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Attitudes about genetic testing for breast cancer susceptibility:

A survey of general practitioners, medical students, and women in the northern region of New Zealand

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ABSTRACT

Aim

To assess attitudes about genetic testing for breast cancer susceptibility held by general practitioners (GPs), medical students, and women varying in familial risk.

Methods

An anonymous survey of randomly selected GPs and samples of medical students, women attending GP clinics, and survivors of breast cancer and their first-degree relatives.

Results

Over 75% of all groups endorsed the use of this genetic test. Medical students had more negative attitudes regarding its health and psychological benefits relative to GPs and women groups (p's < .0001). GPs were more willing than medical students to recommend testing, male GPs were more willing than female GPs to recommend testing, and survivors were less likely than clinic attenders to want their doctors to recommend testing (p's < .01).

Conclusions

The findings indicate generally favourable attitudes about the genetic test among current and future doctors and among potential consumers. Group differences indicate potential attitudinal discrepancies between many doctors and patients, and between established GPs and medical students with educational training in genetics issues.

Key words

Genetic testing, attitudes, physicians

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Introduction

Recent years have witnessed rapid advances in the development of genetic testing for mutations in BRCA1 and BRCA2, two genes predisposing to breast and ovarian cancer. Women identified as mutation carriers are advised to undergo frequent clinical breast examinations and mammography. They may choose to undergo prophylactic mastectomies and oopherectomies, although these surgeries do not completely eliminate cancer risk and they can have psychological costs.[1]

Individuals with family histories of breast/ovarian cancer are primary targets for this genetic test. In New Zealand, patients may be referred to specialist genetics services where staff members assess their familial risk using the NHMRC National Breast Cancer Centre of Australia 2000 criteria. Individuals who are identified as 'potentially high risk' are then offered information and counselling about genetic testing. These individuals must consider many issues when deciding whether or not to undergo testing.

Testing provides risk status information that, with future medical advances, may assist in early interventions for cancer. Presently, however, it is not known whether this procedure will enhance cancer control, prolong survival, or improve quality of life. Additionally, testing may have negative consequences for recipients and their families. Individuals identified as mutation carriers face risks of emotional trauma for themselves and loved ones.[2] There are also concerns that mutation carriers will experience discrimination by insurance companies and employers,[2,3] although at least one study was unable to document any experiences of discrimination based on BRCA1/2 testing results.[4] Finally, individuals need to consider how test results may influence important life decisions regarding activities and child rearing.[3,5]

There is a recognised need to convey comprehensive information to potential users so that they can make fully informed decisions about whether or not to undergo testing.[6,7] Although patients attending genetic testing services in New Zealand receive counselling by staff prior to indicating their testing decisions, testing preferences are likely to be well established at the time of entry into the services. These preferences can bias perceptions of counselling information in ways that promote decisions to obtain testing.[8]

Patients place considerable weight on the opinions of their doctors when making decisions about risk assessment procedures. For example, doctors' recommendations are the strongest determinants of breast cancer screening use.[9] Given that many individuals are referred for genetic testing by their GPs, these practitioners play a pivotal role as de facto gatekeepers in the genetic testing process. It is therefore important to understand the common tendencies and range in their opinions. Their views may determine whether they discuss genetic testing with patients, how they present information about potential consequences, and whether they encourage or discourage testing. Because doctors' beliefs powerfully influence patients' decisions to undergo treatments, some models of informed consent procedures require that doctors understand their own beliefs regarding the therapy and disclose these beliefs to patients.[10]

There are... concerns that mutation carriers will experience discrimination by insurance companies and employers

This survey assessed genetic testing attitudes held by GPs in the northern region of New Zealand. Their attitudes were compared to those of women in the region who, because they use GP services or else have a familial risk of breast cancer, may seek or receive information about genetic testing from these GPs: women patients attending GP clinics, survivors of breast cancer, and first-degree relatives of women with breast cancer. Medical students were also surveyed in order to assess differences in testing attitudes associated with current medical training. Genetic testing issues are being incorporated into medical school curricula, and this training may increase sensitivity to health, social, and psychological risks and benefits of testing.

