

Guidelines for breast and ovarian cancer genetic counseling referral: Adoption and implementation in HMOs

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Purpose: To describe referral guidelines for hereditary breast and ovarian cancer (HBOC) counseling among a group of Health Maintenance Organizations (HMOs) and awareness of such among primary care clinicians. **Methods:** An organizational assessment of plan policies and a primary care clinician survey. **Results:** Five of the 7 HMOs reported having HBOC referral guidelines. Differences between plan's criteria included age of breast cancer onset, inclusion of male breast cancer, and second-degree relatives. Of the 91% clinicians responding, only half were aware of the HBOC guidelines. Awareness was higher in the plan with the most intense implementation effort (OR = 3.0, 1.5–5.9) and among gynecologists (OR = 2.8, 1.5–5.4). **Conclusions:** Although HBOC counseling guidelines within participating HMOs identify persons for referral that can be easily incorporated into routine practice, continued work is needed to better understand how to help primary care providers identify high-risk persons, and new models of providing genetic services may need to be considered. *Genet Med* 2003;5(6):444–450.

Key Words: hereditary, breast cancer, guidelines, managed care

In the mid-1990s germline mutations in the *BRCA1* and *BRCA2* (*BRCA1/2*) genes were found to be associated with an increased risk for breast and ovarian cancers.^{1–2} Genetic testing of the general population for *BRCA1/2* mutations is not endorsed, however, because the prevalence is low and the psychosocial consequences are potentially high.^{3–12} Rather, the current recommendation by professional organizations is to screen the general population at the primary care level to identify those at potentially increased risk for hereditary susceptibility to breast and ovarian cancer.^{3–8,13} Formal genetic counseling and testing would then only be offered to those at the highest level of familial risk.

Primary care providers thus have an important role in identifying patients at increased risk for hereditary susceptibility to breast and ovarian cancer. Studies have confirmed that such providers need and want referral guidance in the emerging area of cancer genetics.^{14–17} A number of organizations have published general guidelines to identify patients for whom offering

genetic testing is appropriate, and all agree on the importance of genetic counseling by trained professionals as the risks and benefits of testing are complex, personal, and subject to change over time as science and legislation evolve.^{3–8}

Very little has been published about the use of guidelines in routine primary care to aid in identifying patients for breast and ovarian cancer genetic counseling referral. As the genetics of common diseases expands with new research, the challenge of translation into clinical practice will heighten. A number of Health Maintenance Organizations (HMOs) began offering hereditary breast and ovarian cancer services in the late 1990s, and implemented clinical practice guidelines for referral to such services.^{18–19} The purpose of this article is to describe the hereditary breast and ovarian cancer genetic counseling referral guidelines among a group of HMOs in the United States, as well as to explore the awareness of such guidelines among primary care clinicians. The illustration of how selected HMOs have adapted counseling referral guidelines to clinical practice guidelines and the current reported impact of these guidelines among their clinicians can be of value to other organizations and health care providers, particularly those in genetic medicine.

MATERIALS AND METHODS

This analysis is based on data collected as part of DETECT (Detecting Early Tumors Enables Cancer Therapy), a project of the Cancer Research Network (CRN). The CRN is a collaboration of 10 HMOs funded by the National Cancer Institute

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to increase the effectiveness of preventive, curative, and supportive interventions for major cancers through a program of collaborative research. DETECT is investigating the reasons why women with prepaid access to preventive services would be diagnosed with late-stage breast cancer or invasive cervical cancer. Seven CRN-HMOs participated in DETECT: Group Health Cooperative, Henry Ford Health System, and the Kaiser Permanente Regions in Colorado, Hawaii, Northern California, Northwest, and Southern California.

