Journal of Genetic Counseling, Vol. 15, No. 5, October 2006 (© 2006)
DOI: 10.1007/s10897-006-9023-x

Original Research

Development of a Communication Aid to Facilitate Risk Communication in Consultations with Unaffected Women from High Risk Breast Cancer Families: A Pilot Study

E. A. Lobb,[1,10] P. N. Butow,[2] A. Moore,[3] A. Barratt,[4] K. Tucker,[5,6] C. Gaff,[7] J. Kirk,[8] T. Dudding,[1] and D. Butt[3]

Published Online: 12 September 2006

The literature on risk perception in women from high-risk breast cancer families reveals persistent over-estimation of risk, even after counseling. In this study, a communication aid was designed to facilitate discussion of risk between clinical geneticists and genetic counselors and women from this high-risk population. *Method:* Stage 1. The aid was developed by an expert panel of clinical geneticists, genetic counselors, psychologists, an epidemiologist, an oncologist, linguists and a consumer. It was guided by the international literature on risk communication and a large multi-centre Australian study of risk communication. The 13 page full-color communication aid used varying formats of words, numbers, graphs and pie-charts to address (a) the woman's subjective risk; (b) the population risk of breast cancer; c) the risk of inherited breast cancer; (d) the cumulative risk for women with *BRCA1* and *BRCA2* mutations; (e) family risk factors; (f) the woman's suitability for genetic testing; (h) screening and management recommendations, and (i) a re-assessment of the woman's subjective risk. Stage 2: A before–after pilot study of 38 women who were unaffected with breast cancer and were attending four Australian familial cancer clinics was undertaken. Baseline and follow-up questionnaires were completed by 27 women. Outcomes were compared to those observed in 107 similar women undergoing genetic counseling without the communication aid in 2001. *Results:* The risk communication aid appears to be beneficial; breast cancer genetics knowledge improved in some areas and importantly, risk perceptions improved in the cohort receiving the communication aid. Psychological measures showed no difference in anxiety or depression between the group receiving the communication aid and the comparison cohort. Women and clinicians were very positive about the usefulness of the communication aid as an adjunct to the genetic counseling consultation.

KEY WORDS: familial breast cancer; risk communication aid.

[1]Western Australian Centre for Cancer and Palliative Care, Edith Cowan University, Churchlands, WA, Australia.
[2]Medical Psychology Research Unit, Department of Psychology, The University of Sydney, Sydney, NSW, Australia.
[3]Centre for Language in Social Life, Department of Linguistics, Macquarie University, NSW, Australia.
[4]Screening and Test Evaluation Program, School of Public Health, The University of Sydney, Sydney, NSW, Australia.
[5]Prince of Wales Hospital Clinical School, University of New South Wales, NSW, Australia.
[6]Hereditary Cancer Clinic, Prince of Wales Hospital, Sydney, NSW, Australia.
[7]Genetic Health Services Victoria, Royal Children's Hospital, and Royal Melbourne Hospital, Parkville, Australia.
[8]Familial Cancer Service, Westmead Hospital, Westmead, NSW, Australia.
[9]Hunter Genetics, Waratah, NSW, Australia.
[10]Correspondence should be directed to E. A. Lobb, Associate Professor, Western Australian Centre for Cancer and Palliative Care, Edith Cowan University, Churchlands, WA 6018 Australia; e-mail: e.lobb@ecu.edu.au.

BACKGROUND

Genetic counseling relies on risk communication to convey information about personal and familial cancer, the risks and benefits of genetic testing for familial cancer, and the chance that, given the family history, this testing will find a mutation. Accurate risk comprehension among participants in genetic counseling programs may be critical to their decision-making regarding genetic testing and risk management, including the possibility of prophylactic surgery (Meiser *et al.*, 1999).

Risk communication in the context of familial breast cancer is complicated by several factors. Firstly, unlike acquired cancer risk factors such as smoking, exposure to an inherited mutation cannot be altered by the at-risk individual. Furthermore, there is uncertainty about the efficacy of risk reduction strategies (such as screening or chemo prevention) in any particular individual, (Burke *et al.*, 1997) and even prophylactic surgery does not completely eliminate the risk of cancer development (Armstrong *et al.*, 2004; Rebbeck *et al.*, 2004). Studies that have examined the effects of genetic testing on risk reduction decisions show that a significant proportion of eligible women do not take any action following feedback on their BRCA1/2 carrier status (Botkin *et al.*, 2003; Lerman *et al.*, 2000; Schwartz *et al.*, 2003). Therefore, genetic counselors must not only present risk information clearly, but also explore the individual's understanding, perceptions and reactions to the information.

A second complexity is that testing does not produce clear answers. If a cancer-related gene mutation is present, it is still uncertain how, when, and where it will manifest itself. If a cancer-related gene mutation is not found after mutation searching in an affected family member (the proband), this does not rule out the possibility that a mutation has been missed on testing or is present in an as-yet unknown cancer predisposition gene. Even if an unaffected woman does not carry the mutation detected in her family, her risk remains at the population risk. Therefore, genetic testing only offers limited additional clarity in an uncertain situation.

A considerable body of literature documents risk perception inaccuracy in individuals undergoing genetic counseling. Unfortunately these inaccuracies improve only moderately following counseling (Lloyd *et al.*, 1996; Lerman *et al.*, 1995; Bluman *et al.*, 1999; Hopwood, 1998). Over-estimation of risk is most common. Lobb *et al.* (2003) found that variations in the way that risk is presented in genetic counseling consultations (e.g., words or numbers, matching the woman's preferences for format or not) were unrelated to risk accuracy following the consultation, suggesting that current counseling strategies are not sufficient to combat these fixed risk perceptions (Lobb *et al.*, 2003). However, there is little available at present in the way of evidence based guidance about how to optimize risk communication, and the Australian clinical practice guidelines on familial aspects of cancer contain virtually no guidance on how to optimize risk communication (NHMRC, 1999).

Thus the project aimed to develop an aid to enhance risk communication between women and geneticists/genetic counselors, and to evaluate the impact of the aid on patient outcomes in a pilot study.

STAGE 1: DEVELOPMENT OF THE COMMUNICATION AID

Risk communication was evaluated in a previous study of 152 consecutive consultations of women from high risk breast cancer families, including both affected and unaffected women. This involved six geneticists and genetic counselors in ten familial cancer clinics in four states of Australia who were audio-taped and transcribed verbatim (Lobb *et al.*, 2003). Risk communication in these consultations was coded and analyzed.

