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Original Paper

Cancer Genetic Clinics: Why Do Women Who Already Have Cancer Attend?

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Cancer patients attend oncogenetic clinics so that the existence of a genetic risk can be checked and the relatives informed. The aim of this study was to describe the expectations of cancer patients about genetic counselling and their beliefs about the aetiology of their disease. A survey based on self-administered questionnaires before and after the consultation was carried out on 115 women with breast/ovarian cancer who attended one of the six French participating clinics. In 59 cases (51)%, the consultees' expectations focused on the preventive options available and in 86 cases (75%) on their offspring; 87 (76%) found the consultation informative. On average, the women rated heredity and diet as lower risk factors ($P < 0.05$) after the consultation than before. Heredity, stress and the environment were thought to be more decisive than diet, smoking and alcohol. 34 patients who seemed unlikely to have a genetic risk in the consultant's opinion thought heredity to be less relevant ($P < 0.05$) after the consultation than before. At the time of the survey, cancer patients accounted for at least half of the consultees attending oncogenetic clinics in France. They need to have the clinical specificities of their disease and its medical management explained. They attend mainly for their offspring's sake, whereas healthy clients attend for their own sake. © **1998 Published by Elsevier Science Ltd. All rights reserved.**

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INTRODUCTION

FAMILY CANCER clinics were introduced in the 1990s in North America and Europe [1, 2] and some of the people who attend them already have cancer. The reason why it is useful to determine whether cancer patients belong to 'at risk' families is that this knowledge can be used to predict whether these patients risk having another cancer, to guide surgical prophylactic decisions and to organise preventive strategies for the patients' healthy relatives. The attendance of cancer patients is now of use to their relatives: if a person who has already developed the disease is found to carry a mutation of one of the identified *BRCA* genes, this information will greatly facilitate future biological testing and may become necessary for their interpretation. Since physicians are advised not to contact directly the relatives 'at risk' who have not attended the consultations, cancer patients also serve as messengers, since they carry information back to the other members of the family [3]. Here the family practitioner plays a key role in helping affected patients to communicate this distressing information to their families. Lastly, cancer genetic research workers need to be able to determine the biological characteristics of both the genetic and non-genetic forms of cancer more closely to be able to weigh up the biological and clinical issues involved. Patients with cancer, therefore, provide a valuable source of information for this purpose.

Although healthy consultees' expectations, risk perception, health beliefs and needs for information about cancer genetic consultations have been described previously [3–6], no studies of this kind have been performed to our knowledge on patients with cancer.

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The number of consultees attending cancer genetic clinics in France every year [7] was estimated to be approximately 2000: 61% of the consultees had cancer, and 39% did not. At most of the 29 French cancer genetic centres registered in 1994–1995, the annual number of attendants was less than 50 and only some of the larger centres dealt with more than 100 consultees every year. Women who have already developed breast or ovarian cancer account, at present, for a large proportion of all the referrals to cancer genetic clinics in France. As the result of recent findings in gene research, they are now being invited to attend 'routine' family cancer clinics. The aim of this study was to describe the expectations and beliefs of women in this category attending cancer genetic clinics for the first time, as opposed to routine biological testing. This study was carried out at cancer genetic clinics located in six French cities, one at a large centre (Marseille) and five smaller ones.

MATERIALS AND METHODS

Population sample

The six regional cancer centres participating in this study were selected with a view to giving a representative picture of the French population as a whole (South: Marseille, Toulouse; North: Lille; West: Nantes; Centre: Paris/St-Cloud, Clermont-Ferrand) and covered a population of more than 4 million inhabitants in total. All adult female cancer patients with breast or ovarian cancer attending these cancer genetic clinics for the first time between January 1994 and January 1995 were asked to participate. They amounted to 51 cases in Marseille, 21 in Paris/St-Cloud, 17 in Lille, 13 in Clermont-Ferrand, 7 in Toulouse and 6 in Nantes. The protocol was approved by the 'Commission Nationale Informatique et Libertés'.

Consultee's questionnaires

The patients were asked to complete a standardised 15 min questionnaire (90 closed items) in the waiting room prior to the consultation, before having any contact with a cancer geneticist. Those who agreed to participate were then mailed a second 'home' questionnaire (closed and open questions) within 1 week of the consultation.

The referral pathways were described as: physician, family or self referral. The patient's willingness to attend the clinics when advised to do so by a physician was assessed on the following scale: coming only on the physician's insistence, being willing to comply with the physician's proposal, very much wanting to come to the clinics.

Expectations about the consultation were defined in terms of the type of information sought (risk, prevention, other) and the person to whom it applied (the consultee him or herself, children, parents, siblings, etc).