In 1999, an organizational assessment (OA) gathered data on plan policies and procedures related to breast and cervical cancer screening. Data sources included plan key informant interviews and plan clinical guideline documents on breast cancer screening, cervical cancer screening, and hereditary breast and ovarian cancer susceptibility referral. Details of the data collection and analysis processes have already been described, and included local Institutional Review Board (IRB) approval.²⁰ Guidelines were submitted by 5 of the 7 plans, with the remaining two plans reporting that no hereditary breast and ovarian cancer susceptibility guidelines for genetic counseling referral existed. For this study, content analysis was performed on the hereditary breast and ovarian cancer susceptibility referral guidelines, an iterative process in which two of the coauthors (J.M., K.V.G.) coded the guidelines into content areas, resolved discrepancies, and then reviewed the findings with each plan's DETECT principal investigator. Content areas included the major risk factors for hereditary breast and ovarian cancer susceptibility, including personal and family history of female breast and ovarian cancers with ages of female breast cancer onset, Ashkenazi Jewish ancestry, and family history of male breast cancer.^{8,13} Further content areas included recommendations concerning the provision of genetic and medical management services for hereditary breast and ovarian cancer risk, such as requiring counseling, informed consent, and exclusion of minors, and making medical management recommendations based on testing outcomes.

In 2000, the DETECT project conducted an anonymous survey of primary care clinicians within 3 of the 7 HMOs, each of which obtained IRB approval. The methodology has been described elsewhere.²¹ The clinician survey was designed to evaluate clinician demographics, knowledge, attitudes, and beliefs, as well as organizational characteristics affecting adoption and implementation of breast and cervical cancer screening guidelines. Eligible clinicians were physicians, nurse practitioners, and physician assistants within the departments of family medicine, internal medicine, and gynecology, who were in the plan for at least one year and who were involved in patient care at least half-time. All eligible clinicians in two plans and a random sample of clinicians in the third plan were surveyed. A four-stage data collection process consisting of a mailing, a follow-up mailing, a reminder telephone call or e-mail from a local leader involved in the project, and a telephone call from a professional survey organization was used to maximize response rates.

The survey included one question on provider awareness of plan referral guidelines for hereditary breast and ovarian can-

cer susceptibility. In the bivariate and multivariate analyses, a "correct" answer for awareness of the hereditary breast and ovarian cancer susceptibility guidelines was based on the organizational assessment data. That is, we created a correct awareness variable by cross-classifying each clinician's self-reported awareness of guidelines with the actual plan guidelines collected during the organizational assessment. Thus, clinician's reporting awareness of a truly existing guideline had "correct" awareness of that guideline.

We hypothesized that awareness of the hereditary breast and ovarian cancer susceptibility guideline might be associated with the reported rating of usefulness for the general breast cancer screening guideline. Using a 5-point scale, respondents were asked about general breast cancer screening, including asking respondents to rate the overall usefulness of their plan's breast cancer screening guideline to their practice. It is important to note that this item referred to the plan's breast cancer screening guideline, not the hereditary breast and ovarian cancer susceptibility guideline, and that this item was located in the general breast cancer screening section of the survey. Logistic regression was performed with the dependent variable being correct knowledge of existence of hereditary breast and ovarian cancer susceptibility referral guidelines, again as determined from the organizational assessment data.

RESULTS

Guideline Content

Table 1 reports the content and criteria of the guidelines from the five plans. Four of the five plans' hereditary breast and ovarian cancer susceptibility guidelines relate to genetic counseling referral only and the remaining plan's guideline is a combination of referral and testing. All of these plans' hereditary breast and ovarian cancer susceptibility guidelines were initially implemented in 1997, although the guideline that was current in 1999–2000 varied in the year of development from 1997–1999. The five plans each have plan-specified policies requiring revisiting and, if applicable, revising the content of the guideline. Thus, the guidelines reported here are not static documents. All the guidelines include text, describing the background of the material and the sources of evidence, as well as tables, flow charts, or bulleted lists indicating patients to consider for referral.

The guidelines all include criteria for counseling/testing referral, with the criteria based on well-delineated personal cancer history factors (breast and ovarian), family cancer history factors (breast and ovarian), and combined personal and family cancer history, as well as family history of a known mutation. As shown in Table 1, there is consistency across the guidelines, yet there is also variation. For the four plans with referral guidelines, the age of breast cancer onset in a woman of Ashkenazi Jewish descent varies with ≤ 40 years of age at three plans, and ≤ 45 years of age at one plan. Two plans do not include male breast cancer in the pedigree within their illustrated indicators for referral. However, both of these plans include discussion of male breast cancer and increased *BRCA1/2*

