ELECTRONIC LETTER

Women's preferences and consultants' communication of risk in consultations about familial breast cancer: impact on patient outcomes

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J Med Genet 2003;**40**:e56(http://www.jmedgenet.com/cgi/content/full/40/5/e56)

The risk information to be conveyed as part of expert counselling of women at increased risk for breast cancer potentially impacts on decision making about screening, prophylactic strategies, and psychological adjustment. Australian geneticists and genetic counsellors working in cancer genetics nominated risk counselling as the central feature of their work.[1] Also, women attending genetic counselling expect to discuss their own and other family members' risk.[2–6]

However, studies have consistently reported high levels of inaccurate risk perception in women at high risk, even after counselling, suggesting that risk counselling as currently practised in not optimal.[7–10]

The information to be conveyed about risk related to breast cancer is exceedingly complex. Statistics commonly presented to patients include population and individual risk, not only for breast cancer, but also for other cancers associated with *BRCA1* and *BRCA2* mutations, for example, ovarian cancer. Risk may be presented separately for different age groups, for men, and for those with an Ashkenazi Jewish background (which conveys a higher risk). The proportion of population risk attributable to germline mutations may be presented. Risk may be given for an unaffected person's chance of developing breast cancer, or for an affected person's chance of developing a second cancer. The risk estimate may apply to the next five years, the next 10 years, or to a lifetime. The probability that a family may have a germline breast cancer susceptibility gene mutation may be raised. Finally, the risk estimates for cancer in proven mutation carriers (and their broad confidence intervals) may be discussed, and the chance of the mutation being found through testing. The multitude of risk statistics possibly presented (sometimes in several formats) has the potential to leave the patient confused and distressed.

Although previous studies have identified the type of information women with breast cancer want at diagnosis,[11–14] there are few data on what risk information women want in the setting of genetic counselling for familial breast cancer. There is also little consensus on the most effective way to communicate risk.[15] However, scientific publications do indicate that the way health care professionals frame clinical information can result in patients making different appraisals of risk and different decisions about future risk management.[16–19] Previous authors have identified as a research priority the detailed examination of communication of risk during genetic counselling and the evaluation of its impact on counsellees.[20 21]

This study explored how women wanted their risk of breast cancer or their risk of a gene mutation in a breast cancer predisposing gene to be described in their consultation. The authors undertook a detailed analysis of risk communication by audiotaping and transcribing verbatim how risk was communicated. We then compared women's preferences with what actually happened in the consultation and against measures such as accuracy of risk perception after counselling and satisfaction with counselling.

Key points

- The detailed examination of communication of risk during genetic counselling and the evaluation of its impact on counsellees has been identified as a research priority.
- This multicentre study documented (1) the process of communication of risk in genetic counselling in familial breast cancer, (2) women's preferences for risk communication, and (3) women's perception of risk. It then examined the influence of communication of risk on women's risk accuracy and satisfaction. In total, 109 unaffected and 84 affected women from 10 familial cancer clinics were included in the study. Participants completed self reported questionnaires two weeks before and four weeks after that initial consultation and the consultations were audiotaped, transcribed verbatim, and coded.
- There was no association between the way genetic risk was communicated and women's accuracy of risk recall or satisfaction with the consultation. Fifty per cent of unaffected women wanted their risk of breast cancer to be communicated in numbers alone, 41% preferred percentages, and 28% preferred proportions. A third of women wanted to know their lifetime risk of breast cancer and a third over the next 10 years. Women's risk accuracy increased from 50% at baseline to 70% after counselling. Baseline accuracy was significantly associated with educational level (p=0.02). Multivariate analysis showed that risk accuracy after counselling was significantly associated with marital status (p=0.01).
- Our findings suggest that risk is a difficult concept to grasp, that women vary in their preferences for ways of hearing risk, and that it may be important to spend time in the consultation exploring women's understanding of risk in different contexts and formats.

We were interested in determining what factors influenced the accuracy of risk perception. In earlier studies, overestimating the risk of breast cancer was associated with being white, employed outside the home, and being married in one study.[22] Another study found that older women were less likely to overestimate risk[23]; however, Cull *et al* found that older women and those with a higher trait anxiety overestimated their risk.[24]

Abbreviations: MRC, Australian Medical Research Council; NH, Australian National Health

In other studies, awareness of increased risk was associated with educational level,[25 26] being white,[23 25 26] and the number of relatives diagnosed with breast cancer.[8] Bluman *et al*[8] found that neither interest in testing nor time since most recent cancer diagnosis was associated with overestimation of risk.

