Why do women attend familial breast cancer clinics?

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Abstract

The increasing demand for genetic assessment for familial breast cancer has necessitated the development of cancer genetics services. However, little is known about the factors motivating the client population likely to approach these services. A cross sectional questionnaire survey of 1000 women with a family history of breast cancer was conducted to identify self-reported reasons for attending a familial breast cancer clinic and possible differences in the characteristics of women who were attending for diverse reasons. Before attendance at clinic, 833 women completed a baseline questionnaire (83% response rate). Women who gave personal risk (n=188), awareness of a family history (n=120), risk to family members (n=84), reassurance (n=69), genetic testing (n=65), breast screening (n=46), or prevention (n=39) as their main reason for attending were compared on demographic and medical variables, and on psychological variables including general anxiety, cancer worry, perceived risk, and attitudes towards prophylactic surgery and genetic testing. Important differences in the psychological characteristics of these groups were found, which were unrelated to reported family history. In particular, women who primarily wanted genetic testing felt extremely vulnerable to developing breast cancer, were more likely to be considering prophylactic surgery, and perceived fewer limitations of testing. Those who primarily wanted reassurance were highly anxious about the disease. We recommend that cancer genetics services take into consideration the informational and psychological needs and concerns of their client group.

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Until recently, genetic aspects of common cancers received relatively little attention from genetics or oncology services. There was little demand and little practical help to be offered. The situation has now changed considerably with the discovery of mutations in specific genes predisposing to breast cancer,[1–3] enabling genetic assessment and predictive genetic testing similar to that which has previously been available in rarer syndromes.

A number of familial cancer clinics have been established in the UK in order to provide individualised genetic risk information and possible genetic testing for women with a family history of breast cancer.[4] The high scientific profile, as well as the extensive media coverage of genetic testing, has led to growing interest among at risk women[5–7] and an increase in the number of referrals made by general practitioners (GPs) and hospital specialists to familial breast cancer clinics. Given the increasing pressure for cancer genetics services, the challenge now is to develop and evaluate a coordinated approach to service provision for women who are concerned about a possible family history of breast cancer.[8 9] Although an increasing body of knowledge is being accumulated with regards to women who attend specialised genetic testing centres,[10] little published research has examined the factors that may motivate the much larger number of people likely to approach the newly developing familial cancer clinics for advice in relation to their family history.

Research to date suggests that at risk women tend to perceive heightened personal risk of developing breast cancer and as a result experience psychological difficulties.[11–13] Their expectations of the familial breast cancer clinic may include provision of breast screening, genetic risk information, or simply reassurance. It has been suggested that women may be more interested in obtaining reassurance and information about cancer detection and prevention than in procuring genetic risk information or genetic testing,[14 15] though there is likely to be wide variety in their reasons for attending. To our knowledge, no published research to date has examined whether there is variance in the psychosocial characteristics of women who are attending the familial breast cancer clinic for different reasons.

The aim of the current study was to build a profile of cancer genetics services' client population by examining women's primary reasons for attending a familial breast cancer clinic and the demographic, medical, and psychological factors associated with those reasons. These data are presented as the first stage of a research project, described in the associated paper by Gray *et al*. Identifying some of the factors that motivate at risk women will increase understanding of their concerns and needs as well as enable identification of subgroups for whom additional support is indicated, hence aiding the development of appropriate service provision.

Patients and methods

PATIENTS

Women who were identified as having a family history of breast cancer and who fulfilled the study entry criteria were referred between 1996 and 1997 into an all Wales randomised controlled trial (the TRACE project). Women were sent a baseline questionnaire to complete before randomisation and therefore were unaware of their study group allocation. A total of 1000 women were referred and 833 (83%) returned questionnaires. Of the 167 women who did not return questionnaires, 111 did not respond and 48 declined to participate in the study. Self-reported reasons for declining were recorded and included difficulties with travelling to the clinic, difficulties in completing the questionnaire, and concerns about possible genetic testing. Eight women were excluded from the study because they did not fit the entry criteria. Of these, four women were found to have had breast cancer, two did not have a relevant family history of breast cancer, and two were no longer resident in Wales.

