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Special Paper

Cancer Genetics Clinics: Target Population and Consultees' Expectations

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The aim of this study was to determine in healthy consultees attending cancer genetics clinics their risk status, their pathways leading to the clinics, their expectations and perception of cancer risk. In 1994, the consultees at six French centres completed a questionnaire before their first oncogenetic consultation. The oncogeneticists subsequently filled in a standardised form giving their risk assessment. Among the 206 healthy consultees, 91.3% were women, 92.2% had at least one cancer-affected first-degree relative and 73% had a "cancer family risk" as assessed by the oncogeneticist. Sixty-nine per cent of the consultees were referred to the clinics by a physician, 10.4% by their family and 18.8% on their own initiative: 83.5% of the sample perceived their family risk of cancer as being high and this belief was confirmed in 74.3% of the cases studied by the oncogeneticist. The families of self-referred consultees were less often at risk than those of consultees referred by a physician or by their family ($P = 0.012$). The majority (78%) expected to be informed about cancer prevention and screening, and this expectation depended on the consultee's level of education ($P = 0.001$). This study shows that medical pathways are more effective than the media as a means of reaching the members of the general population who are genuinely at risk, and shows that fuller information about prevention needs to be provided at cancer genetic consultations.

Key words: cancer, clinical genetics, counselling, consultees, social epidemiology
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INTRODUCTION

THE WAY in which cancer genetic clinics have developed has differed from one country to another. The setting up of family cancer clinics was first mentioned in the literature in the early 1990s [1, 2]. The first cancer genetic clinics were established in France in 1987, and this practice was then organised and diffused throughout the country via a national network of physicians whose original field was either biological or clinical oncology. This clinical network was initiated in 1991 at the instigation of the Genetic Group of the National Federation of Cancer Centers [3]. By 1995, oncogenetic clinics had been set up in more than 30 cities, mainly at the specialised cancer clinics which are to be found in all parts of the country. Although probably no more than 5–10% [4] of all cancer patients are genetically predisposed to cancer, it is such a frequent condition among the general population that cancer genetic predisposition can be said to qualify as a Public Health field. To reach the real target population, i.e. the healthy population with a genetic predisposition, without alarming all the relatives of sporadic cancer patients, is therefore a major issue that can be approached using various information strategies based on either physician or family referrals, or self-referrals.

This study was carried out at six different French Cancer Centres. The objectives were first to determine whether cancer

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genetic clinics as they are organised in France are able to target the at risk population, then to find the pathways leading cancer free consultees to the oncogenetic clinics, and lastly, to establish what expectations the patients had towards genetic consultations. The consultees' *a priori* perceptions of cancer risk were compared with the geneticists' estimations. The effects of sociodemographic, cultural and family factors upon the referral pathways, the patients' expectations and their risk perceptions were studied.

PATIENTS AND METHODS

Population sample

The six participating regional cancer centres were selected with the aim of giving a representative picture of the French population (South, Marseille, Toulouse; North, Lille; West, Nantes; Centre, Paris/St-Cloud, Clermont-Ferrand) and covered a population of more than 4 million inhabitants in all. Only adult cancer-free patients were included and were asked to participate when attending the cancer genetic clinics for the first time during 1994 (January–December). The reference data were from the most recent national census (National Institute of Statistics and Economic Studies, 1992).

Consultee's questionnaire

The healthy consultees were asked to complete in the waiting room a 15 min questionnaire prior to the consultation and before having