Psychological outcomes and risk perception after genetic testing and counselling in breast cancer: a systematic review

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ABSTRACT

Objectives: To conduct a systematic review of the effects of genetic counselling and testing for familial breast cancer on women's perception of risk and psychological morbidity.

Data sources: MEDLINE, PsychLIT and EMBASE were searched for the period 1980–2001.

Study selection: Studies were eligible if published in a peer-reviewed journal in English, included women with a family history of breast cancer who underwent genetic counselling or testing and had either a randomised controlled trial or prospective design, with a pre- and at least one post-counselling assessment.

Data synthesis: As there was considerable heterogeneity in populations and measures, results were summarised rather than subjected to meta-analysis.

Results: Overall, genetic counselling and testing appear to produce psychological benefits and to improve accuracy of risk perception. Carriers of mutations in cancer predisposition genes did not experience significant increases in depression and anxiety after disclosure of their mutation status, while non-carriers experienced significant relief. Women who were tested but declined to learn their results seemed to be at greater risk of a worse psychological outcome.

Conclusions: To date, the data on psychological outcomes after genetic counselling and testing are reassuring. However, few studies used a randomised trial design, limiting the strength of the conclusions. Follow-up to date has been short, and we know little about the long-term impact of testing on patient behaviours, perceptions and psychological state.

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An estimated 3%–5% of breast cancers are caused by dominantly inherited gene mutations.[1] Mutations in two genes, *BRCA1* and *BRCA2*, are associated with an estimated risk of breast cancer of 65%–85% by age 70 and possibly also increased risk of other cancers, notably ovarian, colon, prostate and pancreatic cancer.[1]

Genetic testing for *BRCA1* and *BRCA2* mutations is available, but is psychologically challenging. The information provided is necessarily uncertain and probabilistic and concerns a possible change in health status from current health to ill-health and death.[2] Mutation carriers can do little to control when and if they get the disease, and this can lead to a sense of hopelessness and helplessness.[3] Knowledge of mutation status can influence self-concept and self-esteem and carries implications not just for the individual, but for the entire family.[4] Finally, many high-risk families have already experienced a considerable burden of cancer diagnoses and death.

Current Australian guidelines require that genetic testing be offered only in conjunction with expert counselling and advice.[1] The aim is to help the individual or family comprehend the medical facts, appreciate the hereditary aspects, understand the management options, choose a course of action, and make the best possible adjustment to the disorder or risk.[5] However, commercial and consumer bodies are campaigning to increase the availability of testing services and the anonymity of those who seek them. Ethical practice requires that we are confident that test results and information about risk can be provided without damaging psychological or behavioural consequences.

However, little research has been conducted on the outcomes of genetic counselling and testing for breast cancer predisposition genes. We undertook a systematic review of the effect of counselling and testing on the most-studied outcomes — risk perception and psychological outcomes.

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METHODS

Data sources

We searched the CD-ROM databases MEDLINE, PsychLIT and EMBASE for the period 1980–2001, using the following key words individually and in combination: *breast cancer*, *genetic counselling*, *genetic risk*, *risk perception*, *breast cancer screening*, and *breast cancer genetics*. We also searched the publications of key authors in the field and the reference lists of all identified publications for other relevant studies.

1: Studies describing risk-perception outcomes of genetic counselling in women at high risk of breast cancer

Study (year published)	Design,* sample size†	Outcome measures	Results (mean, 95% CI) ‡	Conclusions
Brain et al (2000)[6]	Randomised controlled trial 263 (treated) 282 (control)	Perceived personal risk of breast cancer (range, 2–10)	*Mean score (treated v control)* *Pre-counselling:* 7.3 (7.1–7.4) v 7.3 (7.2–7.5) *Immediate post-counselling:* 6.4 (6.3–6.6) v 6.6 (6.5–6.8) *9 months post-counselling:* 6.7 (6.6–6.9) v 6.9 (6.8–7.1)	No significant differences between treated and control groups for changes in score between baseline and immediately post-counselling, and between baseline and 9 months post-counselling
Cull et al (1998)[§7]	128 (pre-counselling) 95 (post-counselling)	Percentage of women who accurately estimated their risk[¶] (95% CI)	*Pre-counselling:* 59% (51%–68%) *1 month post-counselling:* 81% (73%–89%)	Proportion of women accurately estimating risk significantly increased after counselling.
Cull et al (1999)[8]	363 (pre- and post-counselling)		*Pre-counselling:* 50% (47%–53%) *Immediate post-counselling:* 67% (62%–72%)	Proportion of women accurately estimating risk significantly increased after counselling.
Evans et al (1994)[9]	308 (pre-counselling) 200 (post-counselling)		*Pre-counselling:* 11% (8%–15%) *1 year post-counselling:* 41% (34%–48%)	Proportion of women accurately estimating risk increased significantly after counselling and was maintained at this level.
Meiser et al (2001)[10]	218 (pre- and post-counselling)		*Pre-counselling:* 54% (48%–61%) *12 months post-counselling:* 55% (48%–62%)	No significant difference in proportion of women accurately estimating risk pre- and post-counselling.
Watson et al (1999)[11]	279 (pre-counselling) 266 (immediate post-counselling) 263 (1 year post-counselling)		*Pre-counselling:* 9% (6%–12%) *Immediate post-counselling:* 31% (26%–37%) *1 year post-counselling:* 17% (12%–22%)	Modest increase in the accuracy of perceived risk, which was maintained at 12-month follow-up.