Table 1
Criteria for referral for breast and ovarian cancer genetic counseling

Criteria supporting a referral:	HMO Site ^a				
	A	B	C	D	E
I. Women or men with a blood relative who has previously been found to have a known deleterious mutation in the <i>BRCA1</i> or <i>BRCA2</i> gene	✓	✓	✓	✓	✓
II. Women with a personal history (but no family history) of breast and/or ovarian cancer as defined at least one of the following:					
Not of Jewish descent and breast cancer at age					
29 or younger	✓	✓	✓	✓	
40 or younger					✓
Not of Jewish descent and ovarian cancer diagnosed at age 50 or younger					✓
Not of Jewish descent and both breast and ovarian cancer diagnosed at any age	✓	✓	✓	✓	
Not of Jewish descent and multiple primary breast cancers	✓	✓	✓	✓	
Of Jewish descent and breast cancer diagnosed at age					
40 or younger	✓	✓	✓		
45 or younger				✓	
50 or younger					✓
Of Jewish descent and ovarian cancer diagnosed at age					
60 or younger					✓
any age	✓	✓	✓	✓	
Of Jewish descent and both breast and ovarian cancer diagnosed at any age	✓	✓	✓	✓	
Of Jewish descent and multiple primary breast cancers	✓	✓	✓	✓	
III. Women or men with a family history (but no personal history) of breast and/or ovarian cancer in maternal or paternal relatives as defined by at least one of the following:					
Breast cancer in at least 2 first- or second-degree relatives, with at least 2 diagnosed at age 49 or younger, and at least one of the relatives is first degree	✓	✓	✓	✓	
Breast cancer in 3 or more first- or second-degree relatives, with at least one diagnosed at age 49 or younger	✓	✓	✓	✓	
Breast cancer in 1 or more first degree relatives					✓
Ovarian cancer in at least 2 first- or second-degree relatives, diagnosed at any age	✓	✓	✓	✓	
Ovarian cancer in 1 or more first-degree relatives					✓
Breast cancer in at least one first- or second-degree relative, and ovarian cancer in at least one first- or second-degree relative	✓	✓	✓	✓	
IV. Women or men with a personal and family history of breast and/or ovarian cancer in maternal or paternal relatives(s) as defined by at least one of the following:					
Women with breast cancer at age 49 or younger plus 1 or more first- or second-degree relatives with breast cancer diagnosed at age 49 or younger	✓	✓		✓	
Women with breast cancer at any age plus 1 or more first-degree relatives with breast cancer diagnosed at any age			✓		
Women with breast cancer at any age plus 2 or more first- or second-degree relatives with breast cancer all diagnosed at age 49 or younger	✓				
Women with breast cancer at any age plus 2 or more first- or second-degree relatives with breast cancer any of whom diagnosed at age 49 or younger		✓		✓	
Women with breast cancer at any age plus ovarian cancer in one or more first- or second-degree relatives	✓	✓	✓	✓	
Women with breast cancer at any age plus a strong family history of early onset breast cancer or ovarian cancer any age (2 or more family members)					✓
Women with ovarian cancer plus breast cancer in 1 or more first- or second-degree relatives diagnosed at any age	✓	✓	✓	✓	
Women with ovarian cancer plus ovarian cancer in 1 or more first- or second-degree relatives diagnosed at any age	✓	✓	✓	✓	
Women with ovarian cancer plus a strong family history of early onset breast cancer or ovarian cancer any age (2 or more family members)					✓
Men with breast cancer plus breast and/or ovarian cancer in 1 or more first- or second-degree relatives	✓	✓	✓		
Additional recommendations within the guideline					
Delineates persons unacceptable for referral	✓	✓	✓	✓	
Counseling required pre and/or post genetic test	✓	✓	✓		✓
Affected relative be tested first			✓		✓
Informed consent required prior to testing	✓	✓	✓	✓	✓
Provides medical management recommendations for mutation carriers	✓		✓	✓	✓

^aPlans A, B, C, D Cancer genetic counseling referral guidelines for *BRCA* genes; E, counseling and testing guidelines for *BRCA* genes.

mutation risk in the text of their guidelines. The plan with referral and testing guidelines does not include the cancer history of second-degree relatives as a referral or testing criteria among unaffected persons.