METHODS

Methods of recruiting study participants are described in detail in the paper by Gray *et al*. Participants completed a baseline questionnaire to assess the following variables.

Demographic and medical characteristics

These included age, marital status, ethnic background, and educational level. Postcode information was used to indicate the region from which participants had been referred to the study. Participants were also asked to indicate the number of first degree and second degree relatives affected with breast cancer, the age of each relative at diagnosis, and whether any family member was currently being treated for cancer.

Reasons for attending

The Manchester Family History Clinic Questionnaire (Hopwood, personal communication) was used to assess reasons for attending the clinic and pattern of referral. In order to identify their main reason for attending the clinic, participants were asked to choose from a list of 10 categorical statements. They were also asked to indicate whether or not they wanted to know their exact risk of developing breast cancer. Referral pattern was assessed by asking participants to state the route by which they had been referred (response options included GP, hospital doctor, self, family member, and other). Since all NHS specialist referrals must be made by general practitioners, participants were also asked to state who had first raised the issue of a family history (options included self, GP, and hospital doctor).

State-Trait Anxiety Inventory (STAI)

The STAI[16] is a well validated questionnaire that measures general anxiety. The Trait Anxiety scale asks participants to indicate how they generally feel regarding 20 statements, while the State Anxiety scale asks participants to describe how they currently feel regarding the same 20 statements. Total scores for each scale range from 20 to 80, with a higher score indicating higher anxiety. Normative data are available in the STAI manual.[16] In the present study, high internal consistency was found for both scales (Trait scale α=0.92, State scale α=0.93).

Breast cancer worries scale

This scale[17 18] measures anxiety that is specific to breast cancer and has been shown to predict adherence to mammography.[17] It assesses frequency of concerns about developing breast cancer, and the impact of breast cancer worry on mood and daily functioning. Items are each rated on a four point scale. Total possible scores range from 6 to 24, with higher scores indicating higher breast cancer worry. In the current study, internal consistency of the scale was found to be satisfactory (α=0.86).

Perceived risk

Two items were used to assess perceived personal risk of developing breast cancer and were derived from previous research.[18 19] The two items were: (1) What level of risk do you personally think you have? and (2) In your opinion, what are your chances of getting breast cancer compared to the average woman? Items were each rated on a five point scale and were summed to form a composite scale with a total score range of 2-10. The composite scale was found to have adequate internal consistency (α=0.71).

Attitudes towards genetic testing

Perceived benefits (pros) and limitations (cons) of testing were measured using 24 items derived from previous studies.[7 20–22] Twelve items reflected possible pros and 12 items reflected possible cons of testing. Participants rated their agreement with each statement on a five point scale and items were summed to form two scores reflecting perceived pros (α=0.82) and perceived cons (α=0.91), respectively. Scores on each scale ranged from 0-60.

Prophylactic surgery

Participants were asked to report whether they were currently considering having prophylactic mastectomy.

DATA ANALYSIS

All statistical analyses were carried out using SPSS for Windows v 6.0. Data were screened before analysis. Two sets of analyses were conducted. First, descriptive statistics were used to examine the characteristics of the study population, including demographic and medical background, self-reported reasons for attending the clinic, source of referral, and perceived personal risk of developing breast cancer. Pearson's product-moment correlation was used to examine the association between participants' age and the age at which a first degree relative had been diagnosed with breast cancer. Second, the factors motivating women to attend clinic were examined by comparing women who endorsed different reasons for attending. In order to identify women's main reason for

