Family history of breast cancer: what do women understand and recall about their genetic risk?

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Abstract

The current study has two aims: (1) to look at people's recall of risk information after genetic counselling and (2) to determine the impact of receiving an audiotape of the genetic consultation on level of recall, cancer related worry, and women's uptake of risk management methods.

Using a prospective randomised controlled design, subjects receiving an audiotape were compared with a standard consultation group. Participants were drawn from attenders at the genetic clinics of two London hospitals and included 115 women with a family history of breast cancer.

Assessment of perceived genetic risk, mental health, cancer worry, and health behaviour was made before counselling at the clinic (baseline) and by postal follow up. Usefulness of audiotapes and satisfaction with the clinical service was assessed by study specific measures.

The data indicate that cancer worry is reduced by provision of an audiotape of the genetic consultation. Recall of the genetic risk figure, however, is not affected by provision of an audiotape and neither is it related to women's overall perception of being more or less at risk of breast cancer than the average woman. Forty-one per cent of women accurately recalled their personal risk of breast cancer at one month follow up; however, 25% overestimated, 11% underestimated, and 23% could not remember or did not know their breast cancer risk. Recall of the risk figure is more accurate when the clinical geneticist has given this to the woman as an odds ratio rather than in other formats. Subsequent health behaviour is unaffected by whether women have an audiotape record of their genetic consultation.

Results suggest that having a precise risk figure may be less important than women taking away from the consultation an impression that something can be offered to help them manage that risk. Provision of an audiotape of the consultation is of limited usefulness. The need for psychological care to be better integrated into genetic counselling at cancer family clinics was highlighted by the study. The results are discussed in terms of future service development.

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Recent advances in cancer genetics, including the cloning of breast cancer predisposition genes,¹⁻³ have contributed to the expansion of genetic counselling services for women with a family history of the disease. Along with this service expansion comes a need to understand how genetic counselling impacts on women in terms of their knowledge of genetic risk, breast cancer worries, and benefits to their health.

Current practice in cancer family clinics is to provide genetic risk information in a numerical format, either as a risk of developing the disease per year or risk by a certain age. The risk estimate is often given as a percentage or a "1 in x" odds ratio. In order to benefit from genetic counselling, women need to understand and feel able to use the information given. As this is often complex, the ability of women to understand and make optimal use of genetic risk figures has been questioned.⁴ This is important to clarify as lack of understanding by patients will impact on their ability to use information when making decisions about future management of their health and may affect their mental health through cancer related worry.

Genetic risk information

Genetic risk information can be expressed as annual percentage risk or relative risk, lifetime risk, or proportion of risk by a specific age, as a probability figure, a percentage figure, or a more general category such as high, medium, or low risk. It has been suggested that the qualitative aspect of risk is more important than the quantitative and that patients are "... bad at probabilistic reasoning and find quantitative estimates difficult to understand".⁵ Parsons and Atkinson,⁶ examining lay perceptions in families with Duchenne muscular dystrophy, noted that "... even if they retained some notion of mathematical probability" families had "translated their risk liability into...more elementary categories". These findings contrast with those of Josten *et al*,⁷ reporting that people say a number gives them "...boundaries rather than having an ambiguous sense of being high risk". Some people express a wish only to know if they fall into a high, moderate, or low risk category; however, it is unclear what these mean to them.⁸

Data from women attending cancer family clinics indicate that the majority are unable to recall accurately the figure for their annual percentage chance of developing breast cancer.⁹ They are better at providing feedback on their lifetime risk but even in this case a substantial minority give an incorrect figure.¹⁰

These findings indicate a need to investigate methods of genetic risk information delivery in

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order to ensure that people are able to make use of the service offered and to clarify the optimal method of information giving to those attending cancer family clinics.

Audiotape medical consultations

There is a substantial body of publications relating to patients' ability to absorb and recall information from medical consultations¹¹ and several approaches have been adopted to improve communication. One method involves the provision of an audiotape of the consultation. North *et al*¹² found that audiotapes of consultations improve patients' recall of information and reduce subsequent anxiety. Hogbin *et al*¹³ showed that breast cancer patients who take away an audiotape of their consultation and make reference to it during the period before breast surgery have a better understanding of treatment and make fewer postoperative visits. However, it should not be assumed that the provision of an audiotape will assuage anxiety or clarify understanding of genetic risk. To date, the benefits of providing an audiotape to people attending for genetic cancer risk assessment has not been investigated.