In addition, a linguistic analysis was conducted of a subset of 20 transcripts, to help explain why risk is so misunderstood, even after specialist genetic counseling. This approach draws on systemic functional linguistics (Halliday, 1994), genre theory (Hasan, 1985; Sinclair and Coulthard, 1975; ten Have, 1989) and in particular the concept of ''semantic variation'' (Hasan, 1989). The linguistic analysis produced a map of the typical discourse strategies used in the breast cancer counseling sessions (to be reported, elsewhere). The main findings of this analysis was that, although counselors were by no means explicitly over-estimating individual women's cancer risk, certain discourse strategies were being used which tended to overemphasize the genetic factors in cancer, and which give a sense of inevitability to cancer. Such discourse strategies are likely to contribute to a ''take-home'' overestimate of individual risk (Moore and Butt, 2004).

On the basis of these findings, and the risk literature, we developed a communication aid to be

used to facilitate risk communication between the geneticists/genetic counselors and women in familial breast cancer clinics. An expert panel of clinical geneticists, genetic counselors, psychologists, an epidemiologist, an oncologist, linguists and a consumer was formed and met regularly during the development phase.

The communication aid was developed in accordance with the National Health & Medical Research Council (Australia) guidelines "How to prepare and present information for consumers of health services," launched in 1999 (NHMRC, 1999).

The communication aid included: (a) a definition of risk and a short discussion of the factors that can influence risk perception; (b) an invitation to record personal risk perception at the beginning and end of the aid, (c) a pie chart depicting population risk (see Fig. 1); (d) a short lesson in cancer genetics with a graphic representation of inheritability; (e) a diagrammatic representation of how a genetic mutation increases risk; (f) pie charts (see Fig. 1a) and cumulative risk graphs depicting level of breast and ovarian cancer risk in those with the mutation; (g) a representation using an adaptation of the 100 woman diagram of the percentage of women at potentially high, low and medium risk in the population (see Fig.2); and (h) three tick-box lists, including a list of risk factors for having a gene mutation, factors determining availability of testing, and things to do to minimize risk.

Each participant in the study received standard genetic counseling with either a genetic counselor or a clinical geneticist. The 13 page color communication aid was used where relevant during the consultation. It was interactive, in that it prompted women to respond to a range of issues, and could be written on. For example, the consultant was able to personalized the aid to the woman's individual family history to identify the likelihood that there was an inherited faulty *BRCA1* or *BRCA2* gene in the family, e.g., breast cancer at a younger age, bilateral breast cancer, male breast cancer or ovarian cancer, by marking a tick box (see Fig. 3). The consultant could list recommended screening and management options for that individual woman. (see Fig. 4) and could indicate through ticking boxes whether the family was suitable for genetic testing, e.g., whether there were any living affected family members who could be tested. (see Fig. 5). The woman was given the 13 page document to take home with her at the end of the consultation where, if she wished, it could be shared with other family members.

Six principles were embodied in the aid. First, that risk perception is based on emotional as well as intellectual factors (Rothman and Kiviniemi, 1999). The aid explicitly reminds the counselee that this is so, and elicits risk perception both at the beginning and end of the aid to allow acknowledgement and discussion of the fact that, despite the material presented, the counselee may still have inaccurate risk perception at the end of the session.

Second, that people prefer and better understand a combination of visual, numerical and word-based representations of risk (Lipkus and Hollands, 1999). All risks communicated within the aid combined these three approaches. In addition, risk was presented in positive and negative framing and was based on risk figures relevant to an Australian population of women reported in the current literature.

Third, that many people remain convinced that states of being at 0 and 100% risk are possible. Several graphical approaches that explicitly address this issue were employed in the aid. We also provided wide confidence intervals in cumulative risk graphs to illustrate the uncertainty and imprecision in risk estimation.

Fourth, that many people overestimate the risk conferred by a genetic mutation. A figure showing steps in the development of "sporadic" breast cancer and familial breast cancer was used to show the interplay of genetic and other factors (e.g., environment) to help counter the overemphasis on relations between genes and cancer and progression to cancer seen in the consultation dialogues. Critically, this figure sets out possible endpoints in which individuals do not develop cancer, as well as the endpoint in which cancer does develop.

Fifth, the introduction of the term "faulty cancer protection gene" to convey that *BRCA1* and *BRCA2* are normal genes that men and women have, but some carry a mutation.

Sixth, that previous risk communication literature has highlighted the importance of personalizing risk communication (Lerman *et al.*, 1996; Rimer and Glassman, 1999). The aid addressed this in several ways. A page titled "How likely is it that your family has an inherited faulty cancer protection gene?" personalized the document to the woman's family. Her eligibility for genetic testing was discussed ("Is your family suitable for testing?") and a personal screening and management program was developed under the heading "Things to do to minimize your risk."

