What do women really want to know? Motives for attending familial breast cancer clinics

C J van Asperen, S van Dijk, M W Zoetewij, D R M Timmermans, G H de Bock, E J Meijers-Heijboer, M F Niermeijer, M H Breuning, J Kievit, W Otten

J Med Genet 2002;**39**:410–414

Genetic counselling is a highly specialised service in medical care. The service is expensive and its task is comprehensive, including “starting a communication process which deals with the human problems associated with the risk of occurrence of a genetic disorder in a family”.¹ For a breast cancer service, this process is an attempt to assist the counsellee in understanding the medical facts, the mode of inheritance, the risk of getting breast and/or ovarian cancer (again), and the implications for daily life. Options for dealing with the risk are discussed and counsellees, depending on their own cumulative risk of getting breast cancer, are presented with a choice of surveillance of their breasts, DNA testing, or prophylactic mastectomy, either with or without oophorectomy.

An ever increasing number of women from breast cancer families visit familial cancer clinics for genetic counselling. Because of the comprehensive task of genetic counselling and the increasing numbers of appointments, it is important that the geneticist optimally and efficiently recognises the informational needs that are essential to the counsellee.² For the counsellee, it is important that she should receive all the information to make a conscious choice. One possible approach is to assess the specific motives for women to attend a familial breast cancer clinic. In this respect, different sets of motives may require different sets of information. Several studies have examined individual motives for attending familial breast cancer clinics and much insight has been gleaned into the most common ones.^{3–9} Motives often encountered for attending these clinics included: “to find out my risk”, “knowledge of my family history”, “to find out the risk to other family members”, “to reduce my worry”, “to find out about genetic testing”, and “to get information about preventive methods”. Some of these studies^{3–4,10} simply focused on a single aspect of genetic counselling, namely DNA testing, but did not include any of the other options counsellees are confronted with, such as breast surveillance or prophylactic mastectomy. Most of these previous studies have focused exclusively on healthy women.^{8–11–13} To our knowledge, only one study has included women with a previous history of breast cancer.⁶ To the best of our knowledge, no other study has ever compared the motives of affected and unaffected women who have attended a familial breast cancer clinic.

Recently, a comprehensive study⁸ examined the motives for attending familial breast cancer clinics and showed that women who endorsed different motives also differed in demographic, medical, and psychological factors. For example, those women who were mainly interested in establishing the risk for family members were generally older than women who had other motives. However, one restriction of this study was that women had to choose just one out of 10 motives, so that mutually exclusive groups could be established. The authors admitted that women might have had multiple motives and that there might have been a general pattern of combined motives. Development of a methodology that would allow women to register multiple reasons would provide more insight into this issue.

The broad population of women from breast cancer families who seek genetic counselling is composed of women both with and without a history of breast cancer from families with and without an identified mutation. For these reasons, the present study includes this whole population of women. It could well be that these two medical factors, that is, a history of breast cancer and a *BRCA* mutation in the family, could influence the type of motives that induce women to seek counselling. Another factor, which may influence motives for seeking advice not yet addressed in published reports, is whether the counsellees had children. The current study has attempted to assess the impact of these three factors, in association with sociodemographic factors such as age and educational level, that prompts women to visit a family cancer clinic. For the very reason that some factors are related, like having children, age, and a history of breast cancer, we have examined the individual effect of each factor.

The primary goal of this study is to examine whether motives mentioned for seeking genetic counselling are mutually related, in order to identify subgroups of counsellees with a specific cluster of informational demands. Secondly, we studied whether sociodemographic and medical characteristics influence the different motives for genetic counselling.

PATIENTS AND METHODS

Patients

Data were collected as part of an continuing study on risk perception and decision making of women at risk for familial breast cancer at the Departments of Clinical Genetics in Leiden and Rotterdam (“Chances and Choices” study). The medical ethics committees of both the Leiden University Medical Center and the Rotterdam University Hospital approved the study protocol. Eligible women had a personal or familial history of breast cancer and were attending the clinic for genetic counselling.