The current study has two aims: (1) to look at people's recall of risk information after genetic counselling and (2) to determine the impact of an audiotape on level of recall, cancer related worry, and women's uptake of risk management methods.

Methods

PARTICIPANTS

A consecutive series of 135 women who were first time attenders at the cancer family clinics of two London hospitals (Royal Marsden, Sutton and London, and St George's Hospitals) was invited to participate. Of these, 18 refused and two were missed because of the logistics of clinic organisation, giving a total of 115. All were referred for genetic counselling and had the standard consultation with a clinical geneticist, which included a pedigree based risk calculation and information regarding management options appropriate to their level of cancer risk. All attenders were routinely offered instruction on breast self-examination and clinical examination as part of the standard consultation.

Inclusion criteria for the study were: a family history of breast cancer, first visit to the genetic clinic, never having been clinically affected with cancer, no known mental illness, age 18 years or over.

PROCEDURE

A prospective controlled design was used with participants randomised at the clinic immediately after counselling to standard consultation plus audiotape or standard consultation only. All women received a follow up summary letter of their consultation. Women were invited to participate in this randomised study at the time of their clinic appointment and were assessed (by the study psychologists VD and MP) before the genetic consultation. All randomisations were performed immediately after the consultation to minimise bias, and in this way

neither the participants nor the clinical geneticists were aware, during the consultation, which of the women would be taking away an audiotape afterwards. All consultations were taped for later analysis. Following written informed consent, assessment was made by self-administered questionnaires given before genetic counselling (baseline) and by postal readministration at one and six months follow up. The study was approved by the local ethical committees.

MEASURES

Standardised instruments were used and focused on four areas: (1) mental health and cancer worry, (2) evaluation of risk perception, (3) evaluation of perceived benefits of the clinic and audiotapes where provided, and (4) uptake of methods of breast cancer detection and prevention.

Mental health

General Health Questionnaire - GHQ12 (baseline, one and six months follow up) is a 12 item measure for detecting psychiatric disorder in non-psychiatric clinical settings,¹⁴ which has been successfully used in studies of cancer genetic counselling.⁹ Scores are calculated as described in the user's manual, a score of 3 or more being defined as a "psychological case".

Cancer Worry Scale (baseline, one and six months follow up). This provides a well validated measure with reference population norms and assesses concerns about developing cancer and impact of cancer worry on daily functioning.^{15 16} Scores range from 6 to 24; no clinical case cut offs are derived.

Genetic risk evaluation

Relative risk (baseline and one month follow up). Derived from Kash *et al*,¹⁷ this assesses perception of breast/ovarian cancer risk relative to the whole population of women (a 5 point scale ranging from "very much lower" to "very much higher" than the average woman).

Risk questionnaire (one month follow up) is based on the content of the genetic consultations. Participants indicated whether they were given genetic information on specific predefined dimensions and then rated whether they found it useful. Ratings were made in relation to: (1) population risk, (2) chance of breast cancer gene in family based on pedigree, (3) individual lifetime risk of breast (or ovarian) cancer, (4) risk of developing disease before age 50, (5) risk of not developing disease before age 50, (6) risk of developing disease over next five years. They were asked to state their actual risk figure provided by the clinical geneticist in the consultation.

Clinic evaluation (one month follow up)

This in house scale assesses satisfaction with the consultation, covering benefits or otherwise of attendance. The four point rating scales assess reassurance derived from attendance, and the extent to which information given was helpful or worrying. At baseline, participants were asked their reasons for attending the clinic.

Audiotape feedback questionnaire (one and six months). Derived from Hogbin *et al.*,¹³ this assesses whether participants have listened to the audiotape, how often, and with whom. The helpfulness of the audiotape is rated using a visual analogue scale. Participants were asked to indicate who had listened to the tape. Finally, they were asked which type of report they would prefer as a summary of their consultation (that is, audiotape, letter, both, neither); space was provided for additional comments.

Medical management uptake (six month follow up)

Uptake of cancer detection and prevention methods was assessed and included mammography, breast examination (both self and clinical), cervical smears and other screenings, prophylactic surgery (ovaries or breasts), and whether they take Tamoxifen.