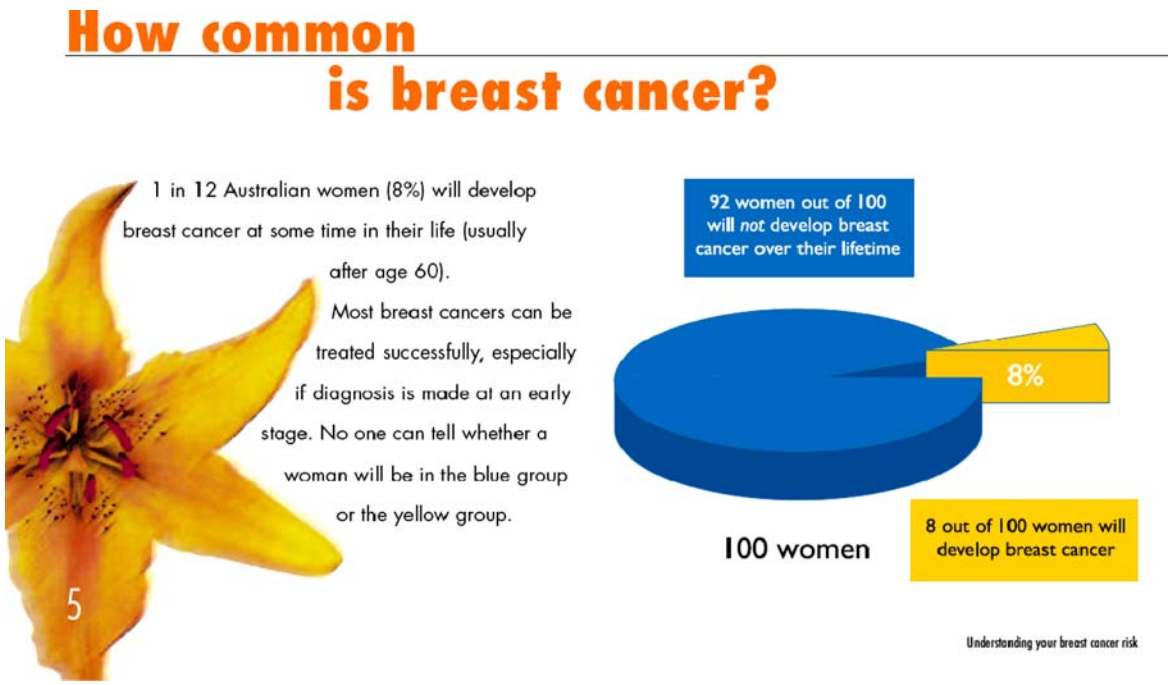

Fig. 1. Describes the population risk for breast cancer with a combination of visual, numerical and word-based representations of risk.

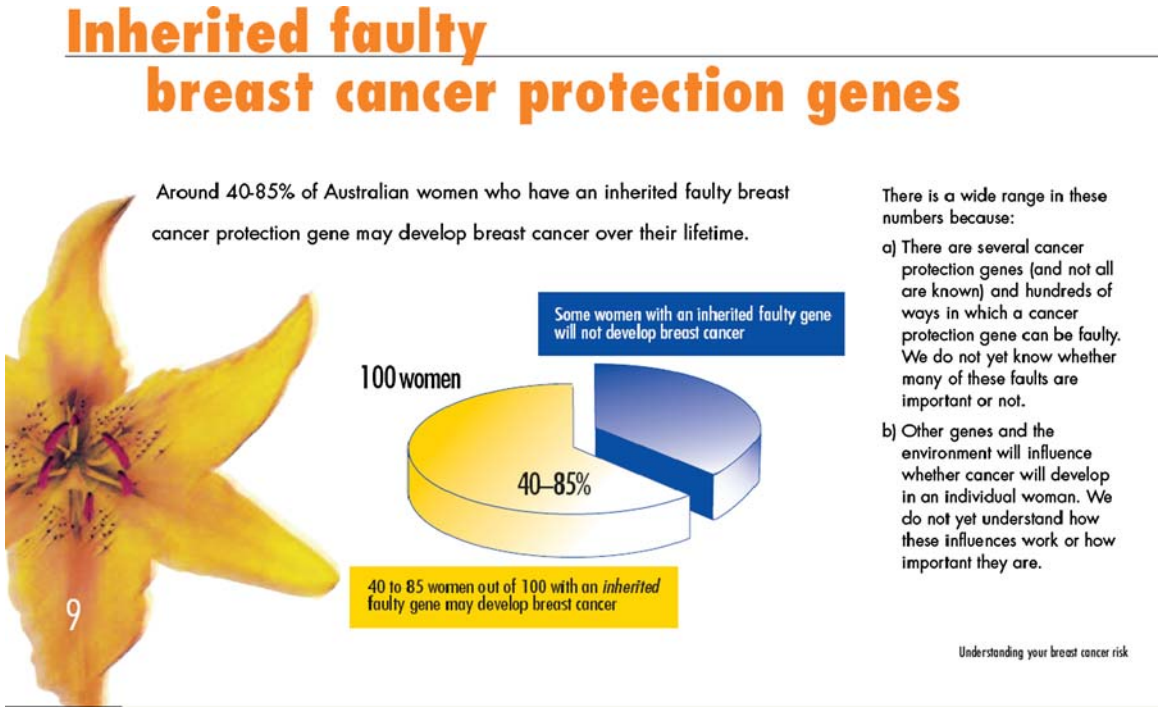

Fig. 1a Describes the risk of an inherited faulty cancer protection gene using varying formats.

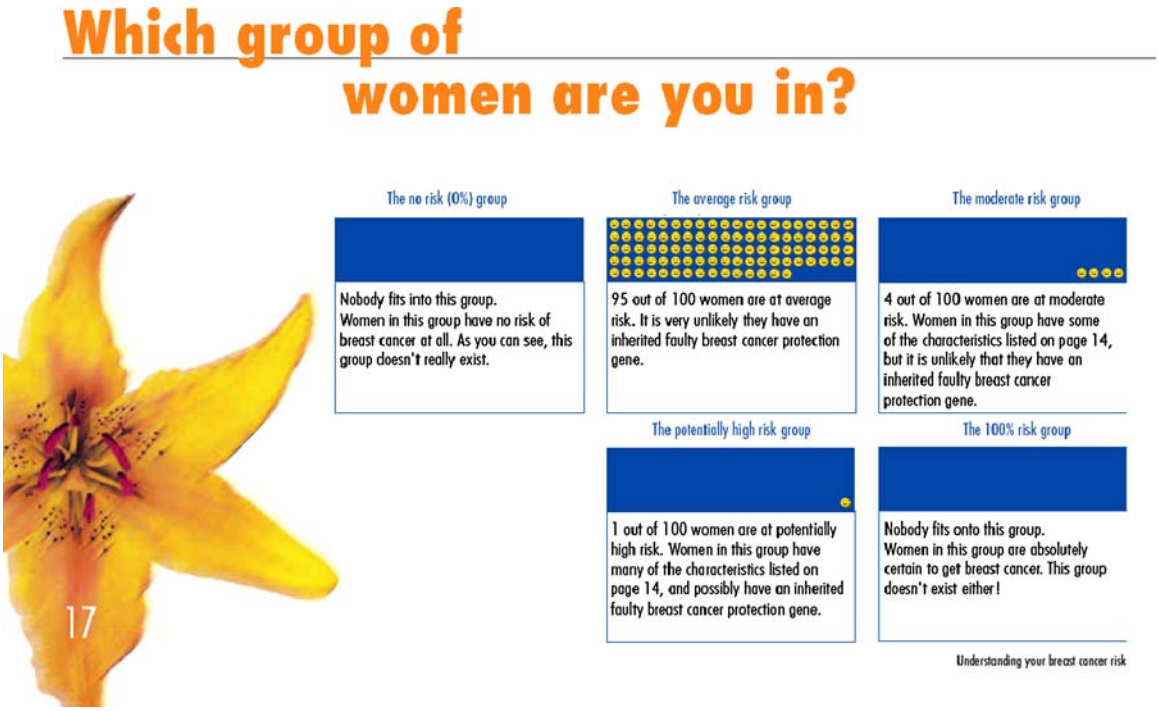

Fig. 2 Illustrates the percentage of women in the population at potentially high, medium and low risk of breast cancer using an adaptation of the 100 woman diagram.