Beliefs about the contribution of six risk factors (diet, heredity, stress, smoking, alcohol, the environment) to the occurrence of their own cancer were measured with a 5-item Likert scale (from 1, 'no importance' to 5, 'very great importance') before and after the consultation. For the analysis, the percentage scores on items 4 and 5 were grouped together and compared before and after the consultation. The perception of a family risk of cancer was assessed via the question : 'Do you think your relatives have a higher risk of cancer than the members of other families?' with a yes/no answer proposed and an open space in which a free statement could be written as to why they thought their family was 'at risk'.

The degree of satisfaction about the content of the consultation was assessed in the postconsultation questionnaire on the basis of three questions: (1) Did the consultation answer the questions you had in mind?; (2) What do you feel about the consultation/was it useless?; (3) was it informative?, with five possible answers (disagree, weakly disagree, weakly agree, agree, undecided).

Details of the patients' sociocultural background (age, level of education, occupational field, number of children, place of residence) were also collected.

An open space was left at the end of the 'home' questionnaire for any spontaneous comments.

Consultant's questionnaire

After each consultation, a two page closed-item questionnaire was completed by the cancer geneticist about the content of the consultation. It included questions as to which of the consultee's relatives had been affected by cancer, which organs were involved, and whether there was a cancer risk running in the family (Figure 1) based on the usual medical criteria (number of first-degree relatives affected, age at onset, bilateral cancer). The probability of having or not having a cancer gene in the family was the main point assessed and used here in the analysis. It was collected on a 10-item Likert scale (from 1, 'not with certainty' to '10, yes with certainty' with a mid-point 5, 'undetermined'. Those with a high score (> 7) were from families corresponding to the criteria adopted at the national level for defining high-risk families, namely: (1) at least 3 cases of breast/ovarian cancer among the first and second-degree relatives on one side of the family; (2) cancer occurring in 2 first-degree relatives including at least 1 case where age of onset was less than 40 years, or where a male relative was involved; (3) 1 case of breast cancer and 1 case of ovarian cancer or 2 cases with an ovarian cancer among the first-degree relatives [8]. According to the Claus model, this corresponds to at least a 65% risk of being genetically predisposed to cancer [8, 9].

Assessing the individual risk levels of those patients who had already developed a cancer, based on current models, such as those previously described [9–11], was not the main

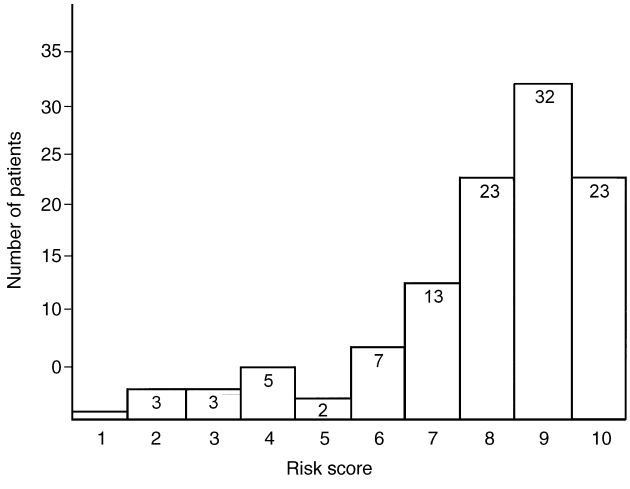

Figure 1. Cancer geneticist's assessment of the genetic risk running in the patient's family from 1 ('definitely not at risk') to 10 ('definitely at risk') ($n = 112$ out of 115). The figures in the rectangles are the numbers of subjects obtaining each risk score.

point. Nor did we deal here with some of the items of risk information with which the consultees were provided at the consultation, such as the probability of having or not having inherited a cancer gene if it was present in the family, the probability of developing or not developing cancer when the gene was present and the probability of developing a cancer when the gene was not present.

Statistical analysis

Descriptive statistics and univariate comparisons were carried out with the SPSS statistical package 6.1, and the level of statistical significance was set at a type 1 error lower than 0.05. Paired comparisons were carried out on the 'before' versus 'after' opinions about the importance of risk factors with non-parametric tests (Wilcoxon paired *t*-test and McNemar test). Non-parametric correlations (Spearman test) were carried out to compare the physician's and the patient's assessment of the family risk.

RESULTS

Sociodemographic characteristics of the sample

During the study period, there were 138 eligible women among the 452 consultees attending the cancer genetic clinics: 115 (83%) of them completed the two questionnaires and were analysed here.