METHOD OF ANALYSIS

Analysis of tapes

Items were coded (M Wade) indicating presence/absence of the information and risk figures on the categories described in the risk questionnaire above. Inter-rater reliability was reviewed initially on a randomly selected 20% of the audiotapes by a second independent investigator (M Watson). Differences in ratings were resolved using a consensus agreement methodology, thereby allowing values for risk information to be subsequently assigned along the dimensions described. Having allocated all the genetic risk information to the above categories, it was then possible to make comparisons between the information given by the clinical geneticist recorded on the audiotape and the information reported by participants in the questionnaire. Participants' responses were rated as accurate if they matched the information provided by the clinical geneticist. (Where women were given both a lifetime risk figure and a risk before age 50, and when determining accuracy between risk figure given and risk figure recalled, either lifetime or before age 50 risk figures were accepted as accurate.) Risk figures were accepted in any of three forms, odds ratio, percentage, or description in words. Only equivalent figures or descriptions were rated as accurate.

Statistical method

The analysis was confined to 107 patients (56 cases, 51 controls) who had returned at least one of the follow up questionnaires (one or six months or both). GHQ12 scores were skewed towards zero and the Cancer Worry Scale was slightly skewed towards the lower end of the scale ($p < 0.01$ on the Shapiro-Wilk test). Therefore, non-parametric statistics were used throughout. Means and 95% confidence intervals were used to illustrate the changes in the cancer worry scores over time. The precounseling characteristics of the participants in the two groups (cases *v* controls) were tabulated and compared using Mann-Whitney (binary variables) or Kruskal-Wallis tests (other categorical variables).

Changes in GHQ12 and Cancer Worry scores from their baseline values were calculated for each patient and at each time (one month and six months) and were assessed using the Wilcoxon signed rank test. Comparison between the treatment groups was done using the Mann-Whitney test.

Participants completed a risk questionnaire reporting their recall of the consultation and accuracy was determined by comparison with the audiotape. For each item of risk information, false positive (and false negative) rates were defined as the number of patients who indicated that they had (had not) been given that information whereas in fact it had not (had) been given. Participants rated the usefulness of each item of risk information and differences were assessed by the Mann-Whitney test. Data were analysed on an intention to treat basis.

It was predicted that (1) recall of genetic risk information would be more accurate in those given an audiotape (cases) relative to those in the standard consultation group (controls); (2) cancer worry would be lower in those given an audiotape relative to controls; and (3) uptake of risk management methods (for example, screening) would be improved in cases compared to controls.

Results

Of the 115 participants (60 cases, 55 controls) there was attrition in eight at the one month follow up; five failed to reply and three declined further participation (total of 107 (93%), 56 cases and 51 controls). The analysis, including the baseline comparison, was carried out on these 107 patients. At six months, 91 participants (79%) had completed both of the follow up questionnaires (48 cases, 43 controls). Eight participants returned just the one month questionnaire and another eight just the six month questionnaire.

At baseline there were no differences between cases and controls for mental health ($p = 0.7$ for GHQ12; $p = 0.9$ for Cancer Worry Scale), age, marital status, or social class; however, those from the Royal Marsden Hospital were marginally younger (median 37, range 28-56) than those from St George's Hospital (median 41, range 23-71, $p = 0.06$).

MENTAL HEALTH

Whole sample

For the groups combined (cases and controls), the GHQ median score was 1 (range 0-11). Thirty-six participants (33.6%) had a score indicating a clinically significant level of psychological morbidity (GHQ12 > 3) at baseline with equal numbers in each group. For the one and six month follow ups, there were 31 participants on each occasion scoring within the clinical range on the GHQ (12 cases, 19 controls at one month; 15 cases, 16 controls at six months).

For both groups, cancer worry median scores at baseline were 11 (range 6-22, CI=10-12 for cases and CI=10-11 for controls; mean 11.14 (SD 3.23) for cases and mean 11.39 (SD 3.37) for controls). Royal Marsden

Table 1 Changes from baseline in cancer worry for cases and controls

		One month				Six months			
		Worse	Same	Improved	p value	Worse	Same	Improved	p value
(1) How often have you thought about your chances of getting cancer?	Case	8	23	21	0.02	4	26	21	<0.001
	Control	9	24	14	0.4	9	19	19	0.1
(2) Have these thoughts affected your mood?	Case	5	31	16	0.03	7	32	13	0.3
	Control	8	27	12	0.5	6	29	12	0.2
(3) Have these thoughts interfered with ability to do daily activities?	Case	1	45	6	0.1	4	42	6	0.8
	Control	4	40	3	1.0	3	41	3	1.0
(4) How concerned are you about the possibility of getting cancer one day?	Case	6	28	18	0.02	7	23	22	0.008
	Control	6	31	10	0.5	8	23	16	0.2
(5) How often do you worry about developing cancer?	Case	5	34	13	0.1	3	41	8	0.2
	Control	5	36	6	1.0	7	33	7	1.0
(6) How much of a problem is this worry?	Case	7	33	12	0.4	4	34	14	0.3
	Control	7	28	12	0.4	8	27	12	0.5