* All studies were pre- and post-counselling comparisons unless otherwise stated.
† For randomised trials, the reported sample size comprised people who completed both baseline and follow-up measures.
‡ For pre- and post-counselling designs, 95% CIs were calculated using the reported sample sizes, unless it was explicitly stated in the study that analyses included only study completers.
§ Although this was a randomised controlled trial of a video of introductory information about inherited susceptibility, all participants received genetic counselling. Thus, for this analysis, the study was treated as a pre- and post-counselling comparison.
¶ Studies varied in the degree of exactness required for risk estimates to be regarded as accurate (from reporting the correct odds ratio to being within one risk category above or below the correct category).

Study selection

Studies were eligible for inclusion if they were published in a peer-reviewed journal in English, included women with a family history of breast cancer who underwent genetic counselling or testing, had a prospective design (with a pre- and at least one post-counselling assessment) or a randomised controlled trial design, and had either risk perception or psychological morbidity as outcome measures.

Data extraction and synthesis

Outcome data were extracted by P N B and B M. As there was considerable heterogeneity in populations studied and measures used, we considered it inappropriate to pool the data in a meta-analysis, and instead present it in summary form.

RESULTS

Risk perception after counselling

One randomised controlled trial[6] and five longitudinal studies[7-10] evaluated the effect of genetic counselling on risk perception (Box 1). Improvements in accuracy of perceived risk were consistently observed immediately after counselling, although 22%–50% of women still overestimated their risk at this time. Longer follow-ups to one year showed either no changes in accuracy of perceived risk,[10] or maintenance of improvement.[9] Overall, we concluded that genetic counselling is successful in improving accuracy of women's risk perception, at least in the short term.

Psychological outcomes of counselling

Two randomised controlled trials[6,12] and seven longitudinal studies[7,8,11,13-16] assessed the effect of genetic counselling, in the absence of genetic testing, on psychological outcomes (Box 2). Results varied from showing some reduction in psychopathology to no changes. This may be due to variations in the populations sampled or the counselling delivered. Reassuringly, no study found that anxiety levels or psychological morbidity were related to a change in perceived risk, or that outcomes were worse for those who had initially underestimated their risk. Thus, in general, it appears that cancer genetic counselling can improve risk perception without causing suffering.

In addition to these nine studies, we identified one meta-analysis which explored the impact of genetic counselling on both risk perception and psychological outcomes.[17] Twelve studies (including the nine already discussed)

2: Studies describing psychological outcomes of genetic counselling in women at high risk of breast cancer