Table 1 Demographic characteristics of the study sample

Variable	*Category*	*No*	*%*
Ethnic background	White	694	99
	Non-white	6	1
Marital status	Single	65	8
	Married/cohabiting	672	81
	Divorced/separated	78	9
	Widowed	16	2
Education	No schooling	4	1
	Primary education only	7	1
	Left school before 16 years	247	30
	Secondary education (16–18)	385	46
	Further education (19+)	93	11
	University degree	92	11
Origin of referral	South east Wales	601	72
	South west Wales	193	24
	North Wales	20	3
	Mid Wales	5	1
Relative receiving cancer treatment	Yes	289	36
	No	521	64

n=833

attending, participants were asked to choose from a list of 10 categorical statements. From the 10 main reasons, we selected those reasons that were endorsed by at least 5% of the sample. Seven main reasons were selected: (1) personal risk, (2) awareness of a family history, (3) risk to family members, (4) reassurance, (5) genetic testing, (6) breast screening, and (7) prevention. There was sufficient power to detect a statistically significant difference between groups (power=0.80, medium effect size at α=0.05). The seven groups were then compared on demographic and medical variables and on psychological variables including general anxiety, cancer worry, perceived risk, attitudes to prophylactic mastectomy, and attitudes to genetic testing. Ethnic background was not included in the analysis owing to low variance. Chi-square tests of association were used for categorical variables and one way analysis of variance (ANOVA) for continuous variables. Before one way ANOVA, the extent to which the data met the assumption of homogeneity of variance was assessed using the Bartlett test. The assumption was met for all variables ($p \leq 0.001$). Significant main effects of one way ANOVA were followed up with post hoc Scheffé tests.

Results

SAMPLE CHARACTERISTICS

Demographic and medical characteristics

Demographic characteristics are displayed in table 1. Women were aged between 17 and 77 years (mean 41.31, SD 9.84) and had an average of two first degree and second degree relatives affected with breast cancer (range 1-9). The majority of participants were white, married or cohabiting, had gained qualifications at or above the secondary education level, and were from south east Wales. Thirty six percent reported that a relative was currently receiving cancer treatment. There was a moderately significant positive correlation between participant's age and the age at which breast cancer was diagnosed in a mother (r=0.44, $p \leq 0.001$) and/or a sister (r=0.49, $p \leq 0.001$). The average age of mothers at diagnosis was 51 years (SD 12.56) and that of sisters was 44 years (SD 8.75).

Table 2 Main reason for attending clinic

Variable	*No*	*%*
To find out about my risk*	188	29
Knowledge of a family history†	120	19
To find out the risk to other family members‡	84	13
To reduce my worry§	69	11
To find out about genetic testing¶	65	10
To have a breast check**	46	7
To find out about prevention methods††	39	6
Other	27	4
Following the advice of my GP	10	1
For advice about the pill/hormone replacement therapy	0	0

n=833
Groups
*Personal Risk
†Family History
‡Risk to Family Members
§Reassurance
¶Genetic Testing
**Breast Screening
††Prevention

Reasons for attending clinic

Table 2 indicates women's main reasons for attending. The majority of women (29%) primarily wanted information about personal risk of breast cancer. Nineteen percent gave awareness of a family history as their main reason, while 13% primarily wanted to find out about the risk to other family members, and 11% wanted to reduce their level of anxiety. Ten percent mainly wanted to find out about genetic testing, 7% wanted access to breast screening, and 6% wanted information about prevention methods. One percent were following the advice of their GP. None gave advice about the pill or hormone replacement therapy as their main reason for attending clinic. Four percent gave other main reasons for wanting to attend, which included helping with research. Eighty two percent of participants (n=682) stated that they did and 2% (n=12) stated that they did not want to receive specific risk information, while 16% (n=133) were unsure.

Referral patterns

Seventy three percent of women (n=608) reported that a medical professional had made the referral, while 16% (n=132) stated that the referral had been initiated by themselves, 7% (n=54) by a family member, and 4% (n=34) by an unspecified other. Of those referred by a medical professional, 60% (n=365) stated that the referral had been made in response to their own initiative in raising the family history.