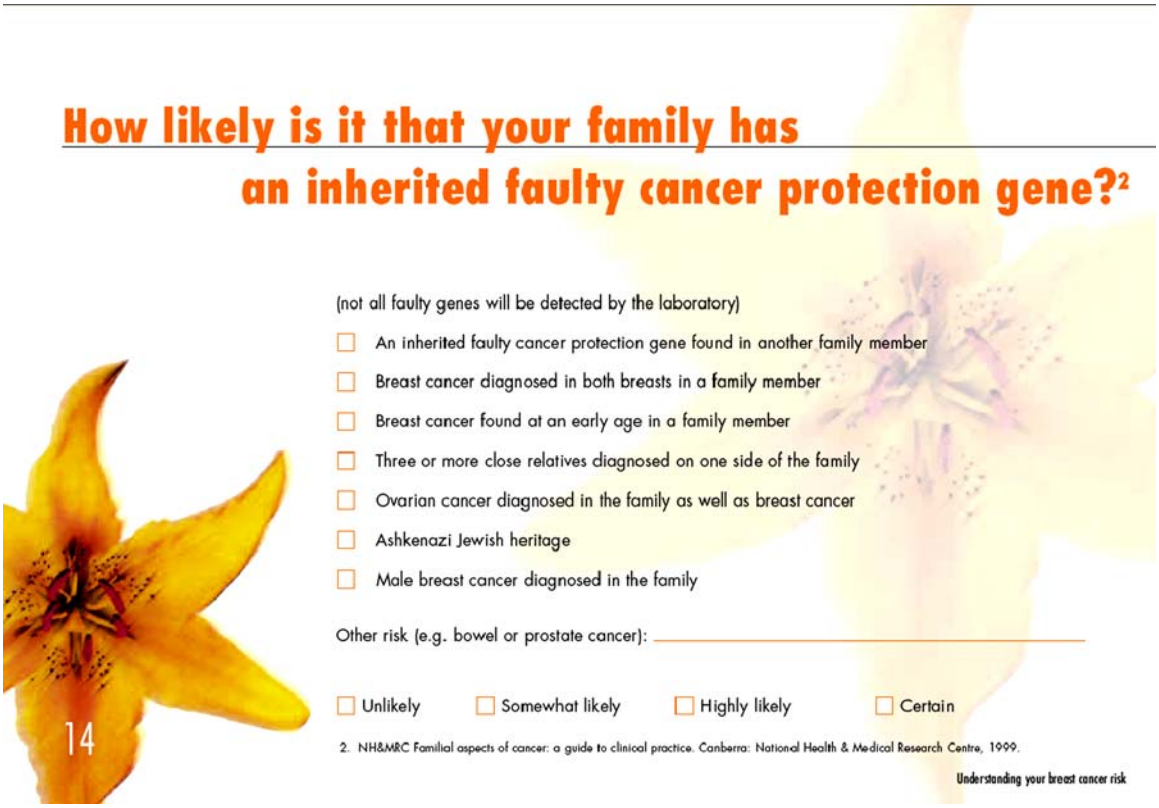

Fig. 3 An example of personalizing the Aid to the woman's family history.

Fig. 4 An example of personalizing the Aid for screening and management recommendations.

Fig. 5. An example of a check list to determine the woman's suitability for genetic testing.

STAGE 2: PILOTING THE COMMUNICATION AID

Methods

Participants

The communication aid was piloted in 2003–2004 with 27 consecutive women from high-risk breast cancer families (as defined by NHMRC Guidelines), who had not previously had breast cancer, and were attending their first genetic counseling consultation. As the risk figures for an affected woman from a high risk breast cancer family would be different, it was decided to keep the sample homogenous by including only unaffected women. Four clinical geneticists and two genetic counselors in one of four familial cancer clinics in two Australian States conducted the consultations. Some consultations were conducted by a clinical geneticist, some by a genetic counselor and some by both. Women were considered ineligible for participation if they were unable to give informed consent, were younger than 18 years, showed evidence of a severe mental illness or had limited literacy in English. None of the women had previously undergone BRCA1/2 testing, and none were obligate carriers of a *BRCA1* or *BRCA2* mutation.

Staff at each of the participating clinics invited women to participate in the study when they telephoned to make their appointment. If verbal agreement was obtained, women were mailed self-administered questionnaires with an information sheet and consent form 2 weeks before and 1 week after their genetic consultation. Ethics approval was obtained from four different ethics committees (IRBs) prior to data collection.

Participating geneticists/genetic counselors were trained in the use of the communication aid and given written instructions. A trial period of three consultations per participating geneticist/genetic counselor was implemented for the consultant to become familiar with using the communication aid in combination with their usual practice. To monitor the extent to which the intervention was being delivered as stated in the protocol a random sample [10%] of all consultations in the trial were audio-taped and analyzed for changes in intervention delivery ($n = 3$).

Measures

Demographic Characteristics. Women were asked to provide details on age, education, occupation, marital status, medical or allied health training, and the number of biological children and age and sex of each child.

Breast Cancer Genetics Knowledge. Before and after the consultation, an eight-item true-false measure derived from one developed by Lerman and colleagues assessed knowledge about breast cancer genetics (Lerman *et al.*, 1996).

Risk Perception. Before and after the consultation women were asked to estimate the general population risk for breast cancer by choosing between three response options—1 in 50 (2%), 1 in 25 (4%) and 1 in 12 (8%); the percentage of breast cancers due to a breast cancer gene mutation by choosing from five options – 100, 50, 25, 10 and <5%; and the approximate lifetime risk of developing breast cancer for women with a breast cancer gene mutation (0–11%, 12–15%, 26–39%, 40–85%, and 86–100%).