In addition to providing criteria for counseling referral, all of the guidelines also include recommendations. All but one plan's guidelines include specific language about requiring pretest genetic counseling. This plan's guideline, however, is written for the purpose of identifying persons appropriate for genetic counseling referral. Informed consent before testing is required within all of the collected guidelines, with indication that persons referred must have the mental competence to provide such written informed consent. Each of the four plans with referral-only guidelines address the appropriateness of referring persons who do not meet criteria but have significant anxiety. These four plans' guidelines also include specific language for unacceptable referrals, such as for minors. Although variable in detail, four plans' referral guidelines further include medical management options for individuals who are tested and found to have a mutation in the *BRCA1/2* genes. Two plans have language to recommend that an affected relative be tested first.

Clinician awareness of guidelines

Three of the HMOs with hereditary breast and ovarian cancer susceptibility referral guidelines also participated in the clinician survey. Overall, the clinician survey had a 91% response rate ($N = 621$) with plans' response rates varying from 83% to 100%. Of the returned surveys, $N = 612$ responded to the awareness of hereditary breast and ovarian cancer susceptibility guideline question and thus were eligible for analyses. Clinician characteristics are reported in Table 2. Family medicine specialty was reported by 45%, with a nearly even split between females and males. The majority of respondents were physicians (74%), 70% reported birth dates in the 1950s or later, and 34% reported employment within the HMO between 11 and 20 years.

Fifty-two percent of respondents reported awareness of these guidelines (Table 3). Awareness was highest at plan B, and among gynecologists at all plans (both values $P < 0.001$). Awareness of hereditary breast and ovarian cancer susceptibility guidelines was also higher among physicians and nurse practitioners than among physician assistants ($P = 0.005$) and was associated with more than five years of employment within the organization ($P = 0.02$). Awareness of the hereditary breast and ovarian cancer susceptibility guidelines was greater among providers reporting higher clinical usefulness of the general breast cancer screening guidelines at their organizations ($P < 0.0001$). Logistic regression was performed with the final model making adjustment for plan, medical specialty, medical discipline, age, numbers of years with HMO, and reported usefulness of the general breast cancer screening guidelines. Gender did not contribute significantly to the final model, nor did possible interactions. The adjusted odds of hereditary breast and ovarian cancer guideline awareness were significantly greater in plan B (OR = 3.0, 1.5–5.9), among gynecologists

Table 2

Respondent characteristics: CRN DETECT Clinician Survey, 2000, ($N = 612$)

Characteristic	Number (%)
Plan	
E	228 (37)
B	203 (33)
D	181 (30)
Specialty	
Family medicine	264 (45)
Internal medicine	222 (38)
Obstetrics/gynecology	100 (17)
Gender	
Male	296 (51)
Female	285 (49)
Year of birth	
1940s or earlier	173 (30)
1950s	264 (45)
1960s or later	149 (25)
No. years with HMO	
1–5	188 (32)
6–10	137 (23)
11–20	205 (34)
21 or more	67 (11)
Medical discipline	
Physician	442 (74)
Nurse practitioner	74 (12)
Physician assistant	80 (14)

(OR = 2.8, 1.5–5.4), and among providers reporting a very high clinical usefulness of plan breast cancer screening guidelines (OR = 2.6, 1.7–3.8).

DISCUSSION

This study found that 5 of 7 HMOs participating in the DETECT project have hereditary breast and ovarian cancer susceptibility clinical practice genetic counseling referral guidelines relevant to routine primary care practice. Of the remaining two plans, both offer and cover the costs of hereditary breast and ovarian cancer susceptibility counseling and testing, but neither have referral guidelines in place to identify high-risk patients for such services.

