risk*	
Terry's level of breast cancer risk	4.2 (1.1)
Likelihood Terry has genetic mutation	2.8 (1.4)
Beliefs about referral decision	
Best clinical decision	4.8 (1.4)
Optimal use of genetic services	4.5 (1.5)
Factors important in the referral decision †	
Terry's level of emotional distress	5.5 (1.2)
Her sister's age at diagnosis of breast cancer	5.1 (1.5)
Her having daughters	4.7 (1.5)
Terry's age	4.3 (1.6)
Her mammography results from last year	3.8 (1.8)
What she told you about her insurance status	3.4 (1.9)
Her race	3.2 (1.7)
Her aunt's age at diagnosis of lung cancer	2.9 (1.7)
That she is not Ashkenazi Jewish	2.9 (1.7)

NOTE: Numbers are missing on some items.

* Seven-point scale: 1, very low; 7, very high.

† Seven-point scale: 1, not at all sure; 7, extremely sure.

‡ Seven-point scale: 1, not at all important; 7, extremely important.

Table 2. Beliefs about the costs and benefits of referral decisions among physicians who reported non-guideline recommended referral decisions for Terry (n = 260)

Item	%*
Agree harm to relationship if refuse to refer Terry*	65
Values of referral to genetic counseling*	
Terry is likely to benefit from your referral to <i>genetic counseling</i>	84
Poor use of resources to refer Terry for <i>genetic counseling</i> if you know she isn't appropriate for testing.	37
Terry could get needed reassurance from your referral for <i>genetic counseling</i> even if she isn't appropriate for testing.	89
No harm to refer to <i>genetic counseling</i> if not appropriate for genetic testing.	61
Values of referral to genetic testing*	
Terry is likely to benefit from your referral to <i>genetic testing</i> .	31
Regardless of what you say, Terry will likely seek <i>genetic testing</i> on her own.	54
In the end, Terry's insurance would probably not pay for <i>genetic testing</i> .	46
No harm to refer to <i>genetic testing</i> if not appropriate for genetic testing.	11

NOTE: Numbers are missing on some items.

*Percentage of respondents answering agree or strongly agree.

We also explored family physicians' beliefs about the costs and benefits of their referral decisions (see Table 2). The majority of family physicians agreed that Terry would be likely to benefit from genetic counseling, could get needed reassurance from the referral to genetic counseling even if she was not appropriate for testing, and that there was no harm in referring Terry for genetic counseling even if she was not appropriate for testing. Responses to the likelihood of benefit from referral to genetic counseling and benefit from referral to genetic testing were significantly associated ($\chi^2 = 7.45$; $df = 1$; $P = 0.01$). Those who indicated Terry could benefit from testing were significantly more likely to say she would benefit from counseling as well, whereas the reverse was not the case. Most respondents (65%) believed that refusing Terry's request might harm their relationship with her. Family physicians who decided to refer Terry were more likely to agree that refusal to refer Terry would harm the relationship than those who did not refer Terry on for genetic services.

Discussion

The USPSTF guidelines recommend against routine referrals of low-risk women for BRCA1/2 genetic services (24). The patient in this report, did not meet the guidelines for referral. Nonetheless, 92% of family physicians chose to refer her to genetic services. No presenting characteristics (e.g., level of worry, insurance status, race) were associated with the referral decision.

Most family physicians believed that the decision to refer was an optimal use of genetic services, suggesting that they may underestimate the "costs" of referral. Indeed, although Myriad's direct-to-consumer marketing campaign increased referrals to genetic services by 240%, the majority of physicians in the market area perceived that the campaign had no effect on clinical practice (6, 7). Moreover, the majority of women referred by physicians reported having delays of more than 6 months to access genetic services (6). Referral of low-risk women could create a bottleneck in getting services to high-risk women who stand to benefit most.

Our results also suggest that family physicians made referral decisions, in part, to preserve their relationship with the patient. Similarly, previous research suggests that cancer susceptibility testing is more likely to be

ordered when directly requested by patients (20, 21). Moreover, direct-to-consumer advertising consistently has been associated with increased patient demand in the form of more requests for prescriptions (34) and other clinical services (22). The fact that these requests frequently are granted even when clinicians deem them to be clinically inappropriate suggests that physicians may need additional support in declining patient requests (19, 22).

In the case of Terry, family physicians may have struck the balance between Terry's request for genetic services and their belief that Terry was unlikely to have a BRCA1/2 mutation by referring her to genetic counseling rather than genetic testing. For example, the challenge of helping women discriminate genetic risk from other risk factors such as age may have seemed more suited to a genetic counseling session than the primary care visit.