Study (year published)	Design,* sample size†	Outcome measures	Results (mean, 95% CI)‡	Conclusions
Brain et al (2000)[6]	RCT 263 (counselling) 282 (control)	*Breast Cancer Worry Scale* (range, 6–24, with a higher score indicating greater worry)	*Mean score (treated v control)* *Pre-counselling:* 11.8 (11.4–12.2) v 11.5 (11.1–11.8) *Immediate post-counselling:* 10.6 (10.3–10.9) v 10.5 (10.2–10.8) *9 months post-counselling:* 10.6 (10.2–10.9) v 10.6 (10.3–11.0)	No significant differences between groups on any psychological outcome
		Spielberger State Anxiety Scale (range, 20–80; higher scores indicate greater anxiety)	*Pre-counselling:* 35.9 (34.6–37.2) v 35.5 (34.2–36.8) *Immediate post-counselling:* 34.3 (33.0–35.6) v 33.1 (31.9–34.3) *9 months post-counselling:* 36.4 (34.9–37.8) v 35.2 (33.8–36.6)	
Lerman et al (1996)[12]	RCT 110 (counselling) 90 (control)§	*Impact of Events Scale* (range, 0–75; score ⩾ 40 strongly predictive of a significant stress response) *Profile of Mood States* (range, 0–224; higher scores indicate greater distress)	*Mean score (treated v control)* *Pre-counselling:* 13.1 (10.9–15.3) v 15.3 (12.7–17.9) *3 months post-counselling:* 10.3 (7.9–12.7) v 14.4 (10.6–17.4) *Baseline:* 17.6 (12.5–22.7) v 22.6 (16.5–28.7) *3 months post-counselling:* 21.1 (14.9–27.3) v 23.8 (16.9–30.6)	Women who received counselling had significantly less breast cancer-specific stress at 3-month follow-up than the control group. No significant differences were found in mood.
Cull et al (1998)§[7]	128 (pre-counselling) 95 (post-counselling)	*Spielberger State Anxiety Scale* *General Health Questionnaire 30 (GHQ)* (range, 0–30; score > 5 indicates psychological distress levels consistent with a need for psychological intervention)	*Pre-counselling:* 37 (34–39) *1 month post-counselling:* 34 (32–36) *Pre-counselling:* 4.8 (3.7–5.9) *1 month post-counselling:* 4.7 (3.3–6.1)	Anxiety scores significantly reduced after counselling, but no significant differences in GHQ.
Cull et al (1999)[8]	363 (pre- and post-counselling)	*Spielberger State Anxiety Scale* *GHQ 30*	*Pre-counselling:* 35.4 (34.6–36.3) *Immediate post-counselling:* 33.7 (31.7–35.7) *Pre-counselling:* 4.5 (3.9–5.1) *Immediate post-counselling:* 3.1 (2.6–3.6)	GHQ and anxiety scores significantly lower after counselling.
Hopwood et al (1998)[13]	105 (pre- and post-counselling)	*GHQ 30 (% of women with score > 5, indicating need for psychological intervention)*	*Pre-counselling:* 30.5% (21.5%–39.5%) *3 months post-counselling:* 24.8% (16.8%–32.8%)	No significant difference between the proportion scoring in the significant psychological distress range before and after counselling.
Julian-Reynier et al (1999)[14]	173 (pre- and post-counselling)	*Spielberger State Anxiety Scale*	*Pre-counselling:* 37.9 (36.3–39.5) *1 week post-counselling:* 34.9 (33.4–36.4)	Anxiety scores were significantly lower after counselling.
Meiser et al (2001)[15]	218 (pre- and post-counselling)	*Beck Depression Inventory* (range, 0–63; higher scores indicate greater depression) *Spielberger State Anxiety Scale* *Impact of Events Scale*	*Pre-counselling:* 6.2 (5.4–7.0) *1 year post-counselling:* 7.4 (6.4–8.4) *Pre-counselling:* 35.8 (33.6–37.4) *1 year post-counselling:* 37.3 (35.6–39.0) *Pre-counselling:* 15.1 (13.1–17.1) *1 year post-counselling:* 13.9 (11.9–15.6)	No significant differences in depression or anxiety scores before and after counselling, but breast cancer-specific anxiety (Impact of Events Scale) was significantly reduced.
Watson et al (1998)[16]	107 (pre- and post-counselling)	*GHQ 12* (% of women with score > 3 on scale of 1–12; indicating psychological distress levels consistent with a need for psychological intervention)	*Pre-counselling:* 34% (24%–42%) *1 month post-counselling:* 31% (22%–40%) *6 months post-counselling:* 31% (22%–40%)	No significant differences in GHQ scores pre- and post-counselling.
Watson et al (1999)[11]	279 (pre-counselling) 266 (post-counselling) 263 (1 year post-counselling)	*GHQ 12* *Cancer Anxiety Scale* (higher scores indicate greater anxiety)	*Pre-counselling:* 2.1 (1.8–2.5) *1 month post-counselling:* 2.0 (1.7–2.4) *6 months post-counselling:* 1.8 (1.3–2.2) *Pre-counselling:* 10.3 (9.9–10.6) *1 month post-counselling:* 10.3 (10.0–10.6) *6 months post-counselling:* 10.3 (10.0–10.6)	No significant differences in GHQ and anxiety scores pre- and post-counselling.