Nearly all of the HMOs that reported hereditary breast and ovarian cancer susceptibility referral guidelines for this project have detailed outlines identifying persons for referral based upon evidence available at the time of guideline development (1997–1999). Among these five plans' guidelines, only two points vary noticeably. First, one plan does not include affected

Table 3
Logistic regression models predicting cancer genetic guideline awareness, CRN DETECT Clinician Survey, 2000

Characteristic	Correct awareness of guidelines ^a number (%)	Crude odds ratios ^b (95% CI)	Adjusted odds ratio ^c (95% CI)
Plan		$P < 0.0001$	
E	118 (52)	Referent group	Referent group
B	143 (70)	2.6 (1.7–4.0)	3.0 (1.5–5.9)*
D	60 (33)	0.5 (0.3–0.7)	0.5 (0.3–0.8)*
Specialty		$P = 0.0007$	
Family medicine	120 (45)	Referent group	Referent group
Internal medicine	118 (53)	1.4 (0.9–2.0)	0.8 (0.5–1.5)
Gynecology	70 (70)	2.6 (1.6–4.4)	2.8 (1.5–5.4)*
Gender		N/A	N/A
Male	155 (52)		
Female	148 (52)		
Year of birth		$P = 0.5020$	
1940s or earlier	94 (54)	1.01 (0.9–1.0)	0.99 (0.96–1.0)
1950s	141 (53)		
1960s or later	72 (48)		
No. years with HMO		$P = 0.0146$	
1–5	82 (44)	1.03 (1.0–1.1)	1.03 (1.0–1.1)
6–10	71 (52)		
11–20	125 (61)		
21 or more	35 (52)		
Medical discipline		$P = 0.0047$	
Physician	242 (55)	Referent group	Referent group
Nurse practitioner	43 (58)	1.2 (0.7–2.1)	0.7 (0.4–1.5)
Physician assistant	27 (34)	0.4 (0.2–0.8)	0.5 (0.3–1.0)*
Usefulness of breast cancer screening guidelines		$P < 0.0001$	
Not at all or a little	23 (42)	Referent group	Referent group
Somewhat useful	88 (43)	Referent group	Referent group
Very useful	201 (61)	2.28 (1.6–3.2)	2.6 (1.7–3.8)*

Note: Sample sizes vary due to missing data.

^a“Correct” based on actual guidelines submitted for review under the organizational assessment.

^bLogistic regression single variable model. This indicates simple bivariate relationship.

^cMultivariable logistic regression model adjusts for other variables in the table. For example, the odds of correct guideline awareness is 2.8 times greater among gynecologists than family practitioners when adjusted for the other variables in the table.

* P -value less than or equal to 0.05 when controlling for all other variables in the model

second-degree relatives in identifying criteria for referral among unaffected persons. It is important for referring providers to understand that mutations in the *BRCA1/2* genes can be transmitted through the paternal lineage, and therefore, cancer history from second-degree relatives within the paternal side is particularly important in referral guidelines. Further, for both maternal and paternal lineages, second-degree family history is important, as these genetic mutations are not fully penetrant.¹³ Secondly, two plans do not address male breast cancer in the pedigree as a criterion for referral in the

guideline figures, but such is included in the text. Although providers can still refer such persons, it is important to include this indicator as a visual diagram in addition to the text so it is not inadvertently overlooked by busy clinicians. Both of these issues indicate the need for input from clinical genetics during future guideline development.

Although the majority of these HMOs' guidelines were for genetic counseling referral, rather than testing, one testing issue with referral implications was also evident. Only two plans' guidelines recommend that an affected relative be tested before

any unaffected persons if possible. Without testing an affected relative first, a negative *BRCA1/2* result can have different interpretations with very different disease risk assessments, with clarity coming only from testing an affected family member. It is possible that some plans did not feel this was needed in a referral guideline, because which family member to be tested first is a decision made after review of a complete pedigree. It is vital, however, for referring providers to understand that another family member may need to be referred in addition to the initial referral. Although testing the family member with the greatest pretest probability may be preferred, in practice this can be difficult. However, as more insurers begin to cover the costs of genetic counseling and testing, it may be necessary for ensuring high quality care that insurance carriers agree to cover the costs of genetic counseling and testing for their respective membership, even if the test would provide the most direct medical benefit for a nonmember. Guideline committees and benefit committees will be challenged when creating future versions of cancer genetic counseling referral guidelines about how to address referral and coverage of nonmembers, and providers of genetic medicine may need to be advocates in these processes.