Further, the family physicians' instinct to refer Terry to genetic counseling may have been an appropriate response to their lack of confidence in their abilities to do genetic risk assessment or their concerns about the time it would take to adequately assess risk and provide related counseling. In this circumstance, referral to genetic counseling may have been viewed by the family physician as the only feasible alternative. This dilemma suggests the need to provide providers and patients with educational tools and decision aids on the appropriateness of BRCA1/2 testing. For example, an interactive computer-based decision aid designed to educate women about breast cancer genetic services has been shown to be beneficial in increasing breast cancer and genetic testing knowledge and in reducing intentions to test and risk perception among low-risk women (35). Additionally, hotlines have also been used to this end. The National Cancer Institute's Atlantic Region Cancer Information Service implemented an educational intervention using the 1-800-4-CANCER line (36). Results at 6 months indicated that average-risk women reported decreased intentions to test and high-risk women reported increased intentions to test. Hence, additional research is needed to evaluate these services in supporting physicians and patients to make decisions about BRCA1/2 testing.

Additionally, physicians need to gain greater familiarity and understanding of what risk factors deem women to be at high genetic risk of breast cancer. Family physicians reported the age of Terry's sister at diagnosis

as one of the most important factors in their decision to refer Terry to genetic services. Terry's sister's age was not consistent with USPSTF referral guidelines (i.e., <50 years at age of diagnosis). Previous research also has noted the lack of physician knowledge about factors important in risk assessment and appropriate referrals for *BRCA1/2* testing (8, 9, 29, 37) and cancer susceptibility testing in general (20, 21). Additionally, patients could also benefit from education on familial breast and ovarian cancer and related genetic testing to further enhance appropriate requests and referrals to genetic services. The services described above could be useful in raising such awareness.

Several limitations of the study must be considered in interpreting these results. Data are cross-sectional and the direction of the associations cannot be established. The response rate to the initial survey was relatively low, although the initial and follow-up survey participants seemed to well represent the larger AAFP membership (38). However, this self-selected sample of family physicians who participated was inclined toward innovation and thus may have included those who were most likely to be knowledgeable of and receptive to genetic innovations in clinical care. Thus these results may overestimate the readiness to refer.

Additionally, the USPSTF guidelines for referral to *BRCA1/2* genetic services were published less than one year before the follow-up survey (24). More than 90% of family physicians in this sample reported having heard of USPSTF, but we did not assess whether family physicians were aware of the new guidelines specific for *BRCA1/2* referral. Future studies should assess the awareness of the guidelines to help differentiate whether physicians are making referral decisions despite knowing practice guidelines. Further, more research is needed to assess how the letter grades used to define USPSTF guidelines may influence clinician referral behaviors. Adherence to guidelines may be influenced by physicians' perceptions about the validity of the data used to devise the guidelines. Family physicians' responses also were based on a hypothetical scenario and may not accurately reflect how they actually would respond in a clinical setting. Prospective studies with real patients that incorporate medical chart reviews are needed to increase the validity of physician responses and more accurately assess referrals rates.

When considering whether genomic medicine has the potential to improve health care delivery and patient health outcomes, it will be important to understand how factors such as patient characteristics, direct-to-consumer advertising, physicians' knowledge of genetics, and adherence to guidelines might influence health care delivery and health disparities. Inappropriate referrals of patients at low risk of carrying genetic mutations to limited genetic professional services could hinder access to these services by high-risk patients and increase out-of-pocket costs to patients. This is especially true for the future of cancer prevention and control as we move toward the dissemination of genetic susceptibility testing not only for rare, hereditary cancers but also for more common "sporadic" cancers that contribute to a greater public health burden (39-41). To maximize appropriate referral for genetic services, research should focus on the role of clinician-patient

relationships in referrals, patient education, and clinician training in genetic risk assessment and counseling skills.

Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

Acknowledgments

The costs of publication of this article were defrayed in part by the payment of page charges. This article must therefore be hereby marked *advertisement* in accordance with 18 U.S.C. Section 1734 solely to indicate this fact.

The contents of this article are solely the responsibility of the authors and do not necessarily represent the official views of the National Human Genome Research Institute or the NIH. We thank the American Academy of Family Physicians for partnering with us in this research; Christopher Price and Amanda Parsad for their statistical expertise; the team led by Donald Dorfman at Esprit Health for designing the Web site; Dr. Alan Guttmacher and Dr. William Feero for their comments on an earlier version of this article; and all the physicians who participated in this study. This research was supported [in part] by the Intramural Research Program of the National Human Genome Research Institute, National Institutes of Health