Communication factors associated with risk perception have been less commonly explored. Some studies have suggested that the number and format of risk figures given have influence on the accuracy of the risk.[27–29] Framing, which has been found to be influential in the clinical context,[30 31] is not relevant here as risk is almost always framed in terms of having a mutation or developing cancer.

It was hypothesised that at baseline, accuracy of risk perception would be positively associated with age,[23] educational level,[25 26] occupation,[23] and breast cancer burden.[22 24 26]

It was also hypothesised that (1) the more risk figures were given to a woman, the less accurate her risk perception would be[27–29]; (2) that if a woman received her risk estimate in her preferred format, that is, words or numbers or both words and numbers, her satisfaction would be higher and her risk recall would be more accurate[32 33]; and (3) that if a woman was told her risk in both words and numbers, her recall would be more accurate.[34–36]

SUBJECTS AND METHODS

Consecutive women attending any one of 10 familial cancer clinics in four Australian States (New South Wales, Victoria, South Australia, and Queensland) were invited to participate in the study. Quota sampling was used to ensure that the sample consisted of equal numbers of affected and unaffected women. Women were considered ineligible for participation if they were unable to give informed consent, that is, if they were younger than 18 years or showed evidence of a severe mental illness. Women with limited literacy in English were also excluded because data collection was based on a self-administered questionnaire. Participants were advised that there were no financial incentives or other benefits associated with involvement in the study.

Procedure

This study is one component of a larger randomised controlled trial of providing women with an audiotape of their genetic counselling consultation.[37] Staff at each of the participating familial cancer clinics invited women to participate in the study when they telephoned to make their appointment. Women were subsequently telephoned by the central research staff and given further information about the study. Questionnaires, consent forms, and reply paid envelopes were posted to consenting women by the coordinating research centre about two weeks before their appointment at the clinic. Their genetic counselling consultation was audiotaped. A follow up questionnaire was posted three weeks after counselling. Ethics approval from 10 different ethics committees responsible for each of the participating clinics was sought and obtained before data collection.

Measures

Demographic characteristics

Age, educational level, occupation, marital status, knowledge of medical terminology (medical or allied health training), number of biological children, and cancer burden (number of first and second degree relatives who had developed breast or ovarian cancer or who had died of the disease) were assessed at baseline.

Risk communication preferences

These questions were adapted from a previous study[11 12] that examined the communication preferences of women with early stage breast cancer for discussing differing risk formats in adjuvant therapy. Women were asked to indicate their preference for receiving risk figures for developing breast cancer in words or numbers, which number they preferred (percentages, proportions, gambling odds), whether they preferred absolute risk or relative risk, comparison with the general population, and which time based figures they wanted (lifetime, next five years, or 10 years).

Risk perception

Women were asked to estimate their risk of developing breast cancer over their lifetime by choosing between nine response options: 1 in 100 (1%), 1 in 25 (4%), 1 in 13 (8%), 1 in 16 (16%), 1 in 4 (25%), 1 in 3 (33%), 1 in 2 (50%), 2 in 3 (66%), or inevitable (100%). A decision was made to code women's risk accuracy within categories, as risk estimates vary widely and often only a risk category (for example, potentially high, moderate, or average) is given in the genetic counselling session. Participants' numerical estimate of lifetime risk was converted to a category according to the figures given in the Australian National Health (NH) and Medical Research Council (MRC) guidelines, for example, a potentially high risk category 25% to 80% lifetime risk of breast cancer; a moderate risk category 12% to 25%, and an average risk category 9% to 12%.[38]

To determine risk accuracy, women's lifetime risk assessment was compared with the objective risk figure or category given by the consultant during the counselling session (contained in the transcript of her counselling) or the follow up letter sent to her after her clinic visit. Clinicians assessed the risk figure from broad categories, based on family history, and defined in national clinical practice guidelines (NH and MRC).[38] These figures were constructed acknowledging the limitations of risk analysis, and based on data with very wide confidence intervals. Thus, standard methods such as the Gail model or Claus data are not commonly used in Australia, particularly in defining high risk.