RCT = randomised controlled trial. * All studies were pre- and post-counselling comparisons unless otherwise stated.
† For randomised trials, the reported sample size comprised people who completed both baseline and follow-up measures.
‡ For pre- and post-counselling designs, 95% CIs were calculated using the reported sample sizes, unless the study stated that analyses included only study completers.
§ Although this was a randomised controlled trial of a video of introductory information about inherited susceptibility, all participants received genetic counselling. Thus, for this analysis, the study was treated as a pre- and post-counselling comparison.

3: Studies describing psychological outcomes of genetic testing in women at high risk of breast cancer

Study (year published)	Design,* sample size	Outcome measures	Results (mean, 95% CI)	Conclusions
Croyle et al (1997)[20]	25 (carriers) 35 (non-carriers)	*Spielberger State Anxiety Scale* (range, 20–80; higher scores indicate greater anxiety)	*Pre-test:* 34.9 (30.2–39.6) *1–2 weeks post-test:* Carriers (unaffected v affected):† 33.6 (30.1–37.1) v 33.8 (31.7–35.9) Non-carriers (unaffected v affected):† 27.4 (24.4–30.4) v 33.8 (30.3–37.3)	Unaffected carriers had significantly higher anxiety scores than unaffected non-carriers after receiving test results.
Lodder et al (2001)[22]	25 (carriers) 53 (non-carriers)	*Hospital Anxiety and Depression Scale* (range, 0–21 on each subscale; score > 10 indicates clinical anxiety or depression; scores 8–10 indicate "borderline" anxiety and depression)	*Pre-test v 1–3 weeks post-test:* Carriers (anxiety): 5.0 (3.4–6.6) v 5.6 (4.1–7.1) Non-carriers (anxiety): 5.7 (4.7–6.7) v 3.8 (2.8–4.8) Carriers (depression): 2.0 (1.0–3.0) v 2.7 (1.3–4.1) Non-carriers (depression): 2.8 (2.0–3.6) v 1.8 (0–4.3)	Non-carriers had significant decreases in anxiety, depression and cancer-related anxiety after receiving test results, while carriers had no significant differences in scores.
		Impact of Events Scale	*Pre-test v 1–3 weeks post-test:* Carriers: 8.2 (4.2–12.2) v 10.3 (6.5–14.1) Non-carriers: 10.2 (7.7–12.7) v 7.3 (5.5–9.1)	
Lerman et al (1998)[21]	97 (carriers) 109 (non-carriers) 121 (decliners)‡	*Centre for Epidemiological Studies – Depression (CES-D) Scale* (range, 0–60; scores ⩾ 16 indicate clinically significant symptoms)	*% Depressed among women with low baseline anxiety* No difference in depression rates immediately post-test between carriers and non-carriers (depression rates of 8%–14%). *% Depressed among women with high baseline anxiety (pre-test v post-test)* Carriers: 20% (12%–28%) v 23% (19%–27%) Non-carriers: 41% (32%–50%) v 11% (5%–17%) Decliners: 26% (18%–34%) v 47% (38%–56%)	Depression was evident only in those with high baseline cancer anxiety. In this group, depression increased significantly in decliners, decreased in non-carriers and remained stable in carriers.
Meiser et al (2002)[23]	30 (carriers) 60 (non-carriers) 53 (not tested)	*Impact of Events Scale*	*Pre-test v 10 days post-test v 12 months post-test* Carriers: 13.1 (8.4–17.8) v 21.2 (16.0–26.4) v 16.1 (10.7–21.5) Non-carriers: 13.4 (9.7–17.1) v 13.9 (9.8–18.0) v 8.2 (4.6–11.8) Not tested: 16 (12–20) v 14.9 (11.6–18.2) v 12.3 (8.4–16.2)	Carriers had significantly higher breast cancer distress 10 days and 12 months post-test results compared with women not offered testing. Non-carriers had a significant decrease in anxiety 10 days post-test results compared with women not offered testing.
		Spielberger State Anxiety Scale	*Pre-test v 10 days post-test v 12 months post-test* Carriers: 36.1 (32.1–40.1) v 38.5 (33.6–43.4) v 31.7 (27.9–35.5) Non-carriers: 33.6 (30.5–36.7) v 31.6 (28.8–34.2) v 36.2 (32.9–39.5) Not tested: 33.6 (30.7–36.5) v 36.8 (33.5–40.1) v 39.0 (35.7–42.3)	
		Beck Depression Inventory (range, 0–63; higher scores indicate greater depression)	*Pre-test v 10 days post-test v 12 months post-test* Carriers: 5.5 (3.5–7.5) v 5.3 (3.1–7.5) v 4.0 (2.2–5.8) Non-carriers: 6.3 (4.6–8.0) v 5.7 (3.9–7.5) v 5.4 (3.8–7.0) Not tested: 5.9 (4.4–7.4) v 7.2 (5.4–9.0) v 6.9 (5.0–8.8)	