References

- Guttmacher AE, Collins FS. Realizing the promise of genomics in biomedical research. *JAMA* 2005;294:1399-402.
- McClain MR, Palomaki GE, Nathanson KL, Haddow JE. Adjusting the estimated proportion of breast cancer cases associated with *BRCA1* and *BRCA2* mutations: public health implication. *Genet Med* 2005;7:28-33.
- Nelson HD, Huffman LH, Fu R, Harris EL. Genetic risk assessment and *BRCA* mutation testing for breast and ovarian cancer susceptibility: systematic evidence review for the U.S. Preventive Services Task Force. *Ann Intern Med* 2005;143:362-79.
- Campbell H, Holloway S, Cetnarskyj R, et al. Referrals of women with a family history of breast cancer from primary care to cancer genetics services in South East Scotland. *Br J Cancer* 2003;89:1650-6.
- Davis S, Stewart S, Bloom J. Increasing the accuracy of perceived breast cancer risk: results from a randomized trial with Cancer Information Service caller. *Prev Med* 2004;39:64-73.
- Mouchawar J, Hensley-Alford S, Laurion S, et al. Impact of direct-to-consumer advertising for hereditary breast cancer testing on genetic services at a managed care organization: a naturally-occurring experiment. *Genet Med* 2005;7:191-7.
- Mouchawar J, Laurion S, Ritzwoller DP, Ellis J, Kulchak-Rahm A, Hensley-Alford S. Assessing controversial direct-to-consumer advertising for hereditary breast cancer testing: reactions from women and their physicians in a managed care organization. *Am J Manag Care* 2005;11:601-8.
- Myers MF, Chang MH, Jorgensen C, et al. Genetic testing for susceptibility to breast and ovarian cancer: evaluating the impact of a direct-to-consumer marketing campaign on physicians' knowledge and practices. *Genet Med* 2006;8:361-70.
- Centers for Disease Control and Prevention. Genetic testing for breast and ovarian cancer susceptibility: evaluating direct-to-consumer marketing- Atlanta, Denver, Raleigh-Durham, and Seattle, 2003. *MMWR Morb Mortal Wkly Rep* 2004;53:603-6.
- National Society of Genetic Counselors. 2006 Annual Report. [updated 2006; cited 2007 Jul 28]. Available from: http://www.nsgc.org/client_files/about/2006AnnualReport.pdf.
- American Board of Genetic Counseling. About ABGC: General information. [updated 2007 Jul 23; cited 2007 Jul 28]. Available from: <http://www.abgc.net/english/View.asp?x=1465>.
- American Board of Medical Genetics. Numbers of certified specialists in genetics. [updated 2007; cited 2008 Mar 31]. Available from: http://www.abmg.org/pages/resources_certspecial.shtml.
- Phillips KA, Veenstra DL, Ramsey SD, Van Bepber SL, Sakowski J. Genetic testing and pharmacogenomics: issues for determining the impact to healthcare delivery and costs. *Am J Manag Care* 2004;10:425-32.

