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# Primary care physicians' knowledge and attitudes towards genetic testing for breast—ovarian cancer predisposition

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#### Summary

Background: Primary health care providers are expected to be directly involved in the genetic testing for cancer susceptibility. This study assessed physicians' knowledge, attitude and perception of their role towards testing for hereditary breast-ovarian cancer.

Design: A mail-in survey was sent to all general practitioners, internists, obstetrician-gynecologists and oncologists in private practice in Geneva county, Switzerland. Questions included socio-demographic variables, knowledge about hereditary breast-ovarian cancer, attitude towards testing and assessment of their role in the pre- and post-test procedure.

Results: Two hundred fifty-nine (65%) of four hundred questionnaires were returned of which two hundred forty-three (61%) were analysed. Response rates were similar between specialties; women answered more frequently. The majority of the respondents (87%) approved of genetic susceptibility testing. The most common objection to testing was the absence of

approved strategies for the prevention and detection of early breast cancer. Most physicians felt they had an active part to play in the pre-test procedure, the disclosure of results, and especially the consultants' long-term care and support (99%). Physicians correctly answered a third (32%) of the knowledge questions. The abstention rate for individual items ranged from 13% to 60%. Scores varied by specialty. Oncologists were more knowledgeable than gynecologists, internists and general practitioners.

Conclusions: The majority of the primary care physicians in this study have a favourable attitude and are ready to play a prominent role in genetic counseling and testing for breast-ovarian cancer predisposition. Defective knowledge scores, however, underline the need for targeted educational programs.

**Key words**: attitudes, breast neoplasms, genetic predisposition testing, genetic screening, knowledge, ovarian neoplasms, physician's role, practice

# Introduction

The characterization of the BRCA1 and BRCA2 genes [1-3] represents a major advance in the field of oncology. It offers the opportunity to identify asymptomatic carriers who are at risk of developing breast and/or ovarian cancer. It also raises complex medical, social, ethical and psychological issues. Primary care physicians will be directly involved as genetic testing becomes widely available [4-7]. Interest among the population is likely to be strong [8-10] and individuals will solicitate their physicians for information and testing. Many questions have to be addressed [11-13]: the potential limitations, risks and benefits of testing, the options for medical surveillance as well as confidentiality issues. Familial cancer risk must be evaluated and counseling provided accordingly. It means a departure from the traditional medical consultation. Information is given about probabilities to develop a disease. It implies a non-directive attitude and a special attention to the emotional needs and moral values of individuals so as to help them make an informed decision. Physicians are also expected to provide ongoing medical care and support to the consultants. Several potential barriers to the integration of genetic counseling into clinical practice have been recognized: the acquisition of specific knowledge [14–16], the handling of probabilistic data [17], the low tolerance to uncertainty [18] and the time and costs constraints [19–21]. Two studies [22, 23] exploring general practitioners' attitudes towards genetic testing for Huntington disease show that most respondents approve of testing. In the Scottish study [22], however, more than 50% wished the genetic clinic to give post-test counseling and support as well as test results. In the Dutch survey [23] the proportion was 30%.

In this study we wanted to assess primary care physicians' knowledge and attitudes towards breast-ovarian cancer susceptibility testing as well as their perception of their own role in the procedure.

#### Patients and methods

For this study a survey was conducted on all 400 general practitioners, internists, obstetrician-gynecologists and oncologists in Geneva county, Switzerland, who are in private practice and involved in direct

patient care. Names were obtained through the 1997 directory of the Geneva Medical Association, which includes the majority of the physicians practising privately in Geneva. Data were collected by means of a mailed questionnaire sent in September 1997. A covering letter assured the participants of the confidentiality of the responses. Respondents were given the opportunity to receive the conclusions of the study if they wished. A stamped return envelope was included. If the questionnaire was not returned within a month a second copy was sent. It was decided that the survey would end two months after the second mailing and questionnaires received later were not considered for analysis.

Socio-demographic characteristics were collected (gender, age, specialty, years in practice) and physicians were asked if they had a personal familial history of breast and/or ovarian cancer in a firstdegree relative. Levels of knowledge were assessed by three questions. The first two had multiple choice answers and inquired about the prevalence of hereditary breast-ovarian cancer (HBOC) (less than 5%, 10%, 20%, 30%, 40%) and the penetrance of BRCA1/BRCA2 (20%, 40%, 60%, 80%, 100%). The last question was made up of five items with three possible answers each (yes, no, do not know): earlier age of onset, dominant inheritance pattern, transmission of susceptibility only through females, characteristic histologic features, bilateral primary breast cancers. One point was ascribed to each correct answer, the maximum score being 7 points. Physicians' views on their role and responsibility for the care of consultants were assessed by three general questions adapted from the Scottish study of Mennie et al. [22] about Huntington disease: 'do you as a general principle approve of presymptomatic testing for individuals at high risk for HBOC?', 'would you be agreeable in principle to referring a high risk individual for genetic testing if she requested it?', 'would you feel that it was your duty to inform a high risk individual that a genetic test is available?'. Respondents were requested to list their objections if they had given a negative answer or were unsure about any of the questions. In addition they were asked more specific questions about the preliminary steps before offering a test, the delivering of test results and the after care of individuals The issues to be addressed before genetic susceptibility testing were chosen in accordance to the recommendations of the American Society of Clinical Oncology [13].

