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Risk perception, screening practice and interest in genetic testing among unaffected men in families with hereditary prostate cancer

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Abstract

Approximately 5–10% of prostate cancer cases are caused by dominantly inherited susceptibility to the disease. Although advances have been made in research concerning the genetic mechanisms of hereditary prostate cancer, little is known about the psychological consequences for men at high risk of developing the disease. The aims of the present study were to examine risk perception, interest in genetic investigations, cancer-specific worry, and screening practice among unaffected men, aged 40–72 years old, with a pedigree consistent with hereditary prostate cancer and an estimated lifetime risk of prostate cancer of 35–45%. A questionnaire was sent by mail to 120 subjects, of whom 110 responded. Most of the men ($n=90$, 82%) worried about having an inherited susceptibility to prostate cancer, and 34 (31%) claimed that worry about prostate cancer affected their daily life (3 (3%) fairly much, 31 (28%) slightly). As many as 40% of the study subjects perceived their lifetime risk of prostate cancer as 67% or more. Perceived high risk was associated with symptoms of depression and with cancer worry affecting daily living. Two-thirds of the men aged 50 years old or more were regularly screened for prostate cancer. Subjects with high levels of cancer-specific stress, as measured by the avoidance subscale of the Impact of Event Scale, were less likely to opt for screening. Almost all of the men (94%) were interested in presymptomatic genetic testing (84 (76%) "definitely yes" and 20 (18%) "probably yes"). We conclude that hereditary susceptibility to prostate cancer has significant psychological consequences although it rarely causes psychiatric morbidity. The present study underlines the importance of giving thorough, repeated information to men at high risk of prostate cancer.

Keywords: Prostatic neoplasms; Risk perception; Hereditary diseases; Genetics; Attitudes; Screening

1. Introduction

The level of knowledge about dominantly inherited cancer susceptibility syndromes has increased dramatically during the last decade. A number of genes involved in these syndromes have been identified. The penetrance of known dominant susceptibility genes for common cancers, such as breast cancer, ovarian cancer, colon cancer and malignant melanoma, is 60–90% [1]. Cloning of these genes has made presymptomatic genetic testing for germ-line mutations possible for unaffected individuals in some families with hereditary cancer susceptibility.

Dominant Mendelian inheritance of prostate cancer susceptibility was first described by Carter and colleagues [2]. The proportion of hereditary in relation to sporadic prostate cancer is estimated to be in the same range as the corresponding proportion of other common forms of cancer, namely 5–10% [2,3]. Three chromosomal loci likely to comprise prostate cancer susceptibility genes have been reported [4–6], but no gene has been identified. Thus, presymptomatic testing for prostate cancer susceptibility is not yet possible, but probably will be available within a few years.

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Notification of inherited cancer susceptibility and the process of genetic testing have important psychological and ethical implications [7,8]. Offering presymptomatic genetic testing to members of breast and ovarian cancer families is now part of standard clinical practice in many countries [9]. Numerous studies have addressed the associated psychological aspects, as exemplified by [10–24] in this article. Only one such study has been published regarding men at high risk of prostate cancer [25]. There are profound differences between hereditary breast cancer and hereditary prostate cancer, such as age at onset, treatment modalities, screening methods and, of course, gender differences. Therefore, the results from studies of women in breast cancer families are of limited help when counselling men at high risk of prostate cancer.

The recent advances in research concerning the genetics of hereditary prostate cancer are thus contrasted by a lack of knowledge about the related psychological aspects. The aims of the present study were to investigate how unaffected men in families with hereditary prostate cancer perceive their risk of prostate cancer, how their increased risk affects them, what factors are related to obtaining regular screening, and whether these men are interested in presymptomatic genetic testing.

2. Patients and methods

Two Swedish research groups, one at the University of Umeå and one at the University of Lund, have been working on the hereditary aspects of prostate cancer for several years. Swedish families with three or more connected cases of prostate cancer have been identified through population-based epidemiological studies [3,26,27] and through referral from practising urologists. Altogether 118 such families were identified up until 1 September 1998. During the primary investigation of these families, men with prostate cancer were asked to inform their unaffected male relatives of their increased prostate cancer risk and ask if they were interested in being contacted by the research group. If so, the unaffected relatives were informed by telephone of the probability of their having a substantially increased risk of prostate cancer, and were recommended regular screening from the age of 50 years (or, if any relative had been diagnosed before the age of 55 years, from the age of diagnosis of the youngest case in the family minus 5 years).