Perceived risk of breast cancer

The majority of participants perceived an increased personal risk of developing breast cancer, with 52% (n=425) perceiving their risk to be above average, 25% (n=208) perceiving their risk to be high or very high, and 2% (n=19) expressing certainty that they would develop breast cancer. Nineteen percent (n=157) perceived their risk to be average, while 2% (n=18) perceived themselves to be at low risk of breast cancer. In terms of relative risk, the majority of women felt that their risk was a little higher (56%, n=466) or much higher (35%, n=292) while the remainder felt it to be the same as (9%, n=75) that of the average woman.

Table 3 Group comparisons (one way ANOVA)

	Main reason for attending clinic																
	Personal risk		*Family history*		*Risk to family members*		*Reassurance*		*Genetic testing*		*Breast screening*		*Prevention*				
Variable	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*F*	*df*	*p*
Age	39.91	9.67	40.76	10.70	47.61	9.08	40.52	10.36	39.28	8.12	41.59	9.36	39.97	9.04	7.19	6, 599	0.000***
Family history	2.35	1.18	2.35	1.25	2.60	1.38	2.23	1.14	2.71	1.72	2.17	1.06	2.26	1.03	1.55	6, 602	0.16
Mother's age at diagnosis	48.66	10.54	51.14	13.44	54.21	12.45	47.46	11.93	49.54	13.60	48.13	12.19	50.00	12.33	2.00	6, 417	0.06
Sister's age at diagnosis	41.61	8.06	45.18	10.89	45.38	9.00	41.33	10.28	45.19	7.96	42.07	7.77	38.09	8.32	1.85	6, 188	0.09
STAI-Trait	40.78	10.96	38.76	9.32	39.63	9.98	42.70	10.99	40.53	12.30	40.81	12.04	38.21	11.36	1.33	6, 592	0.24
STAI-State	37.07	11.74	36.36	11.09	36.97	10.36	39.62	11.12	38.71	12.59	38.53	13.73	35.40	10.64	1.02	6, 593	0.41
Breast cancer worries	12.04	3.39	11.78	3.38	10.45	3.25	13.61	2.96	12.15	3.42	11.39	3.61	11.54	2.32	6.26	6, 604	0.000***
Perceived risk	7.56	1.19	7.16	1.30	7.13	1.28	7.10	1.23	7.77	1.31	6.83	1.27	7.45	1.20	4.70	6, 594	0.0001***
Attitude to genetic testing:																	
Pros of testing	40.97	7.64	40.42	8.97	40.22	8.54	40.07	11.46	42.92	7.95	40.39	9.48	40.67	9.08	.81	6, 594	0.56
Cons of testing	29.13	10.86	30.29	10.92	28.25	11.30	32.97	11.01	26.36	9.82	33.79	7.70	30.96	11.24	3.62	6, 591	0.002**

n=833. *p≤0.05. **p≤0.01. ***p≤0.001.
STAI-Trait = Spielberger State-Trait Anxiety Inventory (Trait scale). STAI-State = Spielberger State-Trait Anxiety Inventory (State scale).

FACTORS MOTIVATING ATTENDANCE

The results of group comparisons are displayed in tables 3 and 4.

Demographic and medical variables

Differences between the seven groups in demographic variables including marital status and educational level were not significant, nor were there significant differences in the number of relatives affected with breast cancer and age at diagnosis of breast cancer in first degree relatives. However, there was a significant difference between groups in age. Women who were primarily attending in order to find out about the risk to other family members were significantly older than all other groups except those who were attending in order to obtain breast screening. There was also a significant difference in source of referral, with those who wanted genetic testing significantly more likely to have initiated the referral themselves. In addition, they were significantly more likely to report that a relative was currently receiving cancer treatment.