Breast Cancer Anxiety. This was measured before and after the consultation using the Impact of Events Scale, a 15-item scale measuring intrusion and avoidance responses in relation to a specific stressor (Horowitz *et al.*, 1979; Thewes *et al.*, 2001). In the current study the particular stressor was concern about being at risk of developing breast cancer. Scores above 40 on either scale indicate a significant stress response.

General Anxiety and Depression. This was measured before and after the consultation by the 14-item Hospital Anxiety and Depression Scale. It consists of two sub-scales of seven items assessing anxiety and depression (Zigmond and Snaith, 1983). Questions have four response options, giving scores ranging from 0–21 for each sub-scale. A score of higher than 10 on either sub-scale is an indication of clinical anxiety or depression.

Satisfaction with the Genetic Counseling Session. Satisfaction was measured after the consultation using a modified version of the 12-item short form of the 36-item "Satisfaction with Genetic Counseling Scale," developed by Shiloh *et al.* (1990). This shorter version of the scale is highly correlated with the full scale ($r = 0.90$) and has good reliability (Cronbach $\alpha = 0.78$) (Shiloh *et al.*, 1990).

Satisfaction with the Risk Communication Aid. Women answered seven additional questions specifically addressing satisfaction with the risk

communication aid. They were asked how useful the aid was in (a) increasing their understanding of cancer genetics; (b) increasing their understanding of their personal risk; (c) decreasing their anxiety about breast cancer; (d) assisting in family communication about the family history of breast cancer; (e) helping the family understand breast cancer genetics; (f) helping to reach a decision about how to manage their genetic risk; (f) helping to reach a decision about having a genetic test (these questions were measured with five options ranging from extremely helpful to very unhelpful).

Finally, women were asked in an open-ended question to list other ways in which the risk communication aid was helpful, if they had shown the aid to other family members, and to whom they had shown the aid.

Practitioner Outcomes

At the end of each consultation, clinical geneticists/genetic counselors were asked to complete a brief measure of their satisfaction with using the communication aid in the consultation using a visual rating scale and to provide written feedback to the investigators regarding the aid and its utility. This feedback was used to modify the final version of the communication aid.

Comparison Study

The geneticists and genetic counselors in the current study are a subset of those who participated in our previous study, (Lobb *et al.*, 2002) and many of the patient outcome measures were the same in both studies. The studies are separated by 18 months. We have compared outcomes for the unaffected women ($n = 107$) from Lobb *et al.*, 2004 (similarly of initial consultations, but without a risk communication aid) with those from the current Pilot Study, to provide a crude estimate of the impact of the aid compared to consultations in which it was not used (Lobb *et al.*, 2004).

Statistical Methods

Descriptive statistics were used to summarize most of the data, including demographics and psychological status. Change scores were calculated for all psychological outcomes by subtracting baseline scores from follow-up scores. Thus a negative change score indicates a reduction in morbidity. Comparisons between the pilot and comparison study were made using Chi-square analyses on categorical variables (most demographics and risk perception), Student *t*-tests for normally distributed continuous variables (change in knowledge) and Mann-Whitney *U*-tests for non-normally distributed continuous variables (change scores for general and breast cancer specific anxiety and depression). Repeated measures *t*-tests were used to compare knowledge before and after the consultation.

RESULTS

Sample

Of the 49 unaffected women who met eligibility criteria, one woman declined participation and 10 women did not attend their appointment. Of the 38 women who completed the baseline questionnaire, 27 completed follow-up questionnaires.

Table I outlines the demographic characteristics of participants. There were no important or statistically significant differences between the two groups on demographic variables such as age, marital status, education and professional status.

Women's Knowledge of Breast Cancer Genetics

The number of knowledge questions in the pilot study was 10. To make meaningful comparisons with the comparison study, where eight knowledge questions were assessed, knowledge date was analyzed in both samples on the same eight questions.

Table II shows the percentage of women in the pilot study who gave correct answers on the eight breast cancer genetics knowledge scale prior to and after genetic counseling. The mean number of correct answers at baseline in the pilot study was 5.07 (*SD* 2.07, range 1–8) and at follow-up the mean number of correct answers was 6.37 (*SD* 1.27, range 3–8). There was a significant difference in knowledge scores between baseline and follow-up in the pilot study ($t_{26} = -4.54$, $p = 0.000$).

Areas where the greatest improvement in knowledge occurred concerned:

- the role of male inheritance (14 accurate at baseline versus 26 at follow-up);

Table I. Demographic Characteristics of Sample

	Pilot study ($n=27$), n (%)	Comparison study study ($n=107$), n (%)	Statistic	p value
Age	Mean 39.4 (*SD* 9.2) (range 20–61)	Mean 39.5 (*SD* 9.4) (range 19–69)	$t_{26} = -0.226$	0.82
Marital status				
Married	21 (77)	78 (73)	$\chi^2_1 = 1.37$	0.25
Not married	6 (22)	26 (25)		
Educational level				
Below HSC (year 12)	8 (29)	27 (26)	$\chi^2_1 = 0.22$	0.48
Above HSC	19 (70)	79 (74)		
Medical/para-medical training				
Yes	7 (26)	36 (34)	$\chi^2_1 = 0.79$	0.33
No	20 (74)	70 (66)		
Occupation				
Professionals	15 (55)	62 (58)	$\chi^2_1 = 1.41$	0.23
Non professional	12 (44)	44 (42)		

- that not every women can be offered genetic testing (six accurate at baseline versus 16 women at follow-up).

The mean number of correct answers at baseline in the comparison study was 5.3 (*SD* 1.56, range 1–8) and at follow up the mean number of correct answers was 6.6 (*SD* 1.52, range 0–8).

There was no significance difference between total knowledge scores at follow up in the pilot study and the comparison group ($t_{14} = -0.190$, $p = 0.85$). Additionally, there was no significant difference in change scores in knowledge between the pilot study and the comparison group ($t_{12} = -1.67$, $p = 0.12$).

Follow-up results in the pilot sample appeared better than those in the comparison group on one out of eight knowledge items, the issue of male inheritance (96% in the pilot vs. 78% in the comparison study). There were two areas where women in the pilot study appeared to have understood less than the women in the comparison study, that there is more than one gene that can cause breast cancer (59% in the pilot versus 71% in the comparison study) and that if a women has a bilateral mastectomy, it will completely remove her risk of breast cancer (48% in the pilot study vs. 57% in the comparison).