Among the respondents, 106 (92%) had breast cancer, 5 (4%) ovarian cancer and 4 (4%) breast and colorectal or breast and ovarian cancer. Their average age was 52.9 years (standard deviation (SD) = 11.7), 83 (72%) were married, 106 (92%) had at least one child, and 38 (33%) had completed studies at more than high school level. These 115 women who answered the pre- and postconsultation questionnaires did not differ in terms of their age, educational level or risk status from the 23 who did not answer them.

Referrals

91 patients (79%) were referred by their physicians, 5 by general practitioners and 86 by specialists; 15 (13%) came by themselves; 3 (3%) on the advice of their family; and 6 on that of other people (5%).

99 women (86%) had heard about cancer genetic clinics for the first time from their physician or from the staff working at cancer centres; the remaining 14% were informed about them by their family, friends or the media.

When the consultation was proposed by the physician ($n = 91$), 47 (52%) readily agreed, 29 (32%) said they wanted the consultation and 15 (16%) only went because the physician insisted that they should do so.

Of the 115 affected consultees, 96 (84%) had at least one first-degree relative with cancer (Table 1), 12 (10%) only a second-degree relative and 7 (6%) were the only person with cancer among their close relatives. The distribution of risks was shifted towards the right (Figure 1) with an average of 7 (SD = 2.17) and a median of 8. The families whose risks were given a score equal to or higher than 8 were those which fulfilled the criteria adopted by the cancer geneticists to define families at risk (see Materials and Methods for the definition of these criteria).

Expectations about cancer genetic clinics

59 women gave prevention as one of the reasons for attending (51%), 54 mentioned risk information (47%) and 44 their own disease surveillance (38%). Before the consultation, 93 (81%) expected to have a blood sample taken and 43 (46%) thought that it would be possible to screen the blood samples for cancer genes, which was not yet the case during the study period.

86 women (75%) wanted to obtain information focusing on their children, 33 (29%) on their siblings and 11 (10%) on their parents. 64 (56%) said that they also wanted information relating to themselves.

Table 1. Details of affected family members (n = 115)

Relatives affected by cancer					
Mother	Sister	Other first-degree	Second-degree	*n*	(%)
Yes	Yes	Yes or No	Yes or No	22	(19)
Yes	No	Yes	Yes or No	9	(8)
No	Yes	Yes	Yes or No	6	(5)
Yes	No	No	Yes	24	(21)
No	Yes	No	Yes	8	(7)
No	No	Yes	Yes	11	(10)
Yes	No	No	No	5	(4)
No	Yes	No	No	4	(3)
No	No	Yes	No	7	(6)
No	No	No	Yes	12	(10)
No	No	No	No	7	(6)
Total				115	(100)

Feelings about the consultation

Before the consultation, 69 (60%) indicated that they had some specific questions to put to the cancer geneticist and 55 (80%) were subsequently satisfied with the answers given by the consultant. After the consultation, the majority of patients declared that the consultation was useful or informative but a minority was less satisfied (Table 2). These indicators of satisfaction were not statistically associated with either the expectations or other characteristics, such as the referral pathways or the patients' willingness to attend.

Beliefs about the risk factors involved in breast/ovarian cancer

99 consultees (86%) thought before the consultation that there was a risk of cancer running in their family, and this was positively correlated with the subsequent cancer geneticist's estimation of the family risk (Spearman $r = 0.33$, $P < 0.001$). The events that led the 99 women to think there was a family cancer risk were dealt with in an open question (Table 3): nearly one-third of the consultees said they had believed this to be the case since the onset of their own disease, 18% because of the large number of cases in their family and 10% because of the vertical pattern of transmission of the disease. The influence of the media was mentioned only once.

The 115 women (Table 4) perceived the aetiological role of diet and heredity as being less important after the consultation than before ($P < 0.05$). The other factors (stress,

Table 2. Some feedback from the consultation (n = 115)

	Disagree	Weakly disagree	Weakly agree	Agree	Undecided
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
It was useless	79 (69)	3 (3)	2 (2)	9 (8)	22 (19)
It was informative	6 (5)	17 (15)	44 (38)	43 (37)	5 (4)

Table 3. *Event that led the women to think prior to the consultation that a genetic cancer risk was running in their family* (n = 99)—*open question*

Occurrence of own disease	31
Many cases occurring in the family	18
Thought so for years, but could not say exactly why	12
Vertical transmission of the disease	10
Sibling's cancer	8
Mother's cancer	7
Father's cancer	5
Children's cancer	2
Realised after a television show	1
No particular event	5
Total	99

environment, smoking and alcohol) listed on the questionnaire were not perceived differently after than before the consultation. The percentages of those uncertain were significantly ($P < 0.05$), lower after than before the consultation. Heredity was thought to be the most decisive factor, but stress and the environment obtained high scores, whereas diet, smoking and alcohol came last on the list.