#### Data analysis

Quantitative variables are described by the mean  $\pm$  standard deviation (SD) They were compared by using *t*-tests and one-way or two-way analyses of variance (ANOVA). When a significant difference was found multiple comparisons according to Newman-Keuls were performed. Qualitative variables were analysed using the  $\chi^2$  test or Fisher's exact test, where appropriate.

#### Results

Two hundred fifty-nine (65%) of the four hundred questionnaires were returned, 75% of which were received after the first mailing. Sixteen questionnaires (4%) were blank: one physician preferred to abstain because none of his patients was at high risk for breast and/or ovarian cancer and three others wished to be sent the results of the survey. Two hundred forty-three (61%) questionnaires were thus analysed. Not all respondents answered every question.

The characteristics of the study population and the mean knowledge score are listed in Table 1. The mean age of the participants who returned questionnaires was  $51 \pm 9$  years; 180 were men and 62 women (the sex of one participant was unknown). Women were younger than men  $(47 \pm 9 \text{ vs. } 52 \pm 9 \text{ years; } P < 0.001)$ . Thirty-nine

Table 1. Characteristics and knowledge score of the study population.

Variable	Number (%)	Responses n (%)	No responses n (%)
Sex			
Male	180 (74)	180 (60)	121 (40)
Female	62 (26)	62 (76) a	20 (24)
Age (years)	,		
Mean ± SD	51 ± 9		
Male	$52 \pm 9$		
Female	$47 \pm 9$		
Repartition			
≤45	80		
46-53	82		
≥ 54	79		
Specialty			
General practitioners	83 (34)	83 (61)	53 (39)
Internists	105 (44)	105 (64)	58 (36)
Obstetrician-gynecologists	50 (20)	50 (67.5)	24 (32.5)
Oncologists	5 (2)	5 (45.5)	6 (54.5)
Years in practice, mean ± SD	$14.5 \pm 9$		
Breast and/or ovarian cancer			
in a first-degree relative	39 (16)		
Knowledge score (maximum:			
7 points), mean ± SD	$2.3 \pm 1.6$	5	

 $<sup>^{\</sup>rm a} P = 0.008.$ 

physicians (16%) had a personal familial history of breast and/or ovarian cancer in a first-degree relative. Participating physicians could be compared to the physicians not returning the questionnaire as to two variables: specialty and gender. Response rates were similar between the specialties. Female physicians however answered more often than male (72% vs. 58%; P = 0.01).

The majority of the participants (n = 211; 87%) approved of genetic susceptibility testing (Table 2). Thirteen percent (n = 32) disapproved of testing or were unsure; this opinion was expressed more frequently among women (23% vs. 10%; P = 0.01). Altogether forty-nine respondents (20%) answered 'no' or 'unsure' at least to one question. The most common reasons given were 'it is not correct to do the test if there are no approved strategies for the prevention and detection of early breast cancer' (n = 39; 80%) and 'testing could do more harm than good' (n = 34; 69%). For six participants (12%) a positive result would imply more support and follow-up care than they could supply. There was no significant difference in the objections given by male and female physicians.

For most physicians the tasks involved in the preliminary stage before performing the test belong to them (from 81% to 89% 'yes') (Table 2). Two-thirds of respondents (67%) would like to disclose the test results, either alone (n = 131; 55%) or in collaboration with a clinical genetics center (n = 29; 12%). Participants were nearly unanimous (99%) in thinking the consultants' long-term support was their responsibility. Fifteen of them (6%) wished to work in collaboration with a clinical genetics center.

Knowledge scores ranged from 0 to 6 points for a maximum of 7 points with an average score of  $2.3 \pm 1.6$ .

Table 2 Susceptibility testing for breast-ovarian cancer: primary care physicians' attitudes and perceived roles.

Attitude	Yes n (%)	No n (%)	Unsure n (%)
Approve of the <i>principle</i> of testing	211 (87)	7 (3)	25 (10)
Agree to refer a high risk patient at her request	238 (98)	2 (1)	3 (1)
Think it his duty to <i>inform</i> a high risk patient that a genetic test is available	217 (89)	4 (2)	22 (9)
Role	Family practitioner n (%)	Genetic center n (%)	Unsure
Document a family history of cancer	214 (89)	19 (8)	8
Recognize families for which genetic testing is indicated	207 (86)	11 (5)	22
Provide counseling regarding familial cancer risk	195 (81)	29 (12)	18
Provide options for prevention and early detection of breast cancer	210 (86)	15 (6)	18
Obtain informed consent before testing	210 (87.5)	24 (10)	6
			Both n (%)

131 (55)