Participants' responses were deemed accurate if their risk estimate fitted within the risk category given by the consultant. If a woman's perception of risk fell on a cut off point of categories (12% or 25%) they were deemed accurate if either of the categories in which they could be placed corresponded with that given by the consultant. This method would tend to increase the percentage of those deemed accurate compared with other methods. However, we thought that this was a more valid approach as it reflects the actual figures (or words) given in consultations that acknowledged the limitations of risk analysis based on data with very wide confidence intervals.

If women were inaccurate it was determined whether they had underestimated or overestimated their risk of breast cancer.

Follow up questionnaires

Discussion of risk

Women were asked to indicate if their risk of breast cancer, as counselled, was much higher, higher, the same, a little lower, or much lower than they had expected. They were also asked their approximate risk of developing breast cancer over their lifetime using the same method as at baseline.

Satisfaction with the genetic counselling session

Satisfaction was measured with a modified version of the 12 item short form of the 36 item "satisfaction with genetic counselling scale", developed by Shiloh *et al*.[39] This shorter version of the scale is highly correlated with the full scale ($r=0.90$) and has good reliability (Cronbach $\alpha=0.78$).

Other measures were included in the protocol (such as psychological status) but are not relevant to this paper.

Coding of transcripts of audiotapes

A detailed coding system and coding manual for the transcribed audiotapes was devised. The presence or absence

of categories of information about genetic risk that apply specifically to women from families potentially at high risk of breast or ovarian cancer was noted. These categories were derived from the NH and MRC guidelines, and a survey given to Australian clinical geneticists and genetic counsellors (if these differed from the guidelines) before the study.[1] The following coding categories were used for general and individual risk: (1) risk as a category, for example, potentially high, moderate, or average; (2) risk described in words, for example, small, quite a lot higher; (3) risk described as a percentage, for example, 50%; (4) as a proportion, for example, 1 in 12; (5) as gambling odds, for example, 12 to 1; and (6) within a time span, for example, lifetime, by age 50, next 10 years.

Other communication factors were coded in the consultation such as whether the consultant asked the woman her preferred risk format, summarised the information, and checked her understanding. These data are presented in a previously published paper exploring the tailoring of communication in familial breast cancer.[2]

Coding reliability

Three coders (including EL) were trained. Two coders recoded a random 10% of their own consultation transcripts and 10% of the other coder's consultation transcripts to determine reliability within and between raters. The average reliability within a rater for risk data was 99% (range 93–100%) and the average reliability between raters was 97% (range 94–100%).

Statistical methods

Descriptive statistics (frequencies, means, and medians) were used to summarise most of the data, including demographics. Frequencies were calculated for each risk communication component. Total scores for the predefined components of communication of risk were calculated by summing the component behaviours.

Univariate analyses (χ^2 and *t* tests) explored associations between consultants' communication of risk behaviours and patient outcomes of risk accuracy and satisfaction. Potential confounders including educational level, occupation, age, medical training, and the number of relatives diagnosed with cancer or who died after having cancer (cancer burden) were explored by determining their association with the outcome measures. All variables significant at $p \leqslant 0.25$ were included in multivariate linear or logistic analysis.[40]

RESULTS

Of the 231 women who met eligibility criteria, 11 declined participation and 27 did not attend their appointment. Of the 193 women remaining, 158 women completed baseline and follow up questionnaires, for whom there was an audible audiotape of their consultation for verbatim transcription. Preference results are reported for the full sample, although analyses of outcomes included only the 158 women with full data. As affected women were not routinely given a risk figure for the chances of a second breast cancer occurring, all analyses involving risk accuracy included only unaffected women (n=109). Demographics of unaffected (n=109) and affected women (n=84) recruited to the study are shown in table 1.