Upon stratifying the analysis depending on the geneticist's conclusions as to whether or not there was a genetic risk running in the family, those ($n = 34$) who were less likely to have a genetic risk in the geneticist's opinion (score < 8) were found to perceive heredity as being less important ($P < 0.05$) after the consultation (21/34, 62%) than before (28/34, 82%). No measurable change was noted in the risk perception of those ($n = 78$) with whom the geneticist had the greatest certainty about the existence of a genetic risk (score > 7): they perceived 'heredity' both before (68/78, 87%) and after (62/78, 79%) the consultation as being an important/very important factor contributing to their own disease.

Some free comments were written on the questionnaire after the consultation by 55 women (48%; Table 5). On average, these patients had a higher educational level ($P < 0.01$), perceived their family risk of cancer as being higher ($P < 0.05$), and were also more easily upset by personal non-health problems ($P < 0.05$) than those who added no comments.

DISCUSSION

Since women with breast/ovarian cancer constitute a large proportion of all the people attending cancer genetic clinics, their needs have to be considered separately from those of healthy consultees, which have been analysed elsewhere [3].

Table 4. *Beliefs before and after the visit to the cancer genetic clinic about the relevance of various risk factors to their own cancer: percentages who thought the factor had great or very great importance*

Risk factor	Before the consultation *n*/total (%)	After the consultation *n*/total (%)	*P*†
Heredity	68/69 (71)	67/105 (64)	0.05
Stress	36/79 (46)	63/105 (60)	NS
Environment	26/63 (41)	35/89 (39)	NS
Diet	22/67 (33)	16/89 (18)	0.05
Smoking	22/66 (33)	21/98 (21)	NS
Alcohol	17/66 (26)	15/97 (15)	NS

The missing values correspond to the 'don't know' answer. †Paired comparisons: McNemar's test. NS, not significant.

Table 5. *Themes mentioned in free comments (open question)*—70 *free comments made by* 55 *persons*

	n
Own experience of the disease:	30 (55%)
History	
Disappointment with treatment	
Medical or family relationships	
Psychological needs	
Fear of relapsing	
More positive aspects of the disease (coping, supportive social network)	
Plea for preventive measures for their offspring	22 (40%)
Wish to know the cause of the disease	11 (20%)
Role of stress and other risk factors: 'if not genetics, then what?'	
Disappointment	3 (5%)
'My blood could not be used to help my children'	
'Interest was taken in the patient for scientific reasons but not as a person'	
'Thought more information would be available'	
Satisfaction with the quality of the medical relationship	4 (75)

In a recent study on 42 healthy women who attended genetic counselling for familial breast or ovarian cancer [6], it was recommended that written information should be delivered to consultees before they attend family history clinics, since some of the consultees in the study thought they would not be told their exact risk of cancer because little personal information was collected prior to the consultation.

In our study, the 115 breast/ovarian cancer patients tended to be older, and their expectations mainly focused on their offspring and on their own experience of their disease. What they stood to gain themselves by attending these clinics seemed to be mainly that their experience would help to prevent cancer in their family, but also that they would understand their illness better. As mentioned above, most of the likely genetic cancer patients already knew before the clinics that their family was 'at risk', and some may have felt there was nothing new about the medical information they received. Those not at risk may have been disappointed at not learning more about the aetiology of their disease, as mentioned in some of their free comments. Because of the lack of knowledge as to how effective preventive interventions may be, others may have been disappointed for their offspring's sake. The majority expressed a high level of satisfaction on the whole with the cancer genetic consultations, and the disappointment felt by the minority was likely to have been due to the reasons given above.

Genetics are now assumed to be involved in 5–10% of all cases of breast cancer. Affected patients' expectations about cancer genetic consultations will vary depending on the target population attending these clinics, which may differ from one country to another, as well as between the clinics in the same country. The target population might consist of outstanding genetic cases only, and stepwise referrals via organised medical channels, including all the medical practitioners in the country, could be arranged to select the most likely cancer genetic cases. Alternatively, the target population could be all those who think they have a family risk of cancer, which was

the case here, although the patients in the present study were referred mainly by medical specialists. Whatever the case may be, the information consultees are given about the aetiology of a case of cancer in a family should include not only the genetic factors but factors of other kinds possibly involved. Medical explanations may differ from lay representation of disease, and 'understanding the understanding of illness' [12] might be a key issue for the message to be communicated properly to the consultees' relatives. This process may be more satisfactory when the family practitioner is able to help the patient to understand the key issues underlying the genetic information received.