Psychological variables

One way ANOVA indicated that there were no significant between group differences in general anxiety. In all groups, except those who principally wanted reassurance, mean scores on Trait anxiety and State anxiety were slightly higher than population norms for working adult females but lower than norms for general medical and surgical patients without psychiatric complications. The Trait anxiety scores of women who wanted reassurance were higher than both these sets of norms. (Population norms are reported in the STAI manual.[16]) Levels of cancer worry in this group of women were significantly higher than in those who were attending in order to find out about risk to other family members, or because of awareness of a family history. Women who wanted personal risk knowledge were significantly more worried about cancer than women who wanted to find out the risk to family members. There was also a significant difference between groups in perceived risk of developing breast cancer, with women who wished to obtain genetic testing perceiving significantly higher risk compared to women who primarily required a breast check. Women who wanted genetic testing were also significantly more likely to be considering prophylactic surgery than the other groups. Although the difference between groups in perceived pros of genetic testing was not significant, those who wanted genetic testing perceived significantly fewer cons of testing in comparison to women who primarily wanted breast screening.

Table 4 Group comparisons (χ^2 test)

	Main reason for attending clinic									
Variable	*Personal risk No (%)*	*Family history No (%)*	*Risk to family members No (%)*	*Reassurance No (%)*	*Genetic testing No (%)*	*Breast screening No (%)*	*Prevention No (%)*	χ^2	*df*	*p*
Marital status:										
Married/cohabiting	155 (83)	96 (80)	74 (88)	54 (79)	51 (79)	35 (76)	32 (82)	4.35	6	0.63
Not married/cohabiting	32 (17)	24 (20)	10 (12)	14 (21)	14 (21)	11 (24)	7 (18)			
Education:										
< Secondary education	52 (28)	42 (35)	33 (39)	22 (32)	21 (32)	14 (30)	11 (28)	4.14	6	0.66
⩾ Secondary education	133 (72)	78 (65)	51 (61)	46 (68)	44 (68)	32 (70)	28 (72)			
Source of referral:										
Medical professional	135 (81)	84 (78)	63 (88)	53 (87)	39 (67)	36 (84)	29 (88)	12.59	6	0.05*
Self	32 (19)	24 (22)	9 (12)	8 (13)	19 (33)	7 (16)	5 (12)			
Relative receiving cancer treatment:										
Yes	74 (40)	47 (41)	26 (32)	16 (24)	33 (51)	15 (33)	8 (21)	17.34	6	0.008**
No	110 (60)	68 (59)	56 (68)	51 (76)	32 (49)	31 (67)	30 (79)			
Prophylactic surgery:										
Considering	33 (21)	11 (11)	8 (11)	9 (17)	21 (41)	4 (9)	3 (8)	30.70	6	0.0003***
Not considering	123 (79)	89 (89)	64 (89)	45 (83)	30 (59)	39 (91)	34 (92)			

n=833. *p≤0.05. **p≤0.01. ***p≤0.001.

Discussion

Recent technological developments have enabled genetic testing for susceptibility to a number of common cancers, and intense media publicity has led to an increased demand for cancer genetics services. The aim of the present paper was to identify some of the factors that may motivate women at risk of familial breast cancer to approach these services.

These preliminary findings of the TRACE project confirm the high level of interest in cancer genetics services and the diversity of reasons for requesting them. The majority of women referred into the study were extremely motivated, reflected in the high rate of response to the baseline questionnaire. Referrals were largely made by general practitioners or hospital specialists, but in most of these cases the referral was catalysed by the woman actively raising the issue of a family history with her doctor. Women gave a variety of reasons for wanting to attend the familial breast cancer clinic, illustrating the importance of a multidisciplinary approach to providing cancer genetics services.[23] Genetic risk assessment should be offered alongside appropriate breast screening, information about prevention, and psychological support. However, women's primary motivation for attending appeared to reflect a desire for information about a high perceived personal risk of breast cancer. That women felt highly susceptible to the disease was confirmed in the finding of a significant association between participants' age and the age at which a close relative had been diagnosed with breast cancer. Hence, the majority of women who are referred to familial breast cancer clinics may assume themselves to be at high risk because of an apparent family history, and the referral may be precipitated because they are nearing the age at which a close relative developed the disease.[15 24] Therefore from the client's perspective, a central function of the familial breast cancer clinic may be to provide information on strategies for dealing with a risk that is already perceived to be high.[14 15] However, there may be a subgroup of older women who are motivated more by concerns about the welfare of family members than by concerns about personal well being.