* All studies were comparisons of scores before genetic testing and after receipt of test results. † Affected = cancer or cancer-related surgical history.
‡ Included women with cancer or a history of cancer-related surgery.

met at least one of the inclusion criteria for this meta-analysis. Most measured several outcomes. Quantitative synthesis showed that genetic counselling leads to statistically significant decreases in generalised anxiety, with an average weighted effect size of $r = -0.17$ ($P < 0.01$). In contrast, the reduction in psychological distress showed only a trend towards statistical significance ($r = -0.074$; $P = 0.052$). The impact of genetic counselling on the accuracy of perceived risk was associated with an effect size of $r = 0.56$ ($P < 0.01$).

Psychological outcomes of genetic testing

Initial reports were based on very small samples[18] or anecdotal evidence.[19] However, we identified four larger prospective studies, from the United States,[20,21] Europe[22] and Australia[23] (Box 3). In most studies, non-carriers of the breast cancer predisposition genes reported a significant reduction in psychological distress, while carriers showed no decline in functioning. However, in one study of 327 members of families in which *BRCA1* mutations had already been identified,[21] rates of depression in those who declined knowledge of their test results increased from 26% pre-testing to 47% at one-month follow-up. The authors concluded that coping with risk by denial or avoidance may ultimately be detrimental.

DISCUSSION

We found that current data on psychological outcomes after genetic counselling and testing are reassuring. Genetic counselling appears reasonably successful in educating women about cancer genetics and risk, although many women continue to overestimate their risk. Overall, genetic testing appears to produce psychological benefits. Carriers do not seem to experience a significant increase in depression or anxiety after disclosure of their mutation status, while non-carriers experience significant relief. These findings provide some ethical basis for future genetic services.

Of concern is the suggestion that women who are tested but decline to learn their results may be at greater risk of psychological distress. However, it is difficult to infer causality; it may be that psychological processes already in place in those who decline test results will lead to a poor outcome, regardless of whether they know their test results or not. Further research is required to separate the effects of these factors, and find ways of assisting this group if denial is indeed a risk factor.

Smith et al explored predictors of psychological outcomes in those tested.[24] Not surprisingly, stress in female carriers was greater if they were the first in the family to be tested, or if their siblings tested negative. Distress in male non-carriers was greater if all siblings tested positive.

Several studies identified benefits from counselling. Whether these outcomes could be achieved by other, less expensive methods has not been examined, and the development of educational interventions to improve comprehension of information remains a challenge for genetic counselling services.

The studies reviewed had limitations. First, only two studies were randomised trials (Level 1 evidence[25]), while most were uncontrolled before-and-after comparisons (Level IV evidence[25]). It is reassuring that both trials showed no adverse effects on psychological outcomes, and that one demonstrated a benefit. We note that, while randomised trials would be preferred, there are practical and ethical considerations which make them difficult to achieve.

All studies to date have had only short follow-up, and we know very little about the long-term impact of testing on patient behaviours, perceptions and psychological state. This review focused on anxiety and risk perception, because of the lack of data on other outcomes. However, outcomes such as depression, family functioning and screening or management behaviour may be equally or more important.

In addition, few studies to date have explored the impact of counsellors' behaviour on outcomes. An analysis of audiotaped counselling sessions found that client concern was lower if understanding or knowledge was checked, if fewer "abnormality" words were used, and if fewer emotional issues were raised.[26] However, this study had several limitations, including a small, heterogeneous sample and unvalidated measures. Only process evaluations of genetic counselling can determine *how* genetic counselling affects outcomes and guide improvements in practice.

In summary, this is still a young field of research, with many unanswered questions.

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COMPETING INTERESTS

None identified.