Table 1 Demographic characteristics of sample (n=193)

Category	Unaffected (%) (n=109)	Affected (%) (n=84)
Age (y):		
Mean (SD)	39.5 (9.4)	51.34 (11.1)
Range	19–69	28–79
Marital status:		
Married	73.1	76.5
Not married	24.8	23.5
Educational level:		
Year 10 or below	25.9	35.8
Year 12/HSC	16.7	19.8
TAFE	16.7	23.5
University	23.1	16.0
Postgraduate	17.6	4.9
Occupation:		
Manager/admin	8.3	10.1
Professional	30.6	20.3
Paraprofessional	19.4	20.3
Non-professional	41.7	49.3
Allied health trained:		
Yes	33.6	28.4
No	66.4	71.6
Children:		
Girls:		
No girls	47.7	27.9
⩾1	52.3	72.1
Boys:		
No boys	54.2	44.2
⩾1	45.8	55.9

Not all categories sum to 100 owing to missing data.

Women's preferences for communication of risk

Women's preferences for communication of risk before the clinic visit are summarised in table 2. No clear majority preference was found for communication of risk. Half of the unaffected women wanted their risk of breast or ovarian cancer communicated in numbers alone. Of unaffected women preferring their risk communicated in numbers, 41% preferred percentages and fewer women (28%) preferred proportions. Just over a third of women (35%) wanted to know their risk of developing breast cancer over an entire lifetime and a third over the next 10 years. Over half of affected women (54%) wanted to know their chance of developing a second cancer in both words and numbers.

When asked why they chose particular formats for communication of risk, women gave various reasons, again, with little consistency. Women who preferred words over numbers tended to find words less confronting. For example one woman said words were "less clinical". For other women, ease of understanding was important. One woman said "I am better able to understand words rather than numbers". Another woman stated that she chose percentages over proportions or gambling odds because "I understand percentages better".

Women also commented that "numbers are more precise than words", and that numbers "sound more accurate". A preference for 10 year risk seemed to be based on a need to know "immediate future prospects", whereas a preference for lifetime risk was seen as "less intrusive". One woman who preferred lifetime risk said "I wouldn't want to be counting time". Comparisons of risk with women in the general population, rather than other high risk women, were seen as being more positive. Women who chose both options presented often commented that they preferred "to know as much as I can" or "I want all the information".

Women's risk perceptions at baseline

According to NH and MRC guidelines, 60% of unaffected participants were categorised as potentially high risk, 31% as moderate risk, and 9% as average risk of developing breast cancer. At baseline, 50% of unaffected women estimated their risk accurately. Of the 50% of women who were inaccurate, 53% underestimated their risk and 47% overestimated it. In comparing themselves with other women with a similar family history, 67% of unaffected women perceived their risk to be about the same, 17% of women considering their risk to be higher and 16% lower.

Predictors of accuracy of risk estimates of unaffected women at baseline

Accuracy of risk perception for unaffected women at baseline was associated with level of education, with 67% of women

Table 2 Baseline risk communication preferences (n=193)

	Unaffected (%)* (n=109)	Affected (%)† (n=84)
Did women want their risk communicated in words or numbers?		
Words	22.1	17.9
Numbers	50.0	19.2
Words and numbers	18.3	53.8
No preference	9.6	9.0
If women wanted words what words did they prefer?		
A general description, for example, low, medium, high	43.6	56.0
A comparison, for example, higher or lower than women in general	27.7	22.7
Both general and comparison	2.0	4.0
No preference	26.7	17.3
If a woman wanted a time based figure		
Lifetime	36.0	28.0
Before age 50	7.8	10.7
Next 10 years	29.1	33.3
All of the above	4.9	4.0
No preference	22.3	24.0
If women wanted numbers, what type of number did they prefer?		
Percentages	40.6	35.1
Proportions	27.7	31.1
Gambling odds	2.0	1.4
All of above	8.9	12.2
No preference	12.9	17.6
Percentage or proportion	7.9	2.7
If women preferred a comparison to other women, what comparison did they prefer?		
Own risk + risk of general population	36.9	39.5
Relative risk only	25.2	26.3
Both	16.5	18.4
No preference	20.4	14.5
Don't know	1.0	1.3

*Unaffected with breast cancer; †affected with breast cancer.

educated above high school certificate level (year 12), being accurate in their risk perception compared with 33% of women educated below year 12 level, (χ^2_1=5.15, p=0.02). There was no association between accuracy of perception of risk, and whether or not a woman had knowledge of medical terminology, her age, her family history (breast cancer alone or breast and ovarian cancer), or her cancer burden.