The current findings highlight important differences in the psychological characteristics of women who were attending for different reasons. Although there was no difference in reported family history, women who primarily wanted to obtain genetic testing perceived greater personal susceptibility to breast cancer in comparison to women who were attending for other reasons. Women who wanted genetic testing were more likely to have been self-referred, to report that a relative was currently being treated for cancer, and to be considering the option of prophylactic mastectomy. They also perceived fewer limitations of testing compared to women who wanted breast screening. These findings suggest that interest in genetic testing may be present not only in families where there is high genetic risk, but also in the much more frequent cases where risk is not significantly increased. Seeking testing may therefore reflect an attempt to gain a sense of personal control over a risk that is perceived to be extremely high. An important element of service provision for these women is to address the issue that genetic testing may only be helpful to a small subset of high risk women and to ensure that they are aware of the limitations of testing. Focusing on the potential benefits of primary and secondary prevention may also help these women to increase their sense of personal control and to manage overwhelming feelings of vulnerability to breast cancer.

The findings in relation to women attending the clinic to gain reassurance suggest that this group may be compelled by high levels of cancer related anxiety, and that they in particular may benefit from additional psychological support. Women who primarily wanted reassurance were significantly more worried about breast cancer compared to women who were attending for other reasons, even though they did not appear to have a more extensive family history of the disease. In addition, the mean general anxiety score of this group of women was higher than population norms. An important area for future research involves the development and evaluation of psychological interventions to address the cancer related concerns of at risk women. Such interventions may include the use of telephone counselling[25] and printed materials.[26] More intensive counselling, involving possible referral to specialist psychological services, may be indicated for the small subset of at risk women who are experiencing high levels of general anxiety.

In light of these findings, we suggest that cancer genetics services take into account the information and counselling requirements of the client population. Eliciting clients' concerns and reasons for requesting the service means that their specific needs can be appropriately addressed.[27 28] Further, identifying subgroups of women who are extremely concerned about breast cancer may enable targeting of additional support and possible referral to specialist services. We acknowledge the methodological difficulty in examining women's reasons for attending, when they may have multiple reasons that are not mutually exclusive. Therefore, we recommend that further research tests the validity of the groups that were identified in the current research. In addition, there are limits to the inferences that can be drawn from these cross sectional data. Subsequent stages of the TRACE project will report prospective data regarding the psychosocial impact of genetic assessment, in order further to inform the development of future cancer genetics services.[9]

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1 Hall JM, Lee MK, Newman B, *et al.* Linkage of early onset familial breast cancer to chromosome 17q21. *Science* 1990;**250**:1684-9.
2 Miki Y, Swensen J, Shattuck-Eidens D, *et al.* A strong candidate for the breast and ovarian cancer susceptibility gene, BRCA1. *Science* 1994;**266**:66-71.