Referrals were based on current guidelines.¹⁴ Additional criteria for participation were fluency in the Dutch language, being older than 18 years, and not at a terminal stage of cancer. From November 1998 (Leiden) and from January 2000 (Rotterdam) until December 2000, all new counsellees referred for familial breast cancer were informed about this study by letter. Women gave their written informed consent and received a first questionnaire, a few days to a few weeks before their first appointment with a clinical geneticist. In total, four questionnaires were collected but the data presented in this study were collected only from the first questionnaire. A total of 539 women were asked to participate in the study and 322 (60%) returned the first questionnaire. Of those who returned their questionnaire, 244 (76%) were eventually seen at the Department of Clinical Genetics at Leiden and 78 (24%) women at the Department of Clinical Genetics at Rotterdam.

Both departments generally used the same protocol for genetic counselling. This included consultation with either a

Table 1 Medical history and sociodemographic characteristics of counsellees (n=322)

	All counsellees	
	No	%
Breast cancer in history	96	30
Mutation already detected in family	37	12
Having children	230	71
Education		
Higher technical or vocational training or a university degree	153	48
Married or cohabiting	251	78
Centre		
Leiden	244	76
Rotterdam	78	24
Age		
≤41 years	158	49
>41 years	164	51

clinical geneticist or genetic nurse. All available management options for the counsellee and her relatives were routinely discussed, a family history was taken, a risk estimation was made, and information about surveillance was given, if applicable. DNA testing was offered if there was a probability of mutation detection of about 10% or more. The choice between prophylactic mastectomy and surveillance, as options for potential *BRCA1* or *BRCA2* mutation carriers, was discussed.

Measurement

Medical and sociodemographic characteristics

Information was collected on personal history of breast cancer, age, educational level, and having had children. Furthermore, the marital status of the counsellee and whether a *BRCA1* or *BRCA2* mutation had already been detected in the family was registered. Mutation status was self-reported.

Motives for attending familial breast cancer clinics

Counsellees were asked to tick all-important motives from a list of 12. This list was based on previous research on Huntington's disease and familial breast cancer and clinical experience of the team (clinical geneticist, psychologist, oncologist).^{3-9 15 16}

Statistical analysis

The SPSS 10.0 statistical package for Windows was used to analyse the data. For the description of the medical and sociodemographic characteristics of the counsellees, frequencies, means, and standard deviations were used. In order to investigate if the motives mentioned for seeking genetic counselling were mutually related, women could select the most important motives from a list of 12. Firstly, the number of

motives was counted by summing all motives selected, which ranged from 0 to 12. Secondly, the kind of motives for each number of motives that were selected were also assessed. Thus, theoretically, for the number of 0 and 12 motives, only one combination could be identified (that is, 0 motives selected or all 12 motives selected); for the number of 1 motive selected, 12 separate motives could be identified; for the number of 2 motives, 66 pairs of different motives could be distinguished; for the number of 3 motives, 220 different triplets of motives could be differentiated, and so on. To check whether a possible variety of chosen motives was uncommon or not, the most common number of motives (three) were examined in closer detail. Logistic multivariate regression analysis was applied to predict the endorsement of motives, as dependent variables, and by several medical and sociodemographic characteristics, as independent variables. In the analyses, only motives selected by more than 5% of the counsellees were used. Some characteristics were dichotomous by themselves, such as "having breast cancer, yes or no". Others like "age" and "education" were dichotomised so that all predictor variables would have the same number of categories in order to give equal weight to all predictors and to ease the interpretation of the odds ratio.

A complete overview of all characteristics and their dichotomisation follows: "breast cancer" (no = 0, yes = 1); "age" (age 41 years and younger = 0, age above 41 years = 1); "mutation known in family" (no = 0, yes = 1); "having children" (no = 0, yes = 1); education (higher technical or vocational training or a university degree; under this level = 0, conform = 1); "married or cohabiting" (no = 0, yes = 1). The two participating centres in this study were categorised as Leiden = 0, Rotterdam = 1.