This study included unaffected men aged 50–72 years with a 50% likelihood of being carriers of a mutation in a dominantly inherited prostate cancer susceptibility gene. A total of 126 such men were identified in the 118 families with hereditary prostate cancer. 5 of these men had not been contacted previously (3 had not been informed of their father's diagnosis and 2 had psychiatric disease), and 1 had refused further contact; these 6 men were excluded from the study. A questionnaire was sent by mail to the remaining 120 men. 76 men (63%) were included by the Umeå group and 44 (37%) by the Lund group. One reminder letter was sent to those not answering within 2 weeks.

Collected sociodemographic and family history data are listed in Table 1. The men were also asked about their perception of general and personal lifetime risk of prostate cancer illness, screening habits, and interest in genetic investigations. Alternatives for prostate cancer

Table 1
Sociodemographic data and family history of cancer for 110 unaffected men in families with hereditary prostate cancer

Variable	Subjects (%)
Age (years)	
40–49	38 (35)
50–59	40 (36)
60–69	30 (27)
70–72	2 (2)
Marital status	
Unmarried/divorced	14 (13)
Married	96 (87)
Having one or more son	
Yes	80 (73)
No	30 (27)
Highest level of education	
Primary school	40 (36)
Secondary school	18 (16)
Tertiary school	16 (15)
University	36 (33)
Residence	
Town ($\geqslant$10 000 inhabitants)	53 (48)
Village ($<$10 000 inhabitants)	32 (29)
Countryside	25 (23)
Relatives with prostate cancer[a]	
1–2	34 (31)
3–4	56 (51)
5–7	20 (18)
Relatives deceased due to prostate cancer[a]	
0–1	49 (45)
2–3	54 (49)
4–5	7 (6)
Relatives with cancer[a]	
2–4	53 (48)
5–9	48 (44)
10–15	9 (8)
Relatives deceased due to cancer[a]	
0–2	48 (44)
3–4	40 (36)
5–12	22 (20)

[a] Numbers refer to family history as reported in the questionnaires. All subjects had 3 or more linked relatives with verified prostate cancer in their pedigree.

risk were given as odds and per cent: 1 in 100 (1%); 1 in 20 (5%); 1 in 10 (10%); 1 in 5 (20%); 1 in 3 (33%); 1 in 2 (50%); 2 in 3 (67%); 4 in 5 (80%); and almost certain (close to 100%). The alternatives 33% and 50% were considered as the correct answers as regards their own risk.

Cancer-specific worry was assessed with direct questions and with the Impact of Event Scale (IES, translation into Swedish by K. Nordin, Uppsala University) [28]. The direct questions read: "Do you worry about a possible inherited predisposition to prostate cancer in your family and that you yourself, therefore, may have an increased risk of the disease?" "If so, does such worry affect your daily life?" The response scales for both questions were: yes, very much; yes, fairly much; yes, slightly; no; uncertain. The IES measures reactions to a specific stressor, in this study defined as concern about prostate cancer, discriminating between intrusion (7 questions) and avoidance (8 questions), which are principle responses to stressful life events [28]. We chose to use the 4-point scale ranging from 0 to 3 (not at all, rarely, sometimes, often) recommended in the original report [28]. The questionnaire also comprised the Hospital Anxiety and Depression Scale (HADS, translation by M. Sullivan, Gothenburg University), which is a self-reported rating scale designed to measure anxiety and depression [29]. It consists of two subscales, each containing seven items on a 4-point scale (ranging from 0 to 3). Both the HADS and the IES scales assess feelings and symptoms the preceding week.

The study was approved by the research ethics committees at the universities of Lund and Umeå.