Cancer patients will always have to attend these clinics and serve as messengers by carrying information back to their family. It is important to realise that their main idea will be to search for aetiological causes, as all patients do when they discover that they have contracted a disease [12]. The specificities of the hereditary forms of cancer [13, 14], which will presumably become better known as time goes by, are, therefore, one of the key issues which need to be dealt with at these consultations. If patients are made aware of the recent medical recommendations for managing persons 'at risk' and informed that these recommendations are based not only on national assessments [15], but also on international ones, and also take into account the psychological and social aspects of this new clinical practice [16], they feel reassured about the real effort being made by cancer geneticists to comply with the best standards of medical management for themselves and their families, and with their duty to keep up with the latest developments in this fast growing field of knowledge.

1. Thompson JA, Wiesner GL, Sellers TA, *et al.* Genetic services for familial cancer patients: a survey of National Cancer Institute Cancer Centers. *J Natl Cancer Inst* 1995, **87**, 1446–1455.
2. Houlston RS, Murday V, Harocopos C, Williams CB, Slack J. Screening and genetic counselling for relatives of patients with colorectal cancer in a family cancer clinic. *Br Med J* 1990, **301**, 366–368.
3. Julian-Reynier C, Eisinger F, Chabal F, *et al.* Cancer genetic clinics: target population and expectations. *Eur J Cancer* 1996, **32A**, 398–403.
4. Lloyd S, Watson M, Waites B, *et al.* Familial breast cancer: a controlled study of risk perception, psychological morbidity and health beliefs in women attending for genetic counselling. *Br J Cancer* 1996, **74**, 482–487.
5. Evans DGR, Burnell LD, Hopwood P, Howell A. Perception of risk in women with a family history of breast cancer. *Br J Cancer* 1993, **67**, 612–614.
6. Hallowell N, Murton F, Statham H, Green J, Richards M. Women's need for information before attending genetic counselling for familial breast or ovarian cancer: a questionnaire, interview, and observational study. *Br Med J* 1997, **314**, 281–283.
7. Sobol H, Bignon Y-J, Cuisenier J, Lyonnet D, Noguès C, Eisinger F, Groupe Génétique et Cancer de la FNCLCC. Le groupe Génétique et Cancer de la FNCLCC. Les consultations d'oncogénétique en 1994 , analyse de l'activité: enquête sur 203 consultations. In Boiron M, ed. *Eurocancer* 95. Paris, John Libbey Eurotext, 1995, 43–46.
8. Stoppa-Lyonnet D, Noguès C, Sobol H, Eisinger F. Consultations de génétiqueet prédisposition génétique aux cancersdu sein. In *Risques héréditaires de cancers du sein et de l'ovaire. Quelle prise en charge?* Paris, INSERM, 1998, 179–191.
9. Claus EB, Risch N, Thompson WD. The calculation of breast cancer risk for women with a first degree family history of ovarian cancer. *Breast Cancer Res Treat* 1993, **28**, 115–120.
10. Berry D, Parmigiani G, Sanchez J, Schildkraut J. Probability of carrying a mutation of breast-ovarian cancer gene BRCA1 based on family history. *J Nat Cancer Inst* 1997, **89**, 227–238.
11. Gail MH, Brinton LA, Byar DP,*et al.* Projecting individualized probabilities of developing breast cancer for white females who are being examined annually. *J Nat Cancer Inst* 1989, **81**, 1879–1886.
12. Bishop GD. Lay disease presentations and responses to victims of disease. *Basic and Applied Social Psychology* 1991, **12**, 115–132.
13. Eisinger F, Stoppa-Lyonnet D, Longy M, *et al.* Germ line mutation at BRCA1 affects the histoprognostic grade in hereditary breast cancer. *Cancer Res* 1996, **56**, 471–474.
14. Verhoog L, Brekelmans C, Seynaeve C, *et al.* Survival and tumour characteristics of breast-cancer patients with germline mutations of BRCA1. *Lancet* 1998, **351**, 316–321.
15. Eisinger F, Alby N, Bremond A, *et al.* Recommendations for medical management of hereditary breast and ovarian cancer: the French National *ad hoc* Committee. *Ann Oncol* in press.
16. Burke W, Daly M, Garber J, *et al.* Recommendations for follow-up care of individuals with an inherited predisposition to cancer II. *BRCA1* and *BRCA2*. *JAMA* 1997, **277**, 997–1003.

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