Presentation is limited to relevant and/or significant odds ratios, starting with the most frequent predictors. Relevant odds ratios have values smaller than 0.5 or larger than 2. Significant odds ratios have p values ≤0.05. In order to balance the relevance versus the significance of the results, both pieces of information are presented

RESULTS

Description of participants

The majority of the counsellees (70%) were unaffected by breast cancer (table 1). The mean age of the whole group of women was 41 years (SD 11.24 years, range 18-72 years). In 12% of the counsellees, a mutation had already been detected in the family, before their first visit to a family cancer clinic. Most women had children (71%) and were either married or living together (78%). The educational level was high; almost half of the women had higher technical or vocational training or a university degree. Three-quarters of the counsellees were seen at the Department of Clinical Genetics in Leiden. There were no differences between the counsellees of the two

Table 2 Motives of counsellees for attending a family breast cancer clinic (n=322)

Motive*	No	%
I want to know if cancer in my family is hereditary	238	74
I want to have more certainty about my own risk of getting breast cancer	223	69
I want to have more certainty about the risk of getting cancer for my children	150	47
Because my physician advised me to make an appointment	122	38
I want a DNA test	122	38
I want to get surveillance of my breasts	111	35
I am worried about getting cancer (again)	106	33
I want to help scientific research	46	14
I am thinking about prophylactic mastectomy	39	12
Because a family member asked me to make an appointment	24	8
I want to raise a family	13	4
I want to plan my future	8	3

*More than one motive could be selected.

Table 3 Number of motives chosen by counselees and number of combinations of these motives

No of motives	No of counselees		No of combinations
	No	%	
1	13	4	8
2	39	12	18
3	102	32	47
4	73	23	29
5	48	15	37
6	27	8	27
7	14	4	14
8	4	1	4
9	2	1	2
10	0	0	0
11	0	0	0
12	0	0	0
Total	322	100	186

participating centres, except for the percentage of women with a known mutation in the family, which was higher in Rotterdam (28%) than in Leiden (9%). For this reason "Centres" was included as one of the variables in the multivariate logistic regression analyses.

Description of motives

Table 2 describes the selected motives. From the possible 12 motives, the mean number selected was 3.8 motives (SD 1.54 motives, range 1-9 motives). Two motives were important for the majority of counselees: "I want to know if cancer in my family is hereditary" (74%) and "I want to get more certainty about my own risk of getting cancer" (69%). Five motives were chosen by a third to a half of the participants, namely motives concerning children's risk of getting cancer, physician's advice to make an appointment, breast surveillance, DNA test, and breast cancer worry. Motives concerning future planning and raising a family were chosen by less than 5% of the counselees.

Combinations of motives

Table 3 provides an overview of the possible combinations of motives chosen by the 322 counselees. The majority of women had chosen an individual combination of three or four motives. Overall, the selected number of motives by the participating women could be divided into 186 different combinations. For example, 13 counselees had chosen one motive. These 13 motives consisted of eight different motives. Nine motives were selected by two counselees and both had chosen a different combination. To examine in more detail whether only unique combinations of motives could be differentiated, we focused on the 102 counselees who had chosen the most common number, that is three motives. In this case, a total of 47 triplets could be discerned (that is, about two women per triplet). The triplet consisting of the three most selected motives (table 2) was chosen by 10 counselees only. These results show that no clusters of motives could be identified.*

Predicting motives

Having a medical history of breast cancer was a significant predictor for five motives (table 4). Affected women less frequently endorsed the two motives regarding their own risk of getting breast cancer and regarding breast surveillance.

*Each kappa for pairs of motives was less than 0.17, which is generally classified as poor.

Table 4 Multivariate analysis to assess unique contribution of counselees' medical and sociodemographic characteristics as predictors for motives

Motives	Medical and sociodemographic characteristics					
	Previous history of breast cancer	Mutation already detected in family	Education	Age	Married or living together	Children
I want to know if cancer in my family is hereditary	1.22	0.13***	0.78	1.68	1.10	0.66
I want to have more certainty about my own risk of getting breast cancer	0.09***	1.36	1.05	0.49*	0.53	0.90
I want to have more certainty about the risk of getting cancer for my children	3.43***	2.22	0.73	1.91*	0.76	29.34***
Because my physician's advised me to make an appointment	0.80	0.62	1.23	1.35	1.23	0.81
I want to get surveillance of my breasts	0.40**	0.85	0.81	0.77	1.27	0.64
I want a DNA test	0.90	1.59	1.18	1.36	1.42	1.23
I am worried about getting cancer (again)	4.68***	1.00	1.08	0.50*	1.00	0.68
I want to help scientific research	2.96***	2.13	0.63	2.24*	0.40*	0.91
I am thinking about prophylactic mastectomy	1.15	0.15	1.23	0.33**	1.79	2.15
Because a family member asked me to make an appointment	1.3	4.07**	0.47	1.53	0.77	1.00

Roman type: relevant odds ratio exp (B) <0.5 or >2.