2.1. Statistics

The variables derived from the questionnaires were grouped into a hierarchical system. The group of the lowest order comprised sociodemographic data and family history of cancer, and was followed by risk perception variables, cancer-specific worry, HADS and IES scores, and finally regular participation in screening. The variables were considered as dependent on variables of lower order and predictive of variables of higher order. Unconditional logistic regression modelling was performed to identify the variables that best predicted overestimation of risk (perceived risk of 67% or more versus 50% or less), relative risk perception (increased versus not increased risk), cancer worry (any degree of worry versus no worry), and adherence to regular screening (yes versus no). Variables associated with the outcome measured at significance level $P < 0.1$ in univariate analyses were included in multivariate backward analyses. Absolute risk estimates and HADS and IES scores were considered less suitable as outcome variables in logistic regression modelling, and associations with these variables were instead tested with Mann–Whitney U-test, Kruskal–Wallis test, and with non-parametric testing for correlation. Outcome variables were tested against all variables of lower order, but only significant associations are described in the 'Results'. No corrections were made for multiple testing. All significance testing was two-tailed.

3. Results

The response rate was 92% (110/120). Sociodemographic data for the responders and their reported family history of cancer are listed in Table 1.

3.1. Risk perception

The study subjects' estimates of their personal lifetime risk of prostate cancer and of the corresponding risk for Swedish men in general varied widely (Fig. 1). The median estimate of personal risk was 50% and of general risk 33%. As many as 40% of the men perceived their own risk as 2 in 3 (67%) or more. Fifty-seven per cent estimated their personal risk as higher than the general risk, whereas 36% gave the same estimate for personal and general risks and 7% thought their own risk was less than the general risk for Swedish men. One-third estimated their personal risk as double or more than the general risk.

Perceived personal risk correlated with the number of affected relatives ($r = 0.23$, $P = 0.001$). In a multivariate logistic regression model including sociodemographic variables and family history of cancer, only the number of relatives deceased due to prostate cancer was significantly associated with perceiving a higher personal risk than men in general (odds ratio 1.6, $P = 0.01$). None of the sociodemographic or family history variables were significantly associated with overestimation of the lifetime risk of prostate cancer.

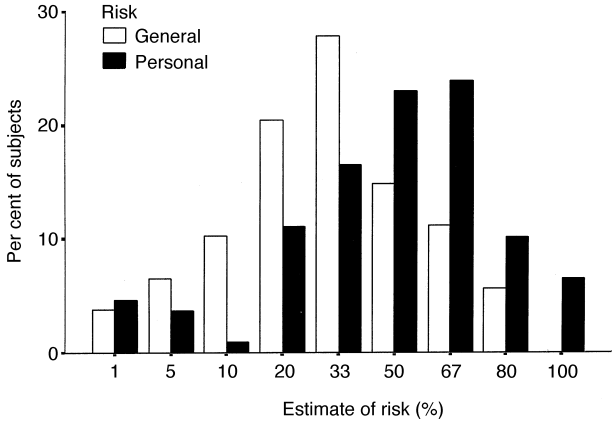

Fig. 1. Estimates of personal and general risk of prostate cancer among 110 unaffected men in families with hereditary prostate cancer.

3.2. Cancer worry; HADS and IES scores

Only 2 (2%) of the 110 participants answered that they worried very much about having an inherited susceptibility to prostate cancer, whereas 27 (25%) worried fairly much, 61 (55%) slightly and 20 (18%) never. The question about the degree of worry was followed by an attempt to assess the impact on daily life of such worry; 3 of the 110 men (3%) claimed that worry about prostate cancer affected their daily life fairly much and 31 (28%) that it did slightly.

In a multivariate logistic regression model including sociodemographic variables, family history of cancer, and perceived risk, only the number of relatives deceased due to prostate cancer predicted worry about inheriting prostate cancer (odds ratio 2.0, $P=0.01$). Perceived personal risk was the only variable associated with cancer worry affecting daily life; 47% (21/45) of those who overestimated their risk reported cancer worry affecting daily life, compared with 20% (13/65) of those who perceived a risk of 50% or less ($P=0.006$). In multivariate analysis, the corresponding odds ratio was 3.1 ($P=0.01$).