Process of communication of risk in the clinic

In the clinic consultation, the most commonly presented risk concepts included: (1) the general population risk for breast cancer, (2) the percentage of breast cancer in the general population resulting from a mutation in either the *BRCA1* or *BRCA2* gene; (3) the woman's hypothetical risk of developing breast cancer should a mutation be detected, and (4) the chance of the woman or other family members having inherited the mutation (table 3). An actual risk figure for ovarian cancer was given in 33% of consultations and a risk figure for bowel or prostate cancer was not often given (2% and 1%, respectively).

Combinations of words, proportions, and percentages were used to discuss these risk concepts and broad categories (rather than exact figures) were most commonly used. Table 4 shows the categories and combinations of risk figures given.

Predictors of accuracy of risk estimates of unaffected women after genetic counselling

At follow up, 70% of unaffected women accurately estimated their risk (compared with 50% at baseline). Twenty per cent of unaffected women underestimated their risk at follow up and 10% overestimated it. Over half of all women (58%) thought that their risk, as counselled, was about the same as they had expected before counselling with a small percentage thinking it was much higher (5%) or much lower (3%). In comparing themselves with others, 62% of unaffected women perceived their risk to be about the same as other women with a similar family history (compared with 67% at baseline) with 26% of women considered their risk to be higher (17% at baseline) and 12% lower (16% at baseline).

Table 3 Summary of the percentage of consultations with unaffected women and affected women where different aspects of risk were identified as being discussed by the audiotape transcript (n=158)

	Consultations in which risk was discussed (%)	
Risk category	Unaffected women (n=89)	Affected women (n=69)
General population risk:		
Breast cancer	76	76
Ovarian cancer	8	8
Bowel cancer	2	2
Prostate cancer	1	1
Male breast cancer	5.9	8
Proportion of general population risk owing to high risk mutations:		
Breast cancer	62	62
Jewish population risk owing to mutation:		
Breast cancer	18	18
Hypothetical risk of breast cancer for unaffected women with a *BRCA* mutation:		
Absolute	52	
Relative risk	52	
Chance of having mutation in self	71	71
Chance of testing finding mutation	17	17
Ovarian cancer risk with mutation	33	33
Bowel cancer risk with mutation	5	5
Risk of second cancer for affected women:		
Without mutation		10
With mutation		39

Table 4 The percentage of consultations in which risk information was given and distribution of different formats used as identified by transcripts (n=158)

Risk for the general population	Category	Words	%	Proportion	Percentage and proportion	Gambling odds	Time span
Breast cancer	Nil	2.6	1.6	50.3	11.4	Nil	19 Lifetime 3 Other
Breast cancer owing to gene	0.5	7.3	28.5	6.2	12.4	0.5	0.5 Lifetime
Breast cancer in men	Nil	3.6	4.1	1.0	Nil	Nil	1
Ovarian cancer	Nil	Nil	3.1	1.6	Nil	Nil	0.5
Bowel cancer	Nil	2.6	0.5	1.0	Nil	Nil	Nil
Prostate cancer	Nil	1.6	Nil	0.5	Nil	Nil	0.5
Jewish population risk owing to gene	Nil	3.1	0.5	11.4	0.5	Nil	Nil
Hypothetical risk of breast cancer if gene mutation present	7.2	13	21.2	3.6	5.7	0.5	9.8 Lifetime 0.5 Other
Relative risk	4.2	23.3	7.3	3.5	2.1	1.6	5.2 Lifetime 1 Other
Chance of having mutation	1.5	14.0	1.0	1.6	3.1	21.2	0.5
Chance of testing finding mutation	Nil	2.6	5.2	0.5	0.5	Nil	Nil
Hypothetical risk of ovarian cancer if mutation present	1.0	9.8	6.2	2.1	1.0	0.5	2.1
Hypothetical risk of bowel cancer if mutation is present	Nil	2.1	Nil	Nil	Nil	Nil	

Univariate analyses showed that married women were significantly more likely to be accurate in their risk perception Kruskal-Wallis test (χ^2=7.49, p=0.01). There was no association between accuracy after counselling and whether or not a woman had knowledge of medical terminology, her age, her family history (breast cancer alone or breast and ovarian cancer), or her cancer burden.

A total score summing the various risk figures given during the consultation was calculated. The median number of risk figures given was 4.0 (SD 1.96, range 0–13).