Only half of clinicians surveyed at these plans were aware of plan referral guidelines for hereditary breast and ovarian cancer susceptibility. Hereditary predisposition for cancer accounts for only a small portion of all cancer, yet genetic services identifying hereditary breast and ovarian cancer susceptibility may be important in reducing cancer morbidity and mortality, as risk reduction efforts could be targeted to those identified with high hereditary cancer risk.^{22–24} Further, such services could allow reassurance for women who are not at high risk for an inherited predisposition to breast or ovarian cancers, and may additionally allow patients a level of informed choice that may not be achievable in daily primary care. Indeed, previous literature suggests that primary care providers are not well-informed to discuss the issues of cancer genetics with patients.^{14–17} Further, studies suggest that in general women are not well-informed regarding inherited risk for cancer and that they seek information from their family members rather than their health care providers.^{25–26}

A referral guideline to help primary care providers identify which members are at increased risk for inherited susceptibility for breast and ovarian cancers would thus seem to be a potential solution to this problem. Indeed, most of the HMOs that participated in this study have such referral guidelines, as well as a long history of cancer prevention guidelines, methods to promulgate those guidelines, and system levels of implementing many of the guidelines.²⁰ That gynecologists reported significantly greater awareness than other specialties is supported by previous studies that show the majority of *BRCA1/2* testing referrals come from gynecologists.¹⁶ That awareness was associated with plan may be explained by the level of implementation effort, which clearly was associated with provider awareness at these three plans. For example, Plan B's implementation included not only dissemination of the guidelines, but also dissemination of educational materials for phy-

sicians, including articles on breast cancer and genetic risk in physician-directed magazines, interactive videoconferencing, and training seminars for physicians. Plan E's implementation effort was posting of the guideline on a well-used internal web page that helped providers sort through who was really at high risk for breast cancer, and well-publicized description of what services were available to the primary care provider. Plan D's implementation was a written guideline that was distributed with other preventive service guidelines, and annual presentation of the preventive services' guidelines at primary care department meetings.

Despite such plan efforts, however, overall our work suggests that even within these HMOs, referral guideline development and implementation for breast and ovarian cancer genetic services may not be enough to assure awareness and use by clinicians. Educating primary care providers would likely only have a limited lasting effect based on the literature on changing physician behavior and because cancer genetic services are not an issue for the majority of primary care patients.^{27–29} Thus, perhaps to best incorporate cancer genetics into medicine, a more system-wide approach or outreach implementation is needed, such as what has been put in place at many HMOs for general breast and cervical cancer.²⁰ For such a new model of genetic risk identification to work, however, those trained in genetic medicine will need to be key players not only in establishing the systems for identification of risk and triage but also in continuing to oversee the translation of new findings into such clinical practice.

One limitation of this work is that the DETECT HMOs are not a representative sample of managed care organizations. Data collection was only conducted on the group or staff model component of these HMOs. However, for study of hereditary breast and ovarian cancer susceptibility referral guidelines, it was important to explore HMOs with a history of provision of preventive services and a history of effective plan guideline adoption and implementation for preventive services. We acknowledge that five of the participating plans are Kaiser Permanente regions formed by exclusive Permanente Medical Group contracts with the Kaiser Foundation Health Plan. Activities undertaken in these organizations may be more interdependent than those of the two non-Kaiser Permanente plans.

The organizational assessment was cross-sectional in design, and as such, may not represent current guideline content. The clinician survey was also cross-sectional and limited by the small number of participating plans, however, our results are strengthened by the markedly high response rate. We acknowledge that outcome measures such as numbers of and criteria of actual referrals to hereditary cancer services were not collected on the clinician survey. Although awareness of the guidelines is important, it is possible that providers are aware of cancer genetic referral services without being aware of the plan's clinical practice referral guidelines. As such, the percentage of actual referrals that comply with the plans' referral guidelines may not vary across the three HMOs regardless of provider awareness. We doubt that this is true, however, because among

these three HMOs the use of plan guidelines for other cancer prevention services is high while the number of referrals for breast and ovarian cancer genetic services during the time period was low. Although across plans the percentages of guideline awareness were lower than was hypothesized, without further data it is difficult to validly interpret the clinical impact of the reported level of awareness. Yet we are confident to conclude that to achieve maximal effect on cancer prevention, continued work needs to be done including potentially new models of providing cancer genetic services in order to learn how best to increase the awareness and use of this information by primary care clinicians.

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