14. Sankar P, Cho MK, Condit CM, et al. Genetic research and health disparities. *JAMA* 2004;291:2985–9.
15. Armstrong K, Micco E, Carney A, Stopfer J, Putt M. Racial differences in the use of *BRCA1/2* testing among women with a family history of breast or ovarian cancer. *JAMA* 2005;293:1729–36.
16. McKinlay JB, Link CL, Freund KM, Marceau LD, O'Donnell AB, Lutfey KL. Sources of variation in physician adherence with clinical guidelines: results from a factorial experiment. *J Gen Intern Med* 2007;22:289–96.
17. Betancourt JR, Maina AW. The Institute of Medicine Report "Unequal treatment." Implications for academic health centers. *Mt Sinai J Med* 2004;71:314–21.
18. Kravitz RL, Bell RA, Azari R, Kelly-Reif S, Krupat E, Thom DH. Direct observation of requests of clinical services in office practice: what do patients want and do they get it? *Arch Intern Med* 2003;163:1673–81.
19. Keitz SA, Stechuchak KM, Grambow SC, Koropchak CM, Tulsy JA. Behind closed doors: management of patient expectations in primary care practices. *Arch Intern Med* 2007;167:445–52.
20. Wideroff L, Freedman AN, Olson L, et al. Physician use of genetic testing for cancer susceptibility: results of a national survey. *Cancer Epidemiol Biomarkers Prev* 2003;12:295–303.
21. Sifri R, Myers R, Hyslop T, et al. Use of cancer susceptibility testing among primary care physicians. *Clin Genet* 2003;64:355–60.
22. Murray E, Lo B, Pollack L, Donelan K, Lee K. Direct-to-consumer advertising: physicians' views of its effects on quality of care and the doctor-patient relationship. *J Am Board Fam Pract* 2003;16:513–24.
23. Franks P, Williams GC, Zwanziger J, Mooney C, Sorbero M. Why do physicians vary so widely in their referral rates? *J Gen Intern Med* 2000;15:163–8.
24. U.S. Preventive Services Task Force. Genetic risk assessment and *BRCA* mutation testing for breast and ovarian cancer susceptibility. *Ann Intern Med* 2005;143:355–61.
25. Wolff M, Bower DJ, Marbella AM, Casanova JE. U.S. family physicians' experiences with practice guidelines. *Fam Med* 1998;30:117–21.
26. Guirguis-Blake J, Calonge N, Miller T, et al. Current processes of the U.S. Preventive Services Task Force: refining evidence-based recommendation development. *Ann Intern Med* 2007;147:117–22.
27. Spring B, Pagoto S, Kaufmann PG, et al. Invitation to a dialogue between researchers and clinicians about evidence-based behavioral medicine. *Ann Behav Med* 2005;30:125–37.
28. Cabana MD, Rand CS, Powe NR, et al. Why don't physicians follow clinical practice guidelines? A framework for improvement. *JAMA* 1999;282:1458–65.
29. Fry A, Campbell A, Gudmundsdottir H, et al. GPs' views on their role in cancer genetics services and current practice. *Fam Pract* 1999;16:468–74.
30. Acton RT, Burst NM, Casebeer L, et al. Knowledge, attitudes, and behaviors of Alabama's primary care physicians regarding cancer genetics. *Acad Med* 2000;75:850–2.
31. Hing E, Cherry DK, Woodwell DA. National Ambulatory Medical Care Survey: 2004 summary. Advance data from vital and health statistics; no 374. Hyattsville (MD): National Center for Health Statistics; 2006.
32. Myriad Genetic Laboratories, Inc. Mutation prevalence tables. [updated 2006 Spring; cited 2007 Jul 10]. Available from: <http://www.myriadtests.com/provider/doc/BRCA-Mutation-Prevalence-Percentages.pdf>.
33. Cohen J. Statistical power analysis for the behavioral sciences. 2nd ed. Hillsdale (NJ): Lawrence Erlbaum Associates; 1988.
34. Kravitz RL, Epstein RM, Feldman MD, et al. Influence of patients' requests for direct-to-consumer advertised antidepressants: a randomized controlled trial. *JAMA* 2005;293:1995–2002.
35. Green MJ, Peterson SK, Baker MW, et al. Effect of a computer-based decision aid on knowledge, perceptions, and intentions about genetic testing for breast cancer susceptibility: a randomized controlled trial. *JAMA* 2004;292:442–52.
36. Miller SM, Fleisher L, Roussi P, et al. Facilitating informed decision making about breast cancer risk and genetic counseling among women calling the NCI's cancer information service. *J Health Commun* 2005;10:119–36.
37. Wideroff L, Vadaparampil ST, Greene MH, Taplin S, Olson L, Freedman AN. Hereditary breast/ovarian and colorectal cancer genetics knowledge in a national sample of US physicians. *J Med Genet* 2005;42:749–55.
38. American Academy of Family Physicians. Facts about family medicine. [updated 2007; cited 2008 Mar 31]. Available from: <http://www.aafp.org/online/en/home/aboutus/specialty/facts.html>.
39. Hay JL, Meischeke HW, Bowen DJ, et al. Anticipating dissemination of cancer genomics in public health: a theoretical approach to psychosocial and behavioral challenges. *Ann Behav Med* 2007;34:275–86.
40. McBride CM, Brody LC. Point: genetic risk feedback for common disease-time to test the waters. *Cancer Epidemiol Biomarkers Prev* 2007;16:1724–6.
41. Hiatt RA, Miller SM, Vernon SW. Translational research and good behavior. *Cancer Epidemiol Biomarkers Prev* 2007;16:2184–5.

Too Many Referrals of Low-Risk Women for *BRCA1/2* Genetic Services by Family Physicians

Della Brown White, Vence L. Bonham, Jean Jenkins, et al.

Cancer Epidemiol Biomarkers Prev 2008;17:2980-2986.

Updated version Access the most recent version of this article at:
<http://cebp.aacrjournals.org/content/17/11/2980>

Cited articles This article cites 34 articles, 4 of which you can access for free at:
<http://cebp.aacrjournals.org/content/17/11/2980.full#ref-list-1>

Citing articles This article has been cited by 1 HighWire-hosted articles. Access the articles at:
<http://cebp.aacrjournals.org/content/17/11/2980.full#related-urls>

E-mail alerts [Sign up to receive free email-alerts](#) related to this article or journal.

Reprints and Subscriptions To order reprints of this article or to subscribe to the journal, contact the AACR Publications Department at pubs@aacr.org.

Permissions To request permission to re-use all or part of this article, use this link
<http://cebp.aacrjournals.org/content/17/11/2980>.
Click on "Request Permissions" which will take you to the Copyright Clearance Center's (CCC) Rightslink site.