Table II. Number of Women with Correct Responses on Breast Cancer Genetics Knowledge Items Before and After Using the Communication Aid

Knowledge item*	Pilot study baseline $n=27$, n (%)	Pilot study follow-up $n=27$, n (%)	Comparison study follow-up $n=107$, n (%)
Breast cancer is always inherited	24 (89)	25 (93)	102 (96)
Men can carry faulty gene	14 (52)	26 (96)	83 (78)
Women with faulty gene will get breast cancer	18 (67)	23 (86)	93 (87)
Women without a faulty gene can get breast cancer	18 (67)	22 (82)	95 (89)
There is more than one breast cancer gene	12 (44)	16 (59)	75 (71)
Familial traits can influence inheritance	18 (67)	23 (85)	96 (90)
Mammography always detects breast cancer	23 (85)	24 (89)	95 (89)
Bilateral Mastectomy completely removes the risk of breast cancer	10 (37)	13 (48)	60 (57)
Families without the gene mutation have the same risk as the general population	11 (41)	19 (70)	—
Not every woman can be offered test	$n=6$ (22)	$n=16$ (59)	—

*True/False.

Psychological Status

Tables III and IV show measures for psychological morbidity in the two samples. Anxiety and depression scores remained much the same after the consultation in the pilot study and the comparison study. There were no significant differences in the change scores in general anxiety ($z = -0.000$, $p = 1.00$) or depression ($z = -0.244$, $p = 0.80$) between the pilot study and the comparison study. Similarly, there were no significance differences in change scores in breast cancer specific anxiety (avoidance) ($z = -0.363$, $p = 0.80$) and intrusion ($z = -0.705$, $p = 0.53$) between the pilot study and the comparison study.

Risk Perception

At follow-up two weeks after the consultation, 21 women accurately estimated the population risk of breast cancer (compared to 15 women at baseline), 10 women accurately estimated the percentage of breast cancers due to a breast cancer gene mutation (compared to two women at baseline) and 17 women accurately estimated the lifetime risk of developing breast cancer for a woman who has a breast cancer gene mutation (compared to 14 women at baseline). There was no significant difference between baseline and follow up estimations. Unfortunately, we lack similar data from the comparison group so cannot compare samples on these variables. (see Table V).

Table III. Comparison of Anxiety and Depression Levels at Follow-Up Between Women in the Pilot Study that Used the Communication Aid and Women in the Comparison Study Without the Use of the Aid

	Pilot study ($n = 27$)	Comparison study ($n = 107$)
Hospital anxiety and depression scale (HADS)—anxiety *n* (%)		
Baseline		
Borderline	3 (8%)	19 (18%)
Clinical anxiety	6 (16%)	14 (14%)
Follow-up		
Borderline	8 (30%)	22 (21%)
Clinical anxiety	4 (15%)	13 (13%)
Change score		
Median score	0.000	0.000 ($z = .000$; $p = 1.0$)
Range	−3 to 16	−8 to 7
Hospital anxiety and depression scale (HADS)—depression *n* (%)		
Baseline		
Borderline	2 (7%)	7%
Clinical depression	0	6%
Follow-up		
Borderline	4 (15%)	7%
Clinical depression	0	5%
Change score		
Median score	0.000	−2.000 ($z = -0.244$; $p = 0.83$)
Range	−3 to 9	−8 to 7

Table IV. Comparison of Breast Cancer Related Anxiety (Avoidance and Intrusion) at Follow-Up Between Women in the Pilot Study that Used the Communication Aid and Women in the Comparison Study Without the Use of the Aid

	Pilot Study ($n = 27$)	Comparison Study ($n = 107$)
Impact of events scale (IES)—avoidance		
Baseline		
Median	13	14
Range	8 to 29	8 to 30
Follow-up		
Median	13	12
Range	8 to 28	8 to 28
Change score		
Median	−1.000	−1.000 ($z = -0.363$; $p = 0.80$)
Range	−9 to 10	−17 to 11
Impact of events scale (IES)—intrusion		
Baseline		
Median	14	11
Range	7 to 22	7 to 27
Follow-up		
Median	12	11
Range	7 to 27	7 to 26
Change score		
Median	1.000	0.000 ($z = -0.705$; $p = 0.53$)
Range	−7 to 8	−17 to 12

Table V. Risk Perceptions

Number of women accurate	Baseline ($n = 27$)	Follow-up ($n = 27$)	Statistic	*p* value
General population risk for breast cancer	15	21	$\chi^2_1 = 0.117$	0.12
Breast cancer risk due to mutation	2	10	$\chi^2_1 = 1.80$	0.29
Lifetime risk with mutation	14	17	$\chi^2_1 = 0.011$	0.67

Satisfaction with Genetic Counseling

The overall mean satisfaction rating that women gave the consultation was 84 out of a possible 100. The majority of women felt that the consultant had explained their situation clearly ($n = 26$), their expectations were met ($n = 25$), the consultant showed enough dedication ($n = 24$), the consultant understood what was bothering them ($n = 25$), they were satisfied with the information received ($n = 23$) and felt listened to ($n = 22$). Fewer women, but still the majority, felt reassured ($n = 21$) and that the consultation helped them cope better with their situation ($n = 17$). These data are very similar to that in the comparison group, with no significant differences emerging.

Usefulness of the Communication Aid

The majority of women found the communication aid extremely or very useful in understanding breast cancer genetics ($n = 17$) and in understanding their personal risk ($n = 18$). Fewer women ($n = 9$) found the aid extremely or very useful in decreasing anxiety, although 14 women reported it was satisfactory in reducing anxiety (see Table VI).

Practitioner Feedback

Consultants were very satisfied with the consultation with the majority (4 out of 5) reporting a satisfaction rating score between 7 and 9 out of 10 for all consultations. Comments made about the aid included: "I found the aid very useful in giving the client some perspective as to her risk." "The only thing I would have changed was the order of the sheets" and "Beautifully laid out," "Finished on a positive note with management (of breast cancer risk)" and "A useful, attractive document for women to take home."