Bold: Odds ratio exp (B) between 0.5 and 2.

Italics: significant odds ratio only.

*p<0.05; **p<0.01; ***p<0.001.

However, they selected more often the motives regarding the risk of their children getting breast cancer, worry about getting cancer again, and helping scientific research.

If a *BRCA1* or *BRCA2* mutation had already been detected in the family of a counsellee, these women were less often interested in the genetics of breast cancer in their family. They selected more often the motive “because a family member asked me to make an appointment for genetic counselling”. This group of women from *BRCA1* or *BRCA2* families endorsed motives concerning the risk of getting breast cancer for their children and helping scientific research. These women chose less often the motive of prophylactic mastectomy.

Age was also a predictor of five motives. Younger women were more often interested in motives regarding their own risk of breast cancer and prophylactic mastectomy. They were also more interested in the motive regarding cancer worry. Older women were more willing to help scientific research and were interested in the risk of their children getting cancer.

Having had children was a very strong predictor for the motive of the counsellee’s children getting breast cancer and also for the motive of prophylactic mastectomy.

Women with a lower level of education were more often asked by a family member to make an appointment for genetic counselling. Married women or women living together less frequently endorsed the motive to help scientific research. In the Leiden Centre, more women were interested in the motive concerning breast surveillance, in the Rotterdam Centre more women chose the motive of prophylactic mastectomy.

Two motives could not be predicted, namely the motive “Because my physician asked me to make an appointment” and “I want a DNA test”.

DISCUSSION

The principal results of this study were two-fold. Firstly, based on a population of women seeking advice at two familial breast cancer clinics, we conclude that women have their own unique combination of motives when seeking advice. Secondly, although clear cut clusters of motives were not detectable, some medical and sociodemographic characteristics could be used to focus on the informational needs and demands of the counsellee.

The present study clearly shows that two motives are the most chosen. As could be expected, most women want to be informed about the genetic nature of breast cancer and their own risk. In addition, our results indicate that an average woman had about four motives for seeking medical advice at the familial cancer clinic. These additional motives illustrate the restrictive nature of the method of Brain *et al.*,⁵ which exclusively assigned women to just one motive.

Counsellees with a personal history of breast cancer are a special group and represent 30% of the women in this study. The data confirm the results of a French study⁶ that reported that such women attended the clinic mainly for their offsprings’ sake. These women with a history of breast cancer wanted to be informed about their children’s risk of getting breast cancer and were less concerned about their own risk. From the present study, we conclude that this group of women was also worried about their own cancer recurrence risk. A higher risk for a contralateral tumour is one of the characteristics of hereditary cancer.¹⁷ This could explain why women with a personal history of breast cancer were more worried than those who had no previous history.

If a *BRCA1* or *BRCA2* mutation had already been detected in the family of a counsellee, these women were less often interested in the genetic nature of the breast cancer in their families, since this had already been proven. One could argue that women from *BRCA* families seriously consider a prophylactic mastectomy as one of the options. However, it appeared that these women, with a 25% or 50% risk of having a *BRCA1* or *BRCA2* mutation, less often endorsed the motive of prophylac-

tic mastectomy. A possible explanation is that these women will only start to think about surgical intervention when they actually receive their own DNA test result and not at the beginning of the genetic counselling process, when the present data were collected.

Younger women were especially interested in their own risk of getting breast cancer and options for prophylactic mastectomy; furthermore they were also worried about recurrence of cancer. As published earlier,¹⁸ serious psychological morbidity may not be prevalent in the general population of younger women at increased risk of breast cancer. However, many of these women may have breast cancer worries that have the potential to compromise their quality of life. It is understandable that younger women would be more worried about the consequences of breast cancer, which could compromise the goals they wanted to attain.