Univariate analysis showed no association between the number of risk figures given to unaffected women and the accuracy (underestimated, overestimated, or accurate) of their risk perception after the consultation (Kruskal Wallis test, χ^2_2= 3.41, p=0.18). Similarly, there was no association between the number of risk figures given to women and the accuracy of their perception of risk when recoded as two categories (accurate or inaccurate; z=–0.217, p=0.83).

Variables were created to indicate whether a woman's preferred format of communication of risk matched that given in the consultation.

Univariate analysis showed that there was no association between women receiving their preferred format of risk (that is, words or numbers or both words and numbers) and the accuracy of their risk perception (χ^2_1=2.19, p=0.14). There was also no association between women receiving their preferred risk format and their satisfaction (z=–478, p=0.63).

Univariate analysis showed that receiving their preferred risk number, that is, a percentage or a proportion, was not associated with risk accuracy (χ^2_1=1.87, p=0.17). There was no association between women receiving their preferred risk number and satisfaction (z=–0.028, p=0.98).

Univariate analysis showed that there was no association between a woman being given a risk figure in both words and numbers and the accuracy of her risk perception after genetic counselling (χ^2_1=1.158, p=0.28). There was no association between women receiving both words and numbers and satisfaction (z=–1.238, p=0.21).

All variables at p<0.25 were included in a multivariate analysis. These included knowledge of medical terminology, education, employment, marital status, wanting and getting risk of breast cancer in words and numbers, getting exactly what format they wanted, wanting and getting a particular number. Only marital status remained significant (OR=4.103; 95% confidence interval 1.42 to 11.90, p=0.01). No other variables were associated with accuracy after counselling.

Satisfaction with the genetic counselling session

Both affected and unaffected women were very satisfied with their genetic counselling session. Ninety-five per cent (95%) of women thought that the consultant had explained their situation clearly and 89% thought that their expectations were met. Eighty-two per cent thought that the consultant showed enough dedication, 86% thought that the consultant understood what was bothering them, and 96% thought that they had been listened to. Finally, 84% were satisfied with the information that they received. The two areas where women, both unaffected and affected, were less satisfied were in feeling reassured (69% and 68%, respectively) and that the consultation helped them cope better with their situation (68% and 57%, respectively).

DISCUSSION

The women recruited to this study had higher education levels and were more likely to be employed in professional occupations than those in the general Australian population.[41] A large percentage of women (74%) had completed the high school certificate (year 12), university, or some form of tertiary training. The percentage of women with tertiary qualifications was 57% compared with 37% in the Australian population. Half (50%) worked (or had worked) in professional or paraprofessional jobs. Additionally, a third of participants has some form of medical or allied health training, a finding noted in a previous Australian study of women with early stage breast cancer.[11]

No clear majority preference for communication of risk was found in this study of women from high risk breast cancer families. The finding that only 20% of women wanted words alone is perhaps mirrored by the concern expressed by physicians about the imprecision associated with communication of risk in words alone.[34 35] A study of women with early stage breast cancer found that there was no consistency in the interpretation of words, in this case the verbal descriptor "good" for the chances of survival.[11] Nevertheless, as over half of these women with early stage breast cancer wanted words either alone or with numbers suggests that words play an important part in their processing of risk. Zimmer[36] suggested that words are perceived to be more flexible and less precise in

meaning and that lay people actively choose this mode of expression, because they perceive numbers as conveying a level of precision and authority that they do not want. Studies in genetic counselling have shown that when provided with numerical estimates, people seem to spontaneously transform their probability information into discrete categories, for example, high or low risk,[32 42] supporting this notion that words are easier and more comfortable to process than numbers.

Of the unaffected women who preferred numbers, 41% preferred percentages, and fewer (28%) preferred proportions. A small percentage of women wanted both and slightly more (13%) had no preference. These findings suggest that women either do not understand the options being offered or that there is wide diversity in preferences. Previous studies have indicated that women prefer proportions, and other studies report that patients have general difficulty with the mathematical concepts and properties of numerical probabilities.[27–29] One strategy to overcome the problem would be to ask each woman her preference and check that she has understood the risk concept being discussed.