3 Wooster R, Neuhausen S, Mangion J, *et al.* Localisation of a breast cancer susceptibility gene BRCA2 to chromosome 13q12-13. *Science* 1994;**265**:2088-90.
4 Evans DGR, Fentiman IS, Mcpherson K, *et al.* Familial breast cancer. *BMJ* 1994;**308**:183-7.
5 Lerman C, Daly M, Masny A, Balshem A. Attitudes about genetic testing for breast-ovarian cancer susceptibility. *J Clin Oncol* 1994;**12**:843-50.
6 Chaliki H, Loader S, Levenkron JC, *et al.* Women's receptivity to testing for a genetic susceptibility to breast cancer. *Am J Public Health* 1995;**85**:1133-5.
7 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**:385-92.
8 Calman-Hine Report. *A policy framework for commissioning cancer services*. Report by the expert advisory group on cancer to the Chief Medical Officers of England and Wales. Department of Health and Welsh Office, 1995.
9 Department of Health. *Genetics and cancer services*. Report of a Working Group for the Department of Health, 1998.
10 Lerman C, Narod S, Schulman K, *et al.* BRCA1 testing in families with hereditary breast-ovarian cancer: a prospective study of patient decision making and outcomes. *JAMA* 1996;**275**:1885-92.
11 Alagna SW, Morokoff PJ, Bevett JM, Reddy DM. Performance of breast self-examination by women at high risk for breast cancer. *Women's Health* 1987;**12**:29-46.
12 Kash KM, Holland JC, Halper MS, Miller DG. Psychological distress and surveillance behaviours of women with a family history of breast cancer. *J Natl Cancer Inst* 1992;**84**:24-30.
13 Evans DG, Burnell LD, Hopwood P, *et al.* Perception of risk in women with a family history of breast cancer. *Br J Cancer* 1993;**67**:612-14.
14 Julian-Reynier C, Eisinger F, Chabal F, *et al.* Cancer genetics clinics: target populations and consultees' expectations. *Eur J Cancer* 1996;**32**:398-403.
15 Richards MPM, Hallowell N, Green JM, *et al.* Counseling families with hereditary breast and ovarian cancer: a psychosocial perspective. *J Genet Couns* 1995;**4**:219-33.
16 Spielberger CD. *Manual of the State-Trait anxiety inventory.* Palo Alto, CA: Consulting Psychologists Press, 1983.
17 Lerman C, Trock B, Rimer BK, *et al.* Psychological and behavioural implications of abnormal mammograms. *Ann Intern Med* 1991;**114**:657-61.
18 Lerman C, Trock B, Rimer BK, *et al.* Psychological side effects of breast cancer screening. *Health Psychol* 1991;**10**: 259-67.
19 Lerman C, Schwartz M. Adherence and psychological adjustment among women at high risk for breast cancer. *Breast Cancer Res Treat* 1993;**28**:145-55.
20 Kessler S, Field T, Worth L, Mosbarger, H. Attitudes of persons at risk for Huntington disease toward predictive testing. *Am J Med Genet* 1987;**26**:259-70.
21 Markel DS, Young AB, Penney JB. At-risk persons' attitudes toward presymptomatic and prenatal testing of Huntington disease in Michigan. *Am J Med Genet* 1987;**26**:295-305.
22 Mastromauro C, Myers RH, Berkman, B. Attitudes towards presymptomatic testing in Huntington disease. *Am J Med Genet* 1987;**26**:271-82.
23 Lynch HT, Watson P, Conway TA, *et al.* DNA screening for breast/ovarian cancer susceptibility based on linked markers: a family study. *Arch Intern Med* 1993;**153**:1979-87.
24 Codori A, Slavney PR, Young C, *et al.* Predictors of psychological adjustment to genetic testing. *Health Psychol* 1997;**16**:36-50.
25 Lerman C, Hanjani P, Caputo C, *et al.* Telephone counseling improves adherence to colposcopy among lower-income minority women. *J Clin Oncol* 1992;**10**:330-3.
26 Lerman C, Ross E, Boyce A, *et al.* The impact of mailing psychoeducational materials to women with abnormal mammograms. *Am J Public Health* 1992;**82**:729-30.
27 Hallowell N, Murton F, Statham H, *et al.* Women's need for information before attending genetic counselling for familial breast or ovarian cancer: a questionnaire, interview, and observational study. *BMJ* 1997;**314**:281-3.
28 Josten DM, Evans AM, Love RR. The cancer prevention clinic: a service program for cancer-prone families. *J Psychosoc Oncol* 1996;**3**:5-20.