Key points

- Individuals with family histories of breast/ovarian cancer can be offered genetic testing for mutations in genes predisposing to breast and ovarian cancer.
- Although patients attending genetic testing services in New Zealand receive counselling by staff prior to indicating their testing decisions, testing preferences are likely to be well established at the time of entry into the services. These preferences can bias perceptions of counselling information in ways that promote decisions to obtain testing.
- This survey assessed genetic testing attitudes held by GPs, medical students,women randomly chosen from attenders in general practice, and cancer survivors and their relatives.
- All groups indicated moderate to strong endorsement of genetic testing for breast cancer risk and positive attitudes regarding its potential health benefits.

Methods

Participants and procedure

GPs (n=192) who were randomly selected from a list of all GPs in the

northern region (Kaitaia to Auckland) received the anonymous survey by mail. Medical students (n=125) enrolled in years two to six of training at the University of Auckland received the survey during lectures in classes that were selected for their representativeness of the medical student population.

Women patients (n=200) were recruited from the waiting rooms of seven clinics. These clinics, selected for their geographical and socioeconomic representativeness of the region, were located in Whangarei, Brown's Bay, Avondale, Kohimarama, Greenlane, Howick, and Papakura.

Breast cancer survivors were recruited from three sources. Firstly, participants of seven breast cancer support groups (in West Auckland, Central Auckland, East Auckland, North Shore, South Auckland, Franklin, and Hibiscus Coast) were invited to complete the survey. Secondly, surveys were mailed to all 50 women in the Breast Cancer Network database living in the northern region. Thirdly, clinic attenders reporting a history of breast cancer were included in this group.

To recruit first-degree relatives, each survivor from a support group or the Breast Cancer Network database received a survey packet to send to a sister, mother, or daughter 16 years or older. Clinic attenders who identified a first-degree relative with breast cancer also were included in this group.

Clinic attenders reported the most positive attitudes about health benefits of genetic testing, whereas medical students reported the least positive attitudes

Survey materials

The survey packet contained a brochure describing the genetic test (including information about its targeted use for individuals at significant familial risk, cancer risks for individuals with and without the mutations, and screening and prophylactic surgery options), the survey, and a return envelope. The survey included questions about demographic characteristics, cancer history (for women groups), professional characteristics (for GPs), and the following measures.

Endorsement of genetic testing

Respondents were asked, *'Overall, to what extent do you endorse or oppose the use of genetic testing for women with an increased risk of breast cancer due to a family history of breast and/or ovarian cancer?'* Responses were made on a 7-point scale where 0 = strongly oppose, 3 = neutral, and 6 = strongly endorse. Responses were categorised as oppose (0–2), neutral (3) and endorse (4–6).

Perceived benefits and costs

Three measures assessed attitudes about health benefits (seven items, e.g. *'Getting this genetic test would help reduce a woman's chances of dying.'*), psychological benefits (four items, e.g. *'The test would reduce the anxiety of not knowing one's genetic background.'*), and psychological costs (seven items, e.g. *'Women found to have the mutation are likely to experience significant depression.'*). For each measure, scores were calculated by averaging the item ratings of agreement (made on 7-point scales). These measures exhibited moderately high internal consistency; Cronbach's a = .76 to .80.

Attitudes about discrimination risks, prophylactic surgery, and use of test results

Respondents rated their agreement (using 7-point scales) with the statements: *(1) 'Women with positive test results may not be able to get health insurance or life insurance'; (2) 'Women with positive test results are likely to face discrimination from employers'; (3) 'A woman with positive test results should get a prophylactic mastectomy in order to reduce her cancer risk'; and (4) 'A woman with positive test results should get a prophylactic oopherectomy in order to reduce her cancer risk'.*

GPs and medical students also rated their agreement with the statements: *(1) 'Clear guidelines or strategies are not available for managing patients with positive test results'*; and *(2) 'It is difficult to ensure that women's test results will remain confidential'.*