The process of communication of risk in genetic counselling

Previous authors have identified as a research priority the detailed examination of communication of risk during genetic counselling and the evaluation of its impact on counsellees.[20 21] Analysis of transcripts of genetic counselling sessions in this study indicates that providers used a contextualised approach to communication of risk. Also, they used a wide array of risk figures and words to communicate different aspects of familial breast cancer risk. Most high risk women (67%) in the study were seen because of their personal and family history of breast cancer. A risk figure for ovarian cancer was given in only a third of consultations. This may be because only one third of the sample had a family history of both breast and ovarian cancer and risk assessment was based on family history.

However, regardless of the format, broad categories were used. The imprecision in communication of risk in consultations of familial breast or ovarian cancer is the result of the uncertainty that surrounds the risk conferred on a woman if a gene mutation is present in her family. This is due to factors such as the incomplete penetrance of the *BRCA1* and *BRCA2* gene mutations, the possible presence of other mutations not yet identified, and the fact that mutations at different sites in the gene may have different effects. It is perhaps not surprising, therefore, that some women emerge from counselling with a lack of clarity about their risk.

Women's risk perception

Half of the unaffected women (50%) estimated their risk of breast cancer accurately before counselling. The percentage of women who accurately estimated their risk of breast cancer reported in other studies has ranged between 9% and 59%.[9 23 33 43–46] Thus our findings fall towards the top end of this range.

Of the 50% of women who were inaccurate, 53% underestimated their risk and 47% overestimated it. Two other studies have reported the number of women underestimating their risk before counselling with figures of 35% and 45% respectively.[10 24] The percentage of women who overestimated their risk reported in other studies ranged from 14% to 89%.[7 9 47 48]

Why did we seem to have a lower percentage of overestimators than most studies? Some studies included women of moderate, rather than high, risk, thus the potential for overestimation was greater. For example, one large study of 969 women aged 35 and over, which found that 85% of women over estimated their risk, included women who had a first degree relative with breast cancer and who were probably at average or moderate risk.[23] Secondly, it is possible that cultural and sociodemographic differences may exist; most earlier studies were conducted in the United States of America and the United Kingdom. Thirdly, perhaps our method of determining accuracy (with three broad categories) versus more stringent criteria, resulted in fewer women being classified as overestimators at baseline.

In comparing themselves with others, at baseline 67% of unaffected women perceived their risk to be about the same as other women with a similar family history with 17% of women considering their risk to be higher and 16% lower. Thus, these measures, had we taken them as the basis for calculating accuracy, would have shown even fewer overestimators. Clearly, the way in which risk perception is elicited may produce widely different estimates. This is a concern in research, but may be a useful clinical strategy for exploring women's understanding of risk. That is, asking women to express their risk using different formats, and then exploring disparities, may help to correct distortion.

Communication of risk with women already affected by breast cancer

Analysis of the consultation transcripts indicated that the chances of affected women developing a second cancer (in the contralateral breast) was not discussed in 61% of consultations. Consequently, it was not possible to determine the objective risk in affected women and calculate their accuracy of perception of risk. It has been suggested that the woman's anxiety around her own diagnosis of breast cancer is an indicator as to whether the consultant will discuss an affected woman's increased risk of a second cancer in the consultation. However, most affected women (77%) attending genetic counselling indicated that they expected to be told their risk of developing a second breast cancer. Similarly, most affected women (98%) wanted to know their family's risk of developing breast cancer and this was given in under half of the consultations (44%).

Affected women did not report lower levels of satisfaction with the consultation than unaffected women, or report that fewer of their expectations were met. However, the satisfaction of both unaffected and affected women with the consultation was uniformly high. It may also be that other aspects of the consultation, for example, an opportunity to discuss their family history or their own diagnosis of breast cancer or to clarify information, were more useful to affected women than the communication of a risk figure. Thus, affected women's reports of satisfaction may be influenced more by these aspects than by not receiving a risk estimation. Indeed, when asked what they liked about the genetic consultation, many affected women reported that the opportunity to speak about their diagnosis of breast cancer with someone who was not a member of their original treatment team, was helpful.