Hospital patients had higher levels of cancer worry at baseline (median 11, range 8-22) than those attending St George's Hospital (median 10, range 6-19). They thought about their chances of developing cancer more often ($p=0.02$), were more concerned ($p=0.006$), and more worried ($p=0.001$).

Case-control comparisons

There were no significant changes in GHQ scores among time points in cases or controls and there were no significant differences between the two groups (one month $p=0.1$, six months $p=0.3$). No differences were found between participants at both follow ups according to doctor seen or hospital attended. This lack of differences between cases and controls is unsurprising; the GHQ is a measure of general psychiatric morbidity which does not aim to pick up specific cancer worry.

Cancer worry scores fell in patients given a tape of their consultation (cases) from a median of 11 at baseline to 10 at one month (CI=9-10.7, mean 10.45, SD 3.30, $p=0.002$) and to 9 at six months (CI=9-10, mean 10.18, SD 2.86, $p=0.003$). This was independent of how often patients had listened to their tape ($p=0.6$). There was no effect of hospital or doctor seen on cancer worry scores.

When items of the Cancer Worry Scale were analysed individually, results indicated significant improvements for cases in (1) how often they thought about their chances of getting cancer (one month $p=0.02$, six months $p<0.001$), (2) if these thoughts affected their mood (one month $p=0.03$), (3) how concerned they are about the possibility of getting cancer (one month $p=0.02$, six months $p=0.008$), (4) how much of a problem the worry is (six months $p=0.03$) (table 1). There were no significant improvements for controls.

There was a significant difference between cases and controls at the one month follow up; 19% of controls indicated that they "frequently worried about cancer" compared to 12% of cases ($p=0.03$). At baseline there was a correlation between cancer worry and risk perception in cases ($p=0.02$) and marginally significant correlation between GHQ and risk perception, but this was not observed in controls ($p=0.1$). Risk perception in this instance was assessed using a five point scale ranging from "much lower than average" to "much higher than average". Cancer worry was

correlated, after consultation, with perceived risk; lower perceived risk was associated with lower cancer worry in both groups ($p=0.02$ cases and $p=0.05$ controls).

RISK PERCEPTION

Accuracy of recall

Recall of risk information was assessed at one month follow up; 37/90 women (41%) accurately recalled their risk of developing cancer, 22 (25%) overestimated, 10 underestimated (11%), and 21 women (23%) did not know/did not remember their risk figure. There was no significant relationship between recalled risk figure and their rating of risk, relative to the average woman, either at baseline ($p=0.8$) or at one month follow up ($p=0.1$). This suggests that the risk figure, regardless of accuracy, does not reflect their more general view about risk compared to the average woman. There was no significant difference in accuracy of recall of risk figure at one month follow up between cases and controls ($p=0.4$).

The issue was examined of whether the format in which risk information is given impacts on recall. Risk figure given as an odds ratio was compared with risk given in any other format (for example, a percentage or in descriptive terms). When given as an odds ratio, 22 (71%) women were accurate in their recall compared to 15 (25%) where risk was given in other formats ($p<0.006$) (table 2). Comparisons for the groups separately indicated that 85% of cases and 61% of controls were accurate in their recall where risk was given as an odds ratio. When given in other formats (59 women), 29% of cases and 20% of controls were accurate. Recall is significantly more accurate ($p<0.0005$) when risk is given as an odds ratio rather than in other formats.

The number of women overestimating their risk ($n=22$) was significantly greater if the figure was given in formats other than odds ratio (two (7%), odds ratio; 20 (34%), other formats; $p=0.009$). Fifty-four cases indicated whether they listened to the tape of their consultation. Of these, 40 participants listened to the tape between one and four (median 1) times. Recall accuracy was not significantly better in those cases who referred to the tape when answering the questionnaire ($p=0.15$). Additionally, accuracy of recall was not influenced by the number of times that the participants listened to the tape ($p=0.5$).