The mean HADS scores were 2.6 on the anxiety subscale (75th percentile 4) and 2.0 on the depression subscale (75th percentile 3). Those who reported worry about inheriting prostate cancer had higher scores on both depression ($P=0.01$) and anxiety subscales ($P=0.02$). Symptoms of depression were also more common amongst those who overestimated their risk of prostate cancer ($P=0.03$).

The mean IES intrusion subscale score was 4.2 (75th percentile 6) and the mean avoidance score 4.4 (75th percentile 7). The IES intrusion score correlated with the number of family members diagnosed with ($r=0.31$, $P=0.001$) and deceased due to ($r=0.26$, $P=0.007$) prostate cancer. The degree of worry about inheriting prostate cancer strongly correlated with both IES scores (avoidance: $r=0.38$, intrusion: $r=0.64$, $P<0.001$).

3.3. Interest in genetic investigations

Of the 110 responders, 89 (81%) definitely wanted and 19 (17%) probably wanted to know whether the aggregation of prostate cancer in their family was caused by inherited susceptibility whilst 2 (2%) did not. To the question as to whether they would want to undergo genetic testing to find out if they were gene carriers or not, 84 (76%) answered "definitely yes" and 20 (18%) "probably yes", whereas 4 (4%) said they would probably not want to be tested and 2 (2%) were uncertain.

Of the 80 participants who had sons, 74 (93%) wanted their sons to know of their increased risk of prostate cancer (57 definitely and 17 probably), and 71 (89%) wanted their sons to have a genetic test (46 definitely and 25 probably). The numbers of uncertain were 4 (5%) and 6 (8%), respectively and the numbers that did not want their sons to know of their increased risk were 2 (3%) and 3 (4%), respectively.

Since so few subjects were negative to genetic investigations, no statistical analyses were performed to find factors associated with interest in knowing about inheritance and in genetic testing.

3.4. Screening

Of the 72 subjects aged 50 years or more, 49 (68%) were regularly screened for prostate cancer. The proportion screened was independent of the centre (Lund or Umeå) from which the subjects were contacted. When including sociodemographic factors, family history of cancer, risk perception, cancer worry, the HADS scores, and the IES scores in a logistic regression model, the number of relatives with prostate cancer (odds ratio 2.6, 95% confidence interval (CI) 1.5–4.6, $P=0.001$) and the IES avoidance score (odds ratio 0.78, 95% CI 0.66–0.92, $P=0.003$) significantly predicted screening behaviour. Of those having an IES avoidance score of 4 (the median value) or less, 85% (33/39) were regularly screened for prostate cancer, compared with only 48% (16/33) of those with a score of more than 4 ($P=0.003$).

4. Discussion

All subjects participating in the present study were members of families with a pedigree consistent with dominantly inherited prostate cancer, and were considered as having a 50% likelihood of being carriers of a mutated prostate cancer susceptibility gene. Accounting for incomplete penetrance [2,30,31], we estimated their average lifetime risk of prostate cancer to be 35–45%, which is an approximately 4- to 5-fold increased risk compared with Swedish men in general. The study subjects commonly overestimated their personal absolute risk; as many as 40% thought their risk of prostate cancer was 67% or more. This is in accordance with women's perceived risk of breast cancer, which often is considerably higher than the objective risk [10–12,19–23]. The finding that men at high risk of prostate cancer commonly overestimate their risk is important, especially in the light of its correlation with symptoms of depression and cancer worry affecting daily life. Our personal experiences from counselling men in families with hereditary prostate cancer are in perfect agreement with the results of the study. It may seem strange, but many unaffected men in families with hereditary prostate cancer feel reassured by being told that they have a risk of prostate cancer between 35 and 45%!

The subjects' frequent overestimation of their personal absolute risk of prostate cancer was contrasted by the common underestimation of relative risk: only 33% of them estimated their own risk as double or more than the general risk. An explanation can be sought in their apprehension of the background risk of prostate cancer in the population: 80% thought that the average risk of the disease for Swedish men was 20% or more, and 32% thought it to be 50% or more. Overestimation of general or personal risk was not related to educational level. We think that benign prostatic hyperplasia is commonly confused with cancer, and that there prevails a widespread misunderstanding that "all men develop prostate cancer if they live long enough" based on reports of the high prevalence of latent cancer in elderly men and nourished by the traditional conservative attitude to prostate cancer treatment in Sweden. Laymen's beliefs about prostate cancer risk are not widely studied, but Australian men, just as the men in the present study, also are inclined to overestimate the risk for men in the general population [32].