DISCUSSION

The aim of this study was to evaluate an interactive communication aid to help women and clinicians to discuss risk, and to pilot test the impact of the aid on patient outcomes.

Our pilot sample reflected the population of women who normally attend genetic counseling clinics for familial breast/ovarian cancer. That is, they were young, with a large percentage in professional employment and educated above high school (year 12) with a quarter having previous medical or paramedical training.

The effectiveness of the risk communication aid in familial breast/ovarian cancer consultations in improving risk perception was evident with risk perception improving from baseline to follow-up in the pilot study. Unfortunately we were not able to compare the women in the cohort receiving the communication aid to those in a study undertaken in a similar Australian population in 2001 as these data were not collected. (Lobb *et al.*, 2004).

There was a significant improvement in breast cancer knowledge from baseline to follow-up in the pilot study. However, it is not clear why there was not a greater improvement in knowledge overall compared to the comparison study. There was improvement only in the area of male inheritance, which could be directly attributed to the Aid which gave an illustrated diagram of male inheritance as an example.

However, there were two areas where women in the pilot study did worse than the women in the comparison study, this was that there is more than

Table VI. Women's View of the Usefulness of the Communication Aid ($n = 27$)

	Extremely helpful/very helpful	Satisfactory	Unhelpful/very unhelpful
Increasing understanding of breast cancer genetics	17 (63%)	6 (22%)	1 (4%)[a]
Increasing understanding of personal risk	18 (66%)	6 (22%)	0
Decreasing anxiety about breast cancer	9 (33%)	14 (52%)	1 (4%)
Assisting family communication about family's history of breast cancer	15 (55%)	9 (33%)	0
Helping family understand breast cancergenetics	15 (55%)	9 (26%)	0
Helping you reach a decision about having genetic testing	15 (55%)	9 (33%)	2 (7%)
Helping you reach a decision about how to manage your genetic risk	15 (55%)	7 (26%)	2 (7%)

[a]Does not add to 100% because of missing data.

one gene that can cause breast cancer (59% in the pilot vs. 71% in the comparison study) and that if a woman has a bilateral mastectomy it will completely remove her risk of breast cancer (48% in the pilot study vs. 57% in the comparison). The lack of improvement may be a chance finding due to the small sample size in the pilot study. An earlier study on the analysis of genetic counseling consultations showed a similar lack of knowledge around the gene mutations that can cause breast cancer (Butow and Lobb, 2004). Perhaps women do not distinguish between *BRCA1* and *BRCA2* and perhaps the message of there being other, yet to be discovered, genes that may influence breast cancer risk has yet to reach women.

Women did not report higher satisfaction with their genetic consultation as a result of receiving the aid, but satisfaction scores were in general very high, with little room for improvement. Women receiving the aid were no more anxious or depressed than those who did not, which is reassuring for those who fear that explicit information may not suit everyone.

In feedback from the women, the majority found the use of the aid increased their and their families' understanding of breast cancer genetics and of risk, and assisted their decision-making. Fewer women found it extremely or very helpful in reducing anxiety, but 63% reported it was satisfactory in reducing anxiety. Practitioners found the aid helpful for facilitating discussion, and were particularly satisfied that the aid could be personalized to woman's individual circumstances.

In the final document, which has been published and distributed for use in familial cancer clinics around Australia, we incorporated written feedback from the women and practitioners and included additional information about the risk of ovarian cancer, a graph showing the ovarian cancer risk in carriers of faulty *BRCA1* and *BRCA2* genes, and information on how genetic testing is conducted.

Few studies have identified ways to increase the accuracy of women's risk perception after genetic counseling. Lobb and colleagues found that the provision of a summary letter after the consultation, and the reading of this letter, increased women's risk perception accuracy (Lobb *et al.*, 2004). However, the current study suggests that an interactive, personalized risk communication aid that can be taken home by the woman is acceptable to practitioners and women, and is able to increase the accuracy of risk perception without increased breast cancer anxiety or depression.

LIMITATIONS

We acknowledge that the sample size in this study is too small to make any generalized conclusions and the use of a historical comparison is not ideal. However, we felt it was important to conduct a pilot study before embarking on a randomized controlled trial as this intervention was designed to guide the counselor/counselee interaction and may not have been acceptable in a clinical setting. We believe this pilot study provides important and reassuring data that such an intervention is welcomed and useful by both counselor and counselee. It is acknowledged that the actual development of the aid, in particular the role of linguists, is in itself an interesting topic, hence, a separate paper on this aspect will be prepared.

FUTURE RESEARCH DIRECTIONS

Only women who were unaffected with cancer were included in this study as the potential risk statistics for this group differs to women who have had a previous breast cancer diagnosis. The development of a risk communication aid for affected women would be useful as our earlier study showed that the chances of affected women developing a second cancer (in the contra lateral breast) was not discussed in 61% of consultations (Lobb *et al.*, 2003). However, the majority of affected women (77%) attending genetic counseling in that study indicated that they expected to be told their risk of developing a second breast cancer. Similarly, the majority of 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%) (Lobb *et al.*, 2003).

A further randomized controlled trial of the aid is needed to establish the impact of the aid both in the short and long-term.

ACKNOWLEDGMENTS

The authors would like to thank the following individuals for their contribution to the development of the Aid and its piloting: Ms. Margaret Gleeson, Ms. Bev Warner, Ms. Elly Edwards, Ms. Rebecca D'Souza, Ms. Sheridan O'Donnell, Dr. Kristine Barlow-Stewart, Ms. Merran Cooper, Ms. Kate Dunlop, Ms. Gerda Evans, Dr. Bettina Meiser and

Ms. Claire Wakefield. Finally, we are grateful for the valuable contribution of all the women who participated in the piloting of the communication aid. This study was funded by the University of Sydney Cancer Research Fund. Elizabeth Lobb is supported by Australian Clinical Research Fellowship 222915 from the National Health & Medical Research Council of Australia. The production of the communication aid was supported by the Centre for Genetics Education in New South Wales, Australia.

REFERENCES

Armstrong, K., Schwartz, J., Randall, T., Rubin, S., & Weber, B. (2004). Hormone replacement therapy and life expectancy after prophylactic oophorectomy in women with *BRCA1/2* mutation: A decisional analysis. *J Clin Oncol*, *22,* 1045–1054.