REFERENCES

1. National Health and Medical Research Council. Familial aspects of cancer: a guide to clinical practice. Canberra: NHMRC, 1999.
2. Hsia YE. The genetic counselor as information giver. In: Capron AM, Lappé MRF, Powledge TM, et al, editors. Genetic counselling: facts, values and norms. New York: Alan R. Liss, 1979: 169-186.
3. Kash KM, Holland JC, Osborne MP, et al. Psychological counselling strategies for women at risk of breast cancer. *J Natl Cancer Inst Monogr* 1995; 17: 73-79.
4. Croyle RT, Achilles JS, Lerman C. Psychologic aspects of cancer genetic testing: a research update for clinicians. *Cancer* 1997; 80 (3 Suppl): 569-575.
5. Fraser F. Genetic counselling. *Am J Hum Gen* 1974; 4: 636-659.
6. Brain A, Gray J, Norman P. Randomised trial of a specialist genetic assessment service for familial breast cancer. *J Natl Cancer Inst* 2000; 92: 1345-1351.
7. Cull A, Miller H, Porterfield T, et al. The use of videotaped information in cancer genetic counselling: A randomised evaluation study. *Br J Cancer* 1998; 77: 830-837.
8. Cull A, Anderson EDC, Campbell S, et al. The impact of genetic counselling about breast cancer risk on women's risk perceptions and levels of distress. *Br J Cancer* 1999; 79: 501-508.
9. Evans DGR, Blair V, Greenhalgh R, et al. The impact of genetic counselling on risk perception in women with a family history of breast cancer. *Br J Cancer* 1994; 70: 934-938.
10. Meiser B, Butow P, Barratt A, et al. Risk perceptions and knowledge of breast cancer genetics in women at increased risk of developing hereditary breast cancer. *Psychol Health* 2001; 16: 297-311.
11. Watson M, Lloyd S, Davidson J, et al. The impact of genetic counselling on risk perception and mental health in women with a family history of breast cancer. *Br J Cancer* 1999; 79: 868-874.
12. Lerman C, Schwartz MD, Miller SM, et al. A randomized trial of breast cancer risk counselling: Interacting effects of counselling, educational level, and coping style. *Health Psychol* 1996; 15: 75-83.
13. Hopwood P, Keeling F, Long A, et al. Psychological support needs for women at high genetic risk of breast cancer: Some preliminary indicators. *Psychooncol* 1998; 7: 407-412.
14. Julian-Reynier C, Eisinger F, Chabal F, et al. Cancer genetic consultation and anxiety in health consultees. *Psychol Health* 1999; 14: 379-390.
15. Meiser B, Butow P, Barratt A, et al Long-term outcomes of genetic counselling in women at increased risk of developing hereditary breast cancer. *Patient Educ Counseling* 2001; 44: 215-225.
16. Watson M, Duvivier V, Wade Walsh M, et al. Family history of breast cancer: what do women understand and recall about their genetic risk? *J Med Genet* 1998; 35: 731-738.
17. Meiser B, Halliday JL. What is the impact of genetic counselling in women at increased risk of developing hereditary breast cancer? A meta-analytic review. *Soc Sci Med* 2002; 54: 1463-1470.
18. Dudok de Wit AC, Meijers-Heijboer EJ, Tibben A, et al. Effect on a Dutch family of predictive DNA-testing for hereditary breast and ovarian cancer. *Lancet* 1994; 344: 197.
19. Lynch HT, Watson P, Convay TA, et al. DNA screening for breast/ovarian cancer susceptibility based on linked markers. *Arch Intern Med* 1993; 153: 1979-1987.
20. Croyle RT, Smith KR, Botkin JR, et al. Psychological responses to BRCA1 mutation testing: Preliminary findings. *Health Psychol* 1997; 16: 63-72.
21. Lerman C, Hughes C, Lemon SJ, et al. What you don't know can hurt you: Adverse psychological effects in members of BRCA1-linked and BRCA2-linked families who decline genetic testing. *J Clin Oncol* 1998; 16: 1650-1654.
22. Lodder L, Frets P, Trijsburg R, et al. Psychological impact of receiving a BRCA1/BRCA2 test result. *Am J Med Gen* 2001; 98: 15-24.
23. Meiser B, Butow P, Friedlander M, et al. Psychological impact of genetic testing for women for breast cancer susceptibility. *Eur J Cancer* 2003. In press.
24. Smith KR, West JA, Croyle RT, et al. Familial context of genetic testing for cancer susceptibility: moderating effect of siblings' test results on psychological distress one to two weeks after BRCA1 mutation testing. *Cancer Epidemiol Biomarkers Prev* 1999; 8: 385-392.
25. National Health and Medical Research Council. A guide to the development, implementation and evaluation of clinical practice guidelines. Canberra: NHMRC, 1999.
26. Michie S, Axworthy D, Weinmann J, et al. Genetic counselling: Predicting patient outcomes. *Psychol Health* 1996; 11: 797-809.

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