Apprehension of prostate cancer risk is of course related to what information has been provided beforehand. Since the men in the present study had not voluntarily consulted us, they were, in general, given rather vague information about their increased risk of prostate cancer and about the potential benefit of regular screening. The majority of them were informed only at the time of primary contact with the family, which was often several years prior to the present study. There is an ethical dilemma in informing relatives about inherited susceptibility to prostate cancer when one scarcely knows whether the receiver really wishes to be informed, which is further emphasised by a lack of evidence for the efficiency of available preventive measures. However, the present study shows that the vast majority of unaffected men in families with hereditary prostate cancer wish to know about their risk, and that notification of risk may actually reduce anxiety since their naïve estimates of personal risk are often higher than the true risk. Thus, our study highlights the need for repeated, detailed information to men with a family history of prostate cancer. Such information should be given face to face by a urologist, an oncologist or a clinical geneticist with experience from genetic counselling. That information was provided by telephone in the present investigation was a consequence of that fact that the research project included families from all over Sweden, with most subjects living far away from the research centres. The majority of the study subjects had thus not received proper genetic counselling, which may partly explain the common inaccuracy in estimates of cancer risk.

The majority of these men experienced cancer-specific worry, and as many as 31% claimed that worry about prostate cancer affected their daily life (although 28% of these worried only slightly). In spite of this, the mean HADS scores for the entire study group were even below the population average for middle-aged Swedes [33] and Dutchmen [34], indicating that although prostate cancer susceptibility is commonly a source of concern, it rarely causes the serious psychiatric morbidity which is usually associated with a mean HADS score of 8 or more.

Three chromosome loci likely to comprise prostate cancer susceptibility genes have been identified [4–6], and presymptomatic genetic testing of men in families with hereditary prostate cancer may soon be feasible. Almost all men in the present study were interested in having such a test, confirming the results of our previous study of sons of men with prostate cancer [25]. Likewise, the vast majority of women in breast cancer families are interested in being tested for mutations in *BRCA1* and *BRCA2* [13,15,18,24]. However, genetic testing for cancer susceptibility is associated with complex psychological and ethical complications [7,8]. It is, therefore, of the utmost importance that testing is preceded by repeated counselling and that elaborate strategies are worked out for follow-up of individuals tested as well as for those declining testing. Lerman and colleagues reported that members of breast cancer families who declined genetic testing were at higher risk of depression than those who were gene carriers [17]. Furthermore, the positive attitude to genetic testing among the men in the present study must be interpreted with caution, considering they had not been offered proper genetic counselling comprising risk notification, and had not been informed about the limitations of the techniques for genetic testing and of the methods available to prevent death from prostate cancer. Whenever presymptomatic genetic testing becomes possible for hereditary prostate cancer, its employment should be accompanied with research concerning the psychological effects.

It is reasonable to assume that the 10 non-responders (8% of those asked) were less positive to genetic investigations and screening than the responders. Thus, although only isolated subjects in this study wished to refrain from genetic investigations, such an attitude may not be quite as rare in the entire population of unaffected men in families with hereditary prostate cancer. This must be kept in mind when families with multiple cases of prostate cancer are investigated, and the right not to know should be respected.

Mammography screening has proved to reduce breast cancer mortality in randomised studies [35], but as regards screening with prostate-specific antigen and digital rectal examination for prostate cancer no such evidence of reduced mortality has been produced. Randomised studies of prostate cancer screening are in progress, but the final results of these will not be available for at least another decade. Meanwhile, we think it

advisable to recommend screening to men at high risk of prostate cancer. It is important that people with increased risk of cancer feel that there are measures for reducing their risk from dying from cancer [21], and at present screening is the only option which can be offered to men with increased risk of prostate cancer. Besides the psychological aspects, the greatly increased incidence of the disease in this group of men and the low average age at diagnosis of hereditary prostate cancer [3], are factors speaking in favour of screening men with multiple relatives affected with prostate cancer, compared with screening men in the general population.