Table 2 Accuracy of risk recall according to format

Risk figure given as	Underestimate	Correct recall	Overestimate	No reply/no recall
1 in ... chance	4 14%	22 79%	2 7%	0
% chance	0	4 44%	3 33%	2 22%
Range of figures	3 11%	5 19%	13 48%	6 22%
Comparative	3 21%	3 21%	2 14%	6 43%
Multiple methods	0	3 33%	2 22%	4 44%

Participants given a risk figure as a 1 in ... chance are more likely to recall a risk figure ($p=0.001$) and that figure is more likely to be accurate ($p=0.006$) than those given another type of risk figure.

Risk recall

Specific items of genetic information were examined to determine accuracy of recall. Participants indicated whether they had been given information on each of the dimensions of risk described. For each item of risk information rated, the overall reporting of whether or not they had been given this information was fairly accurate for both groups. More cases than controls were able to remember correctly whether they had been given information on risk before age 50 (64% *v* 42%, respectively, $p<0.05$). Some participants recalled having been given information which they did not get (that is, false positives).

For population risk, risk of gene in family, and lifetime risk, there were 10, 7, and 13% false positive responses, respectively, and no differences between the groups. For the remaining items of risk information (risk before age 50, risk of no cancer before age 50, risk of cancer in next five years), the false positive rates were higher with 39, 65, and 60%, respectively. There were no other significant differences between groups.

Usefulness of risk information

Participants rated usefulness of information on a visual analogue scale (0=not useful, 10=very useful), regardless of whether this information had actually been given. As there were no differences between the groups, cases and controls were combined (the only exception being that cases rated the information on their chance of cancer before age 50 as more useful than controls, $p<0.01$). Average ratings were high (table 3) ranging from 8.5 for population risk to 9.1 for risk of gene in family. Items 2, 3, and 4 (risk of gene in family, lifetime risk, risk before age 50, respectively) were rated as significantly more useful than items 1, 5, and 6 (population risk, risk of no cancer by age 50, risk of disease over next five years). When ratings of usefulness of information were examined for those questions where the information

was given to a majority of patients, the pattern was the same as the whole group.

EVALUATION OF CLINIC AND AUDIOTAPES

How helpful, reassuring, or worrying was the risk information?

Thirty-seven (35%) clinic attenders found the information about their risk of cancer extremely reassuring, 36 (34%) moderately, 26 (25%) somewhat reassuring, and seven (7%) found the information not at all reassuring. There was no difference between cases and controls for how reassuring they thought the information about cancer risk ($p=0.5$). Fifty-seven women (53%) found the risk consultation extremely helpful, 29 (27%) moderately, 18 (17%) somewhat helpful, and three (3%) not at all helpful, and there were no case/control differences ($p=0.5$). Thirty-five percent of women found the risk information was not at all worrying, 35 (33%) found it somewhat worrying, 21 (20%) moderately, and 14 (13%) found the information extremely worrying. There were no case/control differences ($p=0.25$).

Benefits

An open ended question asked for brief comments about the benefits of attending and the most common response was to get reassurance/peace of mind (23%). The clinic was perceived as informative (17%) and useful (17%). Some women felt reassured because they were told their risk was lower than expected (14%), some because they could better understand the possibility of developing cancer (11%), and others found it beneficial to be taught how to examine their breasts (9%). Some appreciated the opportunity to be clinically examined (5%).

Audiotope rating

The audiotape was rated (by cases) on a visual analogue scale (0=not very helpful; 10=extremely helpful) with a median score of 8.35 (range 0.2-10). Eight women indicated that it was helpful to have a tape to listen to afterwards because they found the information in the consultation to be complicated and difficult to absorb at once. Five participants indicated that it was useful in clarifying what the doctor had said, and four found it reassuring. Three women said the tape reinforced their memory of the visit and the advice given. The fact that it could help to explain to relatives, and that it is personal and you can play it in the future were also mentioned.

When those receiving an audiotape were asked to indicate which type of report they preferred as a summary of their consultation, 44% preferred a letter, the most common comments

Table 3 Usefulness of risk information on visual analogue scale (0 not useful - 10 very useful)

	Median	95% CI for median
(1) Population risk	8.5	7.9-8.9
(2) Risk of gene in family	9.1	8.9-9.4
(3) Lifetime risk	8.8	8.5-9.2
(4) Risk by age 50	8.9	8.7-9.2
(5) Chance of no cancer by age 50	8.8	7.6-9.1
(6) Risk of cancer in the next 5 years	8.6	7.9-9.0

The risk of having a gene in the family was rated more useful than the population risk ($p=0.001$), the chance of not getting cancer by age 50 ($p=0.009$), and the risk of developing cancer in the next five years ($p=0.008$).