Preferences for discussions and recommendations

GPs and medical students were asked, *'If your patient had a family history of breast and/or ovarian cancer that might place her at moderate to high risk of breast and ovarian cancer, would you: (1) emphasise the potential benefits of genetic testing in your communications with her? (2) emphasise the potential costs or negative aspects of genetic testing in your communications with her? (3) recommend that she obtain genetic testing?'* Responses to each of these three questions were made on a 7-point scale ranging from definitely not (0) to possibly (3) and definitely (6). The women groups were asked, *'If you had a family history of breast and/or ovarian cancer that might put you at moderate to high risk of breast and ovarian cancer, would you want your doctor to refer you for genetic testing?'* Responses were made on the 7-point scale ranging from definitely not (0) to possibly (3) and definitely (6).

Statistics

Group differences in endorsements of the genetic test were assessed using x^2 analysis. Group differences in other measures were assessed with one-way ANOVAs, with Bonferroni corrections for post-hoc group comparisons.

For GPs and medical students, paired-samples t-tests compared propensities to discuss testing costs and benefits with patients. For GPs, associations of attitudes with gender and with reported experience in discussing (yes or no) and referring patients for (yes or no) BRCA1/BRCA2 genetic testing were assessed with independ-

Table 1. Demographic characteristics of the sample groups.

	GPs	Medical Students	Clinic Attenders	Survivors	1st-Degree Relatives
Self-reported Ethnicity (%)					
NZ European	77	49	83	94	93
Asian	15	27	5	0	1
Mäori	0	6	5	0	4
Other	8	8	7	6	2
Mean Age (SD)	–	21.83 (2.43)	44.02 (14.93)	55.70 (9.39)	44.18 (14.49)
Median Income Bracket of Family/Household (in Ks)	–	30–40	40–50	40–50	60–70
% With Tertiary Education	100	100	36	51	54

Table 2. Mean attitude ratings and scores for the survey groups.

Measure	GPs	Medical Students	Clinic Attenders	Survivors	1st degree Relatives	F statistic (MSE)	p value
Health benefits	4.43 [a]	3.88 [c]	4.82 [b]	4.52 [a]	4.58 [a]	19.32(0.75)	<0.0001
Psychological benefits	3.35 [a]	2.89 [c]	4.22 [b]	4.18 [b]	3.55 [a]	27.01(1.28)	<0.0001
Psychological costs	3.62 [a]	3.81 [a]	3.88 [a]	3.74 [a]	3.36 [b]	3.03(0.95)	0.018
Insurance discrimination	4.59 [a]	4.10 [ab]	3.53 [b]	4.25 [ab]	3.78 [b]	6.37(3.14)	<0.0001
Employment discrimination	2.59	2.70	2.28	2.97	2.80	2.29(3.04)	0.067
Prophylactic mastectomy	1.90 [a]	1.49 [a]	3.01 [b]	2.07 [a]	1.59 [a]	15.85(2.84)	<0.0001
Prophylactic oopherectomy	2.06 [a]	1.47 [a]	3.13 [b]	1.99 [a]	1.59 [a]	18.77(2.76)	<0.0001

Ratings/scores are on a 7-point scale where 0 = strongly disagree, 3 = neutral, and 6 = strongly agree. Group means that do not have the same superscripts are significantly different, p < .01.

ent samples t-tests; correlation analyses assessed associations of attitudes with time since graduation.

Results

The 101 GPs (61 men, 40 women; years since graduation M=21, SD=8.99) who completed the survey comprise 12% of the GPs in the northern region and 52% of GPs who were mailed surveys. The 125 medical students (50 men, 75 women) selected to complete the survey comprise 23% of medical students in years two to six at the University of Auckland; 93% of them had taken at least one genetics course.