Having had children clearly is a predictor for enquiring about the children’s risk of getting cancer. These women more often endorsed the motive of prophylactic mastectomy. Parenthood was found to be an important predictor of surgical intervention in the Rotterdam centre.¹⁹ It is understandable that parenthood would give women a strong feeling of responsibility. They want to survive to bring up their children, even if a mutilating and irreversible intervention is needed for their future health.

One limitation of our study could be related to the list of preselected motives that we have compiled for the counsellees. Such a list could induce the counsellee to select more than one main topic and this would partially explain the multiple reasons for attending a familial cancer clinic. In addition, our list may not completely represent all the motives that our counsellees considered relevant. Furthermore, a methodology that would allow women to indicate the extent to which a specific motive applied to them might be more sensitive in the detection of clusters of motives than the dichotomous measure used in the present study.

One fundamental question, which needs to be addressed, is whether women’s motives for attending a familial breast cancer clinic for genetic counselling correctly identify their informational needs. These motives have often been formed before their first consultation. However, women’s informational demands could also be influenced by the information they receive during the genetic counselling process. For example, they may learn about new possibilities, for example, prophylactic mastectomy, or they may realise the restrictions of a DNA test. The issue would then be whether women’s pre-counselling motives should completely guide the communication during the genetic consultation or whether a specific programme of information should be communicated irrespective of women’s motives. This in turn raises the question of the content of that specific programme of information. Should information about all aspects of familial breast cancer be communicated so that counsellees can make an informed choice? A possible drawback of this could be that a fully comprehensive programme of information would confuse and frighten the counsellee to such an extent that she would be unable to come to terms with the situation.

However, we can conclude that most women would like to be informed about the genetics of breast cancer and their own risk. Some medical and sociodemographic characteristics of the counsellee might determine a special interest. Four specific characteristics appear important to understand these reasons for additional information: having a history of breast cancer, having a *BRCA* mutation in the family, having children, and the age of the counsellee.

These medical and sociodemographic characteristics should be considered, as specific areas of the information can be dealt with more thoroughly. For example, if a young breast cancer patient applies for genetic counselling, one should pay extra attention to her feelings and emotions concerning her chance of getting breast cancer again. Similarly, the topic of

prophylactic mastectomy can be talked through more extensively for younger women with children. Having a *BRCA* mutation in the family seems to bring on a kind of step by step approach by the counsellor. They start up the process of genetic counselling, are waiting for the test result, and will continue this process by taking a decision about surveillance or prophylactic surgery. In this manner, communication during the genetic counselling process could be more tailored to suit the individual person.

ACKNOWLEDGEMENTS

The authors wish to acknowledge the assistance of Mrs N van Duyn-Bakker in preparing this manuscript. The authors gratefully acknowledge the contribution of Dr G C Beverstock for critical review of this manuscript. This work was supported by the Dutch Cancer Society (grant RUL 98-1740).

Authors' affiliations

C J van Asperen, M W Zoetewij, M H Breuning, Department of Human and Clinical Genetics, Leiden University Medical Center, Leiden, The Netherlands

S van Dijk, G H de Bock, J Kievit, W Otten, Department of Medical Decision Making, Leiden University Medical Center, Leiden, The Netherlands

D R M Timmermans, Department of Social Medicine, VU University Medical Center, Amsterdam, The Netherlands

E J Meijers-Heijboer, M F Niermeijer, Department of Clinical Genetics, University Hospital Rotterdam, The Netherlands

Correspondence to: Dr C J van Asperen, Department of Human and Clinical Genetics, Leiden University Medical Center, K5-R, PO Box 9600, 2300 RC Leiden, The Netherlands; asperen@lumc.nl