Knowing the population risk was rated less useful than knowing a lifetime risk ($p=0.04$) or knowing the risk by age 50 ($p=0.04$).

All other comparisons were non-significant ($p>0.05$).

being that it is simpler to refer to (four women) and easier to file (two women). Thirty-nine percent of women preferred to have both audiotape and letter; nine of them said the tape is an accurate and detailed record, helpful because you do not absorb everything at the consultation, and the letter is a good overview. Some insisted that a tape is more human/personal and a letter is for medical use and quick for referring to. Fifteen percent preferred only a tape, rating it as more convenient and less impersonal. When asked if they had listened to the tape with anyone else, 31 women had listened alone, 10 with someone else (six with partner), and 15 did not reply to this question.

MEDICAL MANAGEMENT UPTAKE

Thirty-two (35%) and 49 (50%) women reported being given a clinical breast examination by the one and six month follow up, respectively. The figures for mammograms were 12 (13%) and 19 (20%) and there was an increase from three to six women for other screenings. No cases of prophylactic surgery were reported. Two women were on Tamoxifen. These results are limited by the brief period of follow up in the study.

There was no significant correlation between cancer worry change scores and either level of breast clinical examination ($p=0.8$) or mammography ($p=0.8$) in the intervening period and no differences between cases and controls for rate of breast self-examination, examination of breasts by a doctor, or mammography at the six month follow up. There were also no differences between the groups for other health behaviours (for example, other screenings, diet) which were unaffected by whether or not the woman had been given an audiotape of the consultation to keep.

OTHER RESULTS

Reasons for attending

The most common response was that a close relative had cancer or had died from cancer (60%). The second most common was that they were referred by a doctor (17%). Five women (6%) emphasised fear of getting cancer, five (6%) their knowledge of being at risk, and four (5%) reported the main reason for attending was to be screened/checked. One woman stated that she wanted to make decisions about fertility treatment and another to decide whether to take Tamoxifen.

Discussion

The primary hypothesis, that providing an audiotape of the consultation would lower cancer related worry, improve recall of risk information, and facilitate uptake of methods of managing their risk, was confirmed in the former but not in the latter two. Level of recall of genetic risk indicated that the audiotapes had little impact. In addition, more than half of the whole sample was inaccurate in recalling their risk figure or could not remember what they had been told. A number of women reported receiving information which was not given and, in some cases, rated this as useful. This was less likely to happen for some items of

information than others, for example, 91% correctly recalled the information about the risk of a gene in the family. Only risk of cancer by age 50 was differentially reported depending on whether an audiotape was available, with a greater accuracy in those who received, and listened to, the tape. This suggests that some changes are needed in the type of information being given within genetic consultations. Perhaps the amount of statistical information given could be tailored to the requirements of individual patients. The assumption on the part of the doctors is that patients attending require particular statistics about risk. The evidence from this study suggests that the purpose of the consultation for the patient and for the doctor may not be the same.

In relation to method of presenting a risk figure, the data indicate that an odds ratio is more likely to be accurately recalled than information in other formats. Interpretation of this requires caution; better recall does not necessarily mean better understanding. Women were asked not only to recall the risk figure, but also to rate what they thought their risk was of developing breast and ovarian cancer relative to the average woman. The data indicate that this rating of breast/ovarian cancer risk correlated poorly with the recalled risk figure. There may be a number of explanations. Women may not find these risk figures very meaningful, or they may have well entrenched beliefs about breast/ovarian cancer risk which remain unchanged by genetic counselling. Perhaps this information is less salient to them than the need for reassurance that the health system will support them through appropriate screening; 50% had their breasts examined for lumps during the intervening six month period. One fifth had received a mammogram in this relatively young sample (mean age 40), many of whom would be under the age limit for the UK national mammography programme. Being able to regurgitate a risk figure accurately should not be taken as proof that the person has incorporated that information into their belief about whether they are more or less at risk of cancer. It seems likely from these data that the genetic consultation has little impact on these beliefs. It may simply be that the statistics are irrelevant to these women when all they want is to have health checks which they hope will provide some measure of reassurance that they have not got breast or ovarian cancer.