Of the 200 clinic attenders approached, 86% completed the surveys. Based on personal/family history, four respondents were allocated to the survivors group and 16 respondents were allocated to the first-degree relatives group. The clinic attenders sample thus included 152 women. Of the survivors approached at support groups, 42 women (54%) returned the surveys. Of the Breast Cancer Network members, 26 women (57%) returned the survey. The survivors included 72 women (years since diagnosis M=6.34, SD=6.26). A total of 41 first-degree relatives returned the survey; six survivors indicated that they had no women relatives, and so the return rate was 67%. The first-degree relatives sample included 57 women. Table 1 presents sample characteristics. There were higher proportions of Asian respondents in the GP and medical student groups than in the other participant groups. Asian GPs and medical students did not differ from the other GPs and medical students in their responses to any of the survey measures (all p's > .06). Any attitudinal differences between the GP or medical student groups and the other groups cannot be attributed to the differences in proportions of Asian respondents.

Genetic testing attitudes

Over 75% of each group endorsed the use of the genetic test (Figure 1). Endorsement rates did not vary significantly across the groups.

Clinic attenders reported the most positive attitudes about health benefits of genetic testing, whereas medical students reported the least positive attitudes (Table 2). Attitudes about psychological benefits were, on average, neutral to mildly positive. GPs had more positive attitudes about psychological benefits than did

medical students; both of these groups had less positive attitudes than did clinic attenders and survivors. Beliefs about psychological costs of testing tended to be neutral. First-degree relatives had lower beliefs of psychological costs compared to the other groups.

GPs (but not medical students) were more sensitive to potential insurance discrimination compared to clinic attenders and relatives. All groups reported low expectations of employment discrimination. All groups except clinic attenders were generally opposed to prophylactic surgeries.

...findings suggest that genetics education in medical school is promoting greater sensitivity to genetic testing issues

GPs (M=4.36, SD=1.38) agreed more than did medical students (M=3.35, SD=1.53) that clear guidelines for managing patients with positive results are not available; F(1, 222)=25.83, p=.0001. Both GPs (M=2.73, SD=1.86) and medical students (M=2.24, SD=1.51) generally disagreed that ensuring confidentiality of test results is difficult, with medical students reporting stronger disagreement; F(1, 222)=4.70, p=.03.

GPs were more inclined to emphasise testing benefits (M=4.48, SD=1.37) than to emphasise psychological costs (M=3.76, SD=1.71) in discussions with patients; t(100)=4.56, p=.0001). In contrast, medical students reported equivalent propensities to emphasise benefits (M=4.14, SD=1.33) and costs (M=4.15, SD=1.44) in patient discussions; t(124)=.06, p=.95.

All groups indicated moderate preferences to give/receive recommendations for genetic testing. GPs (M=4.31, SD=1.43) were more willing than medical students (M=3.59, SD=1.44) to recommend testing; F(1, 221)=13.55, p=.0001. Survivors (M=3.71, SD=1.67) were less desirous of receiving recommendations relative to clinic attenders (M=4.60, SD=1.69) and relatives (M=4.17, SD=1.87); F(2, 254)=6.22, p=.01.

Gender, time since graduation, recommendation behaviour, and attitudes in GPs

Male GPs (M=4.60, SD=1.41) were more likely than female GPs (M=3.79, SD=1.34) to recommend genetic testing; t(100)=2.82, p=.006. Years since graduation was negatively correlated with propensity to discuss genetic testing (r=-.21, p=.03), indicating that recent medical training was associated with greater willingness to discuss genetic testing with patients. Gender and time since graduation were not associated with any other attitudes. In this sample of GPs, 33% had discussed genetic testing for breast cancer susceptibility with patients and 12% had referred patients for this test. Experiences with discussing the test or recommending it to patients were not associated with any attitudes.