REFERENCES

- 1 **Fraser FC**. Genetic counselling. *Am J Med Genet* 1974;**26**:636-59.
- 2 **Shankar A**, Chapman P, Goodship J. Genetic counselling: do we recognise and meet the consultands' agenda? *J Med Genet* 1999;**36**:580-2.
- 3 **Lerman C**, Daly M, Masny A, Balshem A. Attitudes about genetic testing for breast-ovarian cancer susceptibility. *J Clin Oncol* 1994;**12**:843-50.
- 4 **Watson M**, Murday V, Lloyd S, Ponder B, Averill D, Eeles R. Genetic testing in breast/ovarian cancer (BRCA1) families. *Lancet* 1995;**346**:583.
- 5 **Julian-Reynier C**, Eisinger F, Chabal F, Aurran Y, Nogues C, Vennin P, Bignon YJ, Machelard-Roumagnac M., Maugard-Louboutin C, Serin D, Versini S, Mercuri M, Sobol H. Cancer genetics clinics: target population and consultees expectations. *Eur J Cancer* 1996;**32**:398-403.
- 6 **Julian-Reynier C**, Eisinger F, Chabal F, Aurran Y, Nogues C, Machelard M, Maugard C, Vennin P, Sobol H. Cancer genetic clinics: why do women who already have cancer attend? *Eur J Cancer* 1998;**34**:1549-53.
- 7 **Bleiker EMA**, Aronson NK, Menko FH, Hahn DEE, van Asperen CJ, Rutgers EJT, ten Kate LP, Leschot NJ. Genetic counseling for hereditary cancer: a pilot study on experiences of patients and family members. *Patient Education and Counseling* 1997;**32**:107-16.
- 8 **Brain K**, Gray J, Norman P, Parsons E, Clarke A, Rogers C, Mansel R, Harper P. Why do women attend familial breast cancer clinics? *J Med Genet* 2000;**37**:197-202.
- 9 **Metcalf KA**, Lies A, Hoodfar E, Scott A, Foulkes WD, Narod SA. An evaluation of needs of female BRCA1 and BRCA2 carriers undergoing genetic counselling. *J Med Genet* 2000;**37**:866-74.
- 10 **Capelli M**, Surh L, Humphreys L, Verma S, Logan D, Hunter A, Allanson J. Psychological and social determinant of women's decisions to undergo genetic counseling and testing for breast cancer. *Clin Genet* 1999;**55**:419-30.
- 11 **Audrain J**, Rimer B, Cella D, Garber J, Peshkin BN, Ellis J, Schildkraut J, Stefanek M, Vogel V, Lerman C. Genetic counseling and testing for breast-ovarian cancer. Susceptibility: what do women want? *J Clin Oncol* 1998;**16**:133-8.
- 12 **Bowen D**, McTiernan A, Burke W, Powers D, Pruski J, Durfy S, Gralow J, Malone K. Participation in breast cancer risk counseling among women with a family history of breast cancer. *Cancer Epidemiol Biomark Prev* 1999;**8**:581-5.
- 13 **Burke W**, Culver JO, Bowen D, Lowry D, Durfy S, McTiernan A, Andersen MR. Genetic counseling for women with an intermediate family history of breast cancer. *Am J Med Genet* 2000;**90**:361-8.
- 14 **de Bock GH**, Vliet Vlieland TP, Hageman GC, Oosterwijk JC, Springer MP, Kievit J. The assessment of genetic risk of breast cancer: a set of GP guidelines. *Fam Pract* 1999;**16**:71-7.
- 15 **Tibben A**, Frets PG, van de Kamp JJ, Niermeijer MF, Vegter-van der Vlis M, Roos RA, van Ommen GJ, Duivenvoorden HJ, Verhage F. Presymptomatic DNA-testing for Huntington disease: pretest attitudes and expectations of applicants and their partners in the Dutch program. *Am J Med Genet* 1993;**48**:10-16.
- 16 **Dudok de Wit AC**. Thesis, Erasmus University Rotterdam, The Netherlands, 1997.
- 17 **Anderson DE**. Some characteristics of familial breast cancer. *Cancer* 1971;**28**:1500-5.
- 18 **Lerman C**, Kash K, Stefanek M. Younger women at increased risk for breast cancer: perceived risk, psychological well-being, and surveillance behavior. *J Natl Cancer Inst Monograph* No 16, 1994.
- 19 **Meijers-Heijboer EJ**, Verhoog LC, Brekelmans CT, Seynaeve C, Tilanus-Linthorst MM, Wagner A, Dukel L, Devilee P, van den Ouweland AM, van Geel AN, Klijn JG. Presymptomatic DNA testing and prophylactic surgery in families with a BRCA1 or BRCA2 mutation. *Lancet* 2000;**355**:2015-20.