223 (92.5)

79 (33)

3(1)

29 (12)

15 (6)

Thus, respondents gave correct responses to about a third (32%) of the items. Scores differed according to specialties: on average oncologists numbered 4.8 points, obstetrician-gynecologists 2.6, internists 2.2 and general practitioners 1.9 (P = 0.0001). On multiple comparisons oncologists scored higher than the other specialists (P = 0.01 for internists and general practitioners;P = 0.05 for obstetrician-gynecologists). Scores did not differ with regard to sex, age and a personal familial history of breast and/or ovarian cancer. As shown in Table 3 the percentage of respondents answering correctly to individual knowledge items ranged from 19% to 96%. The abstention rate ('do not know') ranged from 13% to 60%. Nearly half the respondents (n = 99, 49%) overrated the prevalence of HBOC; 81% (n = 156) underrated the penetrance of BRCA1/BRCA2. More than 50% did not know the inheritance pattern of the mutations.

### Discussion

Deliver test results and give

Provide follow-up support

post-test counseling

Much attention has been directed towards women's interest and knowledge about genetic testing for breast-ovarian cancer susceptibility [8, 9, 24-31]. Despite a

Table 3. Knowledge items.

Item	Correct	Incor- rect	'Do not know'	'Blank'
	answers $n (\%)^a n$		answers n (%) <sup>b</sup>	n
Percentage of breast cancer patients having an inherited susceptibility to breast cancer (answer: 10%)	70 (35)	131	30 (13)	12
Risk of developing a breast cancer for carriers of a predisposing mutation (answer: 80%)	36 (19)	156	37 (16)	14
Features of breast cancer associated with an inherited susceptibility				
Earlier age of onset <sup>c</sup>	174 (96)	7	52 (22)	10
Dominant inheritance pattern <sup>c</sup>	44 (45)	53	128 (57)	18
Transmission of susceptibility only through females	33 (36)	59	136 (60)	15
Characteristic histologic features	71 (64)	40	118 (51.5)	14
Bilateral primary breast cancers <sup>c</sup>	122 (80)	30	79 (34)	12

<sup>&</sup>lt;sup>a</sup> Percent relative to the total number of answers minus 'do not know'.

widespread agreement about the prominent role family physicians are likely to play in clinical practice, few data are available about their attitudes towards BRCA1/BRCA2 gene testing and how knowledgeable about hereditary breast-ovarian cancer they actually are [32–34]. In this survey we assessed primary health care physicians likely to be directly involved in the testing process. We asked specifically for their opinions about the part they expect to play in both the pre- and post-test procedure and evaluated how familiar they are with HBOC and some of its specific features.

The satisfactory response rate suggests that primary health care physicians feel concerned by the genetic testing for susceptibility to breast—ovarian cancer. The similar participation among specialties and the wide range in the respondents' age show that this interest is not restricted to a sub-group of practitioners. The choice of pathology rather than genetic testing in itself most probably accounts for the higher response rate among women. No such difference was found in a previous study [23] exploring general practitioners' attitudes to presymptomatic testing for Huntington disease, a neuro-degenerative disorder affecting both sexes, whereas gender bias has been shown to affect the utilisation of cancer screening tests [35].

The majority of respondents have a favourable opinion about genetic testing. They approve of the principle of testing and 98% would refer an individual at her request.

<sup>&</sup>lt;sup>b</sup> Percent relative to the total number of answers.

<sup>&</sup>lt;sup>c</sup> Correct answer.

Moreover they consider they have an active part to play in all the stages of the testing procedure. They especially affirm their responsibility as primary health care physicians in the consultants' long-term support. Only six respondents mentioned they might not be able to supply the necessary follow-up care. Opinions about the delivery of test results are divided. Half the respondents (55%) would give the results themselves, 33% would like the clinical genetics center to disclose the results and 12% would collaborate with the clinical genetics center. This can be explained by the technical aspect involved in the communication of test results. Primary care physicians may feel that it is beyond their scope to master the complex and specific knowledge necessary to interpret the results.

It is generally agreed that educational issues must be addressed so that genetic counseling and testing can be successfully integrated into clinical practice. Responses to the questions of knowledge underscore the need for educational programs. A high proportion of participants cannot answer or give incorrect answers to the questions (up to 60%, respectively, up to 81%). Oncologists, however, demonstrate a higher knowledge score than gynecologists and general practitioners. It is in accordance with previous observations that the greatest knowledge about specific pathologies is found among physicians caring for affected persons [14, 36, 37]. It can be inferred that family practitioners will become more knowledgeable not only through formal teaching but also by encountering patients in their everyday practice.

Our findings suggest that primary care physicians are favourable to genetic susceptibility testing for breast–ovarian cancer and think it their responsibility to be in charge of the consultants throughout the whole procedure and for the ongoing medical care and support. To help them perform the comprehensive tasks involved in genetic counseling and testing, priority must be given to targeted educational programs.

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Received 5 April 2000; accepted 13 June 2000.

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