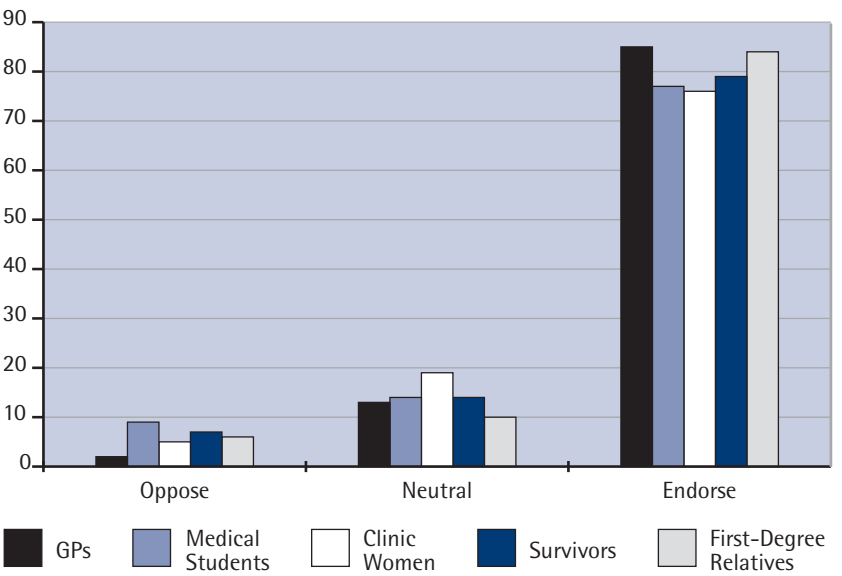
Discussion

All groups (GPs, medical students, and the women groups) indicated moderate to strong endorsement of genetic testing for breast cancer risk and positive attitudes regarding its potential health benefits. These groups reported neutral to mildly affirmative attitudes that this test could lead to a variety of psychological benefits and costs. Although all groups recognised the potential risks of discrimination by insurance companies, they generally did not believe that the test might create problems of discrimination by employers.

There were also numerous group differences in testing attitudes. These differences may suggest potential areas of discordance between opinions held by many current and future medical practitioners and those held by many women who are potential candidates of testing or who wish to learn more about the genetic test. GPs and/or medical students differed from at least one of the women groups on all but three of the attitude measures. In all cases, the GPs or medical students held less favourable attitudes about genetic testing in relation to the women groups. These differences highlight the need for doctors to be aware of potential attitudinal discrepancies in discussions with patients.

The high interest in genetic testing and positive attitudes reported

Figure 1. Proportions endorsing use of genetic testing for breast cancer susceptibility.



by the clinic attenders correspond with findings from international surveys indicating high interest levels in women from the general population.[11,12] Survivors and first-degree relatives were less positive than clinic attenders about health benefits and the use of prophylactic surgeries, possibly due to greater familiarity with psychological and health consequences of breast cancer.

Compared with GPs, medical students were relatively cautious about recommending testing and expecting positive outcomes. There was also a positive association between recency since graduation and willingness to discuss testing with patients. These findings suggest that genetics education in medical school is promoting greater sensitivity to genetic testing issues. GPs and medical students are aware of the potential insurance problems, but they are disinclined to expect employer discrimination or problems ensuring confidentiality of test results. Further research is necessary to determine whether these beliefs are warranted. GPs typically felt that there are no clear guidelines for managing patients with positive test results. Genetic services in the northern region use the best practice guidelines co-ordinated by the Anti-Cancer Council of Australia, and there appears to be a need to provide more information about these guidelines to GPs in the region.

The attitudes reported by the respondents may have been informed by the facts provided in the genetic testing pamphlet. However, considerable care was taken to design the pamphlet so that it provided objective information about the genetic testing process without promoting or discouraging any of the attitudes assessed. This information served to provide all participants with a common understanding of the genetic test as a targeted risk assessment (and not as a potential screening programme).

The moderate response rates are higher than typical rates (approximately 30%) for mailed surveys, and so the samples represent substantial proportions of the populations of interest. Nevertheless, the samples may not be fully representative of all group members in the northern region. Furthermore, the findings cannot be assumed to reflect attitudes of groups living in the other regional quadrants of New Zealand or in other countries. The convenience sampling of survivors also limits their potential representativeness. This limitation carries over to the first-degree relatives, although our estimated response rate of 67% for relatives receiving the survey from a survivor may be inaccurately low because some survivors may not have had eligible relatives and did not spontaneously inform us. Nevertheless, the findings elucidate key patterns in attitudes about genetic testing that may influence many doctor-patient discussions and choices.[13,14]

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