The results for mental health indicate that the benefit of an audiotape can be seen in the lower scores for cancer worry at each of the follow up assessments. Specific analysis of the items on the Cancer Worry Scale indicate that controls were more often worried about cancer at the one month follow up.

More general psychological morbidity (GHQ) was unchanged by the genetic counselling or the availability of the audiotape and this is consistent with results reported elsewhere.⁹ Scores for general psychological morbidity were quite high; one third reached GHQ criteria for "caseness" and this was consistent across assessments. This suggests that genetic clinics

may be picking up more generally anxious women and this characteristic is not changed by the brief intervention of a single genetic consultation or the introduction of an audiotape for post-consultation use. Lerman *et al*¹⁵ and Kash *et al*¹⁷ have also observed similar high levels of psychological morbidity in women attending for cancer genetic counselling. Kash¹⁸ suggests that some anxiety may be necessary to optimise and motivate engagement in genetic counselling. Data from the present study show that cancer worry was significantly associated in both groups with greater perceived risk of cancer regardless of actual risk. There was a strong correlation between the change in clients' risk perception and the change in their worry following consultation. If they now think they are less likely to get cancer than previously assumed, they worry about it less. In trying to explain the impact of the tape upon subsequent specific cancer worry, it is interesting to note that a substantial number of women who did not receive the tape (that is, controls) and were later offered this at the end of the study opted to have a tape. One possibility is that these rather worried women require regular reassurance and may feel that as long as they have a tape they can use it for this purpose regardless of whether or not they actually do so.

There was no association between cancer worry and uptake of screening mammography and clinical breast examination, but this may be limited by the short follow up (six months) and the fact that various factors other than a woman's worry may influence whether or not she receives, demands, or is offered this care.

The provision of an audiotape had no impact on subsequent rates of breast self-examination. This appears to confirm the observation that other more complex psychological factors and beliefs may be more important determinants of this behaviour. This needs further investigation. Although self-examination is considered of unproven efficacy in reducing deaths from breast cancer, it is one of the few things that women can do for themselves and it is important to understand how risk perception and genetic counselling impact on this behaviour.

Overall, participants were satisfied with the service offered in the genetic clinic; the highly dissatisfied were a tiny minority. The audiotape was well received; however, recall of risk was not improved by tape provision. A few had listened with someone else and this sharing of information may provide some reassurance. In terms of future service provision, a useful rule of thumb might be that, as it appears to do no harm and may help with worries, people might be offered this option and be allowed to exercise choice. One or two provisos are relevant here. For instance, consultations can cover sensitive issues other than the assessment of cancer risk and family history of disease (for example, paternity issues) which patients may choose not to have recorded and these would need to be excluded from the recordings. The issue of providing a taped or written record of the genetic consultation which might be passed to other family members raises the thorny problem that genetic counselling by proxy may

be occurring. In the present study this applied to a minority of cases with only four women listening to their tape with someone other than their partner. Nevertheless, this may be less than ideal as family members who may share a genetic predisposition should have a full and complete risk assessment with the opportunity to ask questions of the clinical geneticist, rather than getting this information second hand. The option to have an audiotape should remain with the patient; however, the clinical geneticist may want to make explicit that this should not replace the need for a personal consultation for other family members who want information about their own genetic risk.

The data on risk recall are consistent with a number of studies^{9 10 19} which indicate that women are often inaccurate in their recall of risk figures despite receiving genetic counselling. Perhaps having precise figures about risk is less important to patients than their taking away from the clinic a general perception of risk and an impression that a system is in place to help manage their risk. The study suggests that further research is needed to clarify the role of clinical genetics in management of women at increased risk because of family history if the provision of risk information has little impact on their beliefs and health related behaviour. These results also point to the need for genetic counselling clinics to be well integrated with cancer screening services, as it is likely to be the latter which women want.

Where women continue to hold the irrational belief that they are at high risk, despite genetic counselling indicating the contrary, this suggests that the service needs to attend to the psychological needs of these women. If the disproportionate cancer worries are not addressed, these women are likely to turn up elsewhere in the health care system requesting unnecessary screening services.

The general impression from the present study is that a substantial minority of clinic attenders are very anxious women for whom psychological counselling might be helpful. The issue of whether cancer family clinics are currently appropriately resourced to deal with the mental health needs of attenders needs to be examined.

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