All subjects aged 50 years or more in the present study had been recommended screening, but only two-thirds were screened regularly. Adherence to screening was associated with the number of relatives with prostate cancer, but surprisingly not with worry about inheriting prostate cancer or perceived risk. The reason may be that there is a U-shaped relationship between fear of cancer and participation in screening programmes for early detection of cancer. According to the Fear Arousing Communications Theory, a moderate level of arousal of fear is optimal for preventive health care behaviours, whilst low and high levels may lead to denial of risk or avoidance [36]. The present study provided support for this theory, since participation in screening was less common among men who had high levels of cancer-specific stress on the IES avoidance subscale. Similar findings have been reported regarding adherence to mammography amongst women at high risk of breast cancer [14,16,22]. These findings add weight to the previous arguments stressing the importance of assiduous counselling for men at high risk of prostate cancer.

In summary, almost all of these unaffected men in families with hereditary prostate cancer had a positive attitude towards genetic investigations. Overestimation of the lifetime risk of prostate cancer was common and was associated with symptoms of depression and cancer worry affecting daily life, but in spite of this, symptoms of depression and anxiety were not particularly common among the study subjects. Indications were found that some men may refrain from screening because of fear of prostate cancer. This study clearly stresses the importance of giving thorough, detailed information to men at high risk of prostate cancer.

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References

1. Eeles R, Ponder B, Easton D, Horwich A. *Genetic Predisposition to Cancer*. 1st edn. Oxford, Chapman & Hall, 1996.
2. Carter BS, Beaty TH, Steinberg GD, Childs B, Walsh PC. Mendelian inheritance of familial prostate cancer. *Proc Natl Acad Sci USA* 1992, **89**, 3367–3371.
3. Bratt O, Kristoffersson U, Lundgren R, Olsson H. Familial and hereditary prostate cancer in southern Sweden. A population-based case–control study. *Eur J Cancer* 1999, **35**, 272–277.
4. Smith JR, Freije D, Carpten JD, *et al*. Major susceptibility locus for prostate cancer on chromosome 1 suggested by a genome-wide search. *Science* 1996, **274**, 1371–1374.
5. Xu J, Meyers D, Freije D, *et al*. Evidence for a prostate cancer susceptibility locus on the X chromosome. *Nature Genetics* 1998, **20**, 175–179.
6. Berthon P, Valeri A, Cohen-Akenine A, *et al*. Predisposing gene for early-onset prostate cancer, located on chromosome 1q42.2-43. *Am J Hum Genet* 1998, **62**, 1416–1424.
7. Lerman C, Rimer B, Engstrom P. Cancer risk notification: psychosocial and ethical implications. *J Clin Oncol* 1991, **9**, 1275–1282.
8. Croyle R, Achilles J, Lerman C. Psychologic aspects of cancer genetic testing. A research update for clinicians. *Cancer* 1997, **80**, 569–575.
9. Burke W, Daly M, Garber J, *et al*. Recommendations for follow-up care of individuals with an inherited predisposition to cancer. II. *BRCA1* and *BRCA2*. *J Am Med Assoc* 1997, **277**, 997–1003.
10. Daly M, Lerman C, Ross E, Schwartz M, Burke Sands C, Masny A. Gail model breast cancer risk components are poor predictors of risk perception and screening behavior. *Breast Cancer Res Treat* 1996, **41**, 59–70.
11. Evans DGR, Burnell LD, Hopwood P, Howell A. Perception of risk in women with a family history of breast cancer. *Br J Cancer* 1993, **67**, 612–614.
12. Gagnon P, Massie M, Kash K, *et al*. Perception of breast cancer risk and psychological distress in women attending a surveillance program. *Psycho-Oncology* 1996, **5**, 259–269.
13. Julian-Reynier C, Eisinger F, Vennin P, *et al*. Attitudes towards cancer predictive testing and transmission of information to the family. *J Med Genet* 1996, **33**, 731–736.
14. Kash KM, Holland JC, Halper MS, Miller DG. Psychological distress and surveillance behaviors of women with a family history of breast cancer. *J Natl Cancer Inst* 1992, **84**, 24–30.
15. Lerman C, Daly M, Masny A, Balshem A. Attitudes about genetic testing for breast–ovarian cancer susceptibility. *J Clin Oncol* 1994, **12**, 843–850.
16. Lerman C, Daly S, Sands C, *et al*. Mammography adherence and psychological distress among women at risk for breast cancer. *J Natl Cancer Inst* 1993, **85**, 1074–1080.
17. Lerman C, Hughes C, Lemon J, *et al*. What you don't know can hurt you: adverse psychologic effects in members of *BRCA1*-linked and *BRCA2*-linked families who decline genetic testing. *J Clin Oncol* 1998, **16**, 1650–1654.
18. Lerman C, Seay J, Balshem A, Audrain J. Interest in genetic testing among first-degree relatives of breast cancer patients. *Am J Med Genet* 1995, **57**, 385–392.
19. Lloyd S, Watson M, Waites B, *et al*. Familial breast cancer: a controlled study of risk perception, psychological morbidity and health beliefs in women attending for genetic counselling. *Br J Cancer* 1996, **74**, 482–487.
20. McCaul K, O'Donnell S. Naive beliefs about breast cancer risk. *Women's Health* 1998, **4**, 93–101.
21. 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.
22. Lerman C, Kash K, Stefanek M. Younger women at increased risk of breast cancer: perceived risk, psychological well-being,