Bluman, L. G., Rimer, B. K., Berry, D. A., Borstelmann, N., Iglehart, J. D. Regan, K., *et al.* (1999). Attitudes, knowledge and risk perceptions of women with breast and/or ovarian cancer considering testing for *BRCA1* and *BRCA2*. *J Clin Oncol*, *17*(3), 1040–1046.

Botkin, J. R., Smith, K. R., Croyle, R. T., Baty, B. J., Wylie, J. E., Dutson, D., *et al.* (2003). Genetic testing for *BRCA1* mutation: Prophylactic surgery and screening behavior in women 2 years post testing. *Am J Med Gen*, *118A,* 201–209.

Burke, W., Daly, M., Garber, J., Botkin, J., Kahn, M. J. E., Lynch, P., *et al.* (1997). Recommendations for follow-up care of individuals with an inherited predisposition to cancer. II. *BRCA1* and *BRCA2*. *JAMA*, *277*(12), 997–1003.

Butow, P. N., & Lobb, E. A. (2004). Analyzing the process and content of genetic counseling in familial breast cancer consultations. *J. Genet Counsel*, *13*(5), 404–424.

Halliday, M. A. K. (1994). *An introduction to functional grammar.* 2nd ed. London: Edward Arnold.

Hasan, R. (1985) The structure of a text. In: M. A. K. Halliday, R. Hasan (Eds.), *Language, context, and text: Aspects of language in a social-semiotic perspective* (pp. 52–69). Burwood, Victoria: Deakin University Press.

Hasan, R. (1989). Semantic variation and sociolinguistics. *Aust J Linguist*, *9,* 221–275.

Hopwood, P. (1998). Genetic risk counseling for breast cancer families. *Eur J Cancer*, *34*(10), 1477–1479.

Horowitz, M. J., Wilner, N., & Alvarez, W. (1979). Impact of event scale: A measure of subjective stress. *Psych Med, 41,* 209–218.

Lerman, C., Lustbader, E., Rimer, B., Daly, M., Miller, S., Sands, C., *et al.* (1995). Effects of individualised breast cancer risk counseling: A randomized trial. *J Nat Cancer Inst*, *87,* 286–301.

Lerman, C., Hughes, D., Croyle, R. T., Main, D., Durham, C., Snyder, C., *et al.* (2000) Prophylactic surgery decisions and surveillance practices 1 year following *BRCA1/2* testing. *Prev Med*, *1,* 75–80.

Lerman, C., Narod, S., Schulman, K., Hughes, C., Gomez-Caminero, A., Bonney, G., *et al.* (1996). *BRCA1* testing in families with hereditary breast-ovarian cancer. *JAMA*, *275*(24), 1885–1892.

Lipkus, I. M., & Hollands, J. G. (1999). The visual communication of risk. *JNCI Monogr*, *25,* 149–163.

Lloyd, S., Watson, M., Waites, B., Meyer, L., Eeles, R., Ebbs, S., *et al.* (1996). Familial breast cancer: A controlled study of risk perception, psychological morbidity and health beliefs in women attending for genetic counseling. *Br J Cancer*, *74*(3), 482–487.

Lobb, E., Butow, P., Meiser, B., Barratt, A., Gaff, C., Young, M. A., *et al.* (2002). Tailoring communication in consultations with women from high-risk breast cancer families. *Br J Cancer*, *87*(5), 502–508.

Lobb, E., Butow, P., Meiser, B., Barratt, A., Gaff, C., Young, M. A., *et al.* (2003). Women's preferences and consultants' communication of risk in consultations about familial breast cancer: Impact on patient outcomes. *J Med Genet*, *40*, e56.

Lobb, E., Butow, P., Meiser, B., Barratt, A., Gaff, C., Young, M. A., *et al.* (2004). Communication and information-giving in high-risk breast cancer consultations: Influence on patient outcomes. *Br J Cancer*, *90*(2), 321–327.

Meiser, B., Butow, P., Barratt, A. L., Friedlander, M., Gattas, M., Kirk, J., *et al.* (1999). Screening utilisation and attitudes to prophylactic oophorectomy in women at increased risk of developing hereditary ovarian cancer. *Gynecol Oncol*, *75,* 122–129.

Moore, A., & Butt, D. (2004). *Risk and meaning potential: why a network?* Paper presented to International Systemic Functional Linguistics Conference, Koyoto, August 30–September 4, 2004.

National Health and Medical Research Council. (1999). *How to present the evidence for consumers: Preparation of consumer preparations.* (ISBN 1864960388) Canberra: Commonwealth of Australia, 1999.

National Health and Medical Research Council. (1999) *Familial aspects of cancer: a guide to clinical practice.* (ISBN 1 8864960205) Canberra: Commonwealth of Australia.2000.

Rebbeck, T. R., Levin, A. M., Eisen, A., Snyder, C., Watson, P., & Cannon-Albright, L. (1999). Breast cancer risk after prophylactic oophorectomy in *BRCA1* mutation carriers. *JNCI*, *91*(17), 1475–1479.

Rimer, B. K., & Glassman, B. (1999). Is there a use for tailored print communications in cancer risk communication? *JAMA Monogr*, *25,* 140–148.

Rothman, A. J., & Kiviniemi, M. T. (1999). Treating people with information: An analysis and review of approaches to communicating health risk information. *JAMA Monograph*, *25,* 44–51.

Schwartz, M. D., Kaufman, E., Peshkin, B. N., Isaacs, C., Hughes, C., DeMarco, T., *et al.* (2003) Bilateral prophylactic oophorectomy and ovarian cancer screening following *BRCA1*/*BRCA2* mutation screening. *J Clin Oncol*, *21,* 4034–4041.

Shiloh, S., Avdor, O., & Goodman, R. M. (1990) Satisfaction with genetic counseling: Dimensions and measurement. *Am J Med Genet*, *37,* 522–529.

Sinclair, J., & Coulthard, M. (1975). *Towards and analysis of discourse. The English used by teachers and pupils*. London: Oxford University Press.

ten Have P. (1989). The consultation as a genre. In B. Torode (Ed.), *Text and talk as social practice* (pp. 115–135). Dordrecht: Foris.

Thewes, B., Meiser, B., & Hickie, I. (2001). Validation of the impact of events scale in women at increased risk of developing hereditary breast cancer. *Psychoncology*, *10*(6), 459–468.

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatr. Scand*, *67*(6), 361–370.