Impact of genetic counselling on perception of risk

This study found that genetic counselling was effective in increasing the accuracy of women's perceptions of risk. At baseline, 50% of unaffected women estimated their risk of breast cancer accurately and this increased to 70% at follow up. This is a higher accuracy recall than the 41% reported after counselling in an English study with a similar design and at a similar follow up time[49]; however, it is lower than the 78% and 90% accuracy reported after consultations in moderate and high risk women respectively in a recent French study.[50] However, the French study used a largely dichotomous method of determining risk accuracy (at risk or not).

Marital status was the only factor significantly associated with risk accuracy. Esplen *et al*[51] suggested that emotional factors play an important part in risk assessment. Perhaps marital status in this study was a surrogate for social support or

perhaps these women discussed what was said in the consultation with their partner and this contributed to more accurate recall. The current study measured medical and allied health training, which was not associated with risk accuracy. This contrasts with a recent French study that found that having a health related occupation improved accuracy after consultation in women at moderate risk.[50] Perhaps these two concepts are sufficiently different to explain the disparity.

Regardless of whether a woman was given her risk both as words and numbers, or whether she received her preferred format or her preference for a particular risk figure, her accuracy or satisfaction was not increased. A previous study found that risk recall was significantly more accurate when risk was presented in relative terms rather than in other formats, but this study found no such associations.[33 49] Meeting or not meeting women's preferences for risk figures within a particular time frame had no association with outcomes. Also, contrary to our hypothesis, women's accuracy was not related to the number of risk concepts discussed in the consultation. Even though our sample size was larger than that in other studies of this type, perhaps statistical power was inadequate in this instance. Perhaps the format of presentation, preferred or otherwise, is simply not important. Alternatively, the wide ranges in risk estimates genetic consultants currently provide by necessity and our decision to code accuracy within these wide categories resulted in insufficient variability to detect meaningful relations. Future studies may need to focus on subsets of women who receive more specific risk information, perhaps after results of genetic testing.

Interestingly, Huiart *et al*[50] reported that the actual clinic influenced perception of risk in both low and moderate risk groups. As the current study did not find that variations in the ways the consultants presented risk influenced perception of risk, this suggests that other characteristics of consultants and clinics may be of importance.

Future research

As already noted, ways of communicating risk, at least as measured in the current study were surprisingly unrelated to perception of risk. Further exploration of the features of clinics and consultants that may influence perception of risk is needed.

Australian geneticists and genetic counsellors working in cancer genetics nominated risk counselling as the central feature of their work, and the development of information resources for patients was ranked within the top three priorities for improved care.[52]

Analyses have indicated that the information to be conveyed about risk related to breast cancer is complex. Yet the clinical practice guidelines on familial aspects of cancer endorsed by the National Health and Medical Research Council in Australia in 1999 contain virtually no guidance on optimising communication of risk.

Before starting the current study, all information aids given currently by the genetic counselling clinics in Australia participating in the study were reviewed. This review showed only one, one page aid targeting the facilitation of women's understanding of their individual risk. This aid gave numerical labels to verbal descriptors of risk. Individualised information about women's chances of having a mutation, of genetic testing identifying the mutation, and of developing breast cancer with and without a mutation over varying periods, is lacking. Future research is needed into the development and piloting of such an aid to communication of risk in the familial cancer setting.

Another possible influence on women's perception of risk that could be considered in future research is that of unresolved grief. Although the cancer burden was assessed in this study, no significant association was found between perception of risk and the number of family members who had been diagnosed or who had died of breast cancer. Perhaps unresolved grief which may not be captured in measures of anxiety or depression, but are related to personal experience with familial breast cancer (such as the death of a mother at an early age or the death of important other female family members) can be considered in future studies on perception of risk.

ACKNOWLEDGEMENTS

We thank the following people for their contribution to this study: Eric Haan, Meryl Smith, Monica Tucker, Sue Shanley, Karen Harrop, Annette Hattam, Jillian Parkes, Anne Baxendale, Linda Warwick, Lisette Curnow, Graeme Suthers, Jacqueline Armstrong, Elizabeth Dent, Lynda Gill, Mercedes Moreno, Rebecca Hagerty, and Rhonda Devine for assistance with recruiting patients, data collection, and audiotape coding. Finally, we are grateful for the valuable contribution of all the women who participated in this study. This study was funded by the University of Sydney Cancer Research Fund. BM is supported by Public Health Australia Fellowship 007079 from the National Health and Medical Research Council of Australia.

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