and surveillance behaviour. *Monogr Natl Cancer Inst* 1994, **16**, 171–176.
23. Lerman C, Lustbader E, Rimer B, *et al*. Effects of individualized breast cancer risk counseling: a randomized trial. *J Natl Cancer Inst* 1995, **87**, 286–292.
24. Struewing J, Lerman C, Kase R, Giambarresi T, Tucker M. Anticipated uptake and impact of genetic testing in hereditary breast and ovarian cancer families. *Cancer Epidemiol Biomarkers Prev* 1995, **4**, 169–173.
25. Bratt O, Kristoffersson U, Lundgren R, Olsson H. Sons of men with prostate cancer: their attitudes regarding possible inheritance of prostate cancer, screening, and genetic testing. *Urology* 1997, **50**, 360–365.
26. Bratt O, Kristoffersson U, Lundgren R, Olsson H. The risk of malignant tumours in first-degree relatives of men with early onset prostate cancer: a population-based cohort study. *Eur J Cancer* 1997, **33**, 2237–2240.
27. Grönberg H, Damber L, Damber J-E. Familial prostate cancer in Sweden, a nationwide register cohort study. *Cancer* 1996, **77**, 138–143.
28. Horowitz M, Wilner N, Alvarez W. Impact of event scale: a measure of subjective stress. *Psychosom Med* 1979, **41**, 209–218.
29. Zigmond A, Snaith R. The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand* 1983, **67**, 361–370.
30. Grönberg H, Damber L, Damber J-E, Iselius L. Segregation analysis of prostate cancer in Sweden: support for dominant inheritance. *Am J Epidemiol* 1997, **146**, 552–557.
31. Schaid D, McDonnel S, Blute M, Thibodeau S. Evidence for autosomal dominant inheritance of prostate cancer. *Am J Hum Genet* 1998, **62**, 1425–1438.
32. Ward J, Hughes A, Hirst G, Winchester L. Men's estimates of prostate cancer risk and self-reported rates of screening. *Med J Aust* 1997, **167**, 250–253.
33. Lisspers J, Nygren A, Söderman E. Hospital Anxiety and Depression Scale (HAD): some psychometric data for a Swedish sample. *Acta Psychiatr Scand* 1997, **96**, 281–286.
34. Spinhoven P, Ormel J, Sloekers P, Kempen G, Speckens A, van Hemert A. A validation study of the Hospital Anxiety and Depression Scale (HADS) in different groups of Dutch subjects. *Psychol Med* 1997, **27**, 363–370.
35. Kerlikowske K, Grady D, Rubin S, Sandrock C, Ernster V. Efficacy of screening mammography: a meta-analysis. *J Am Med Assoc* 1995, **273**, 149–154.
36. Janis IL, Feshbach S. Fear arousing communications. *J Abnorm Soc Psychol* 1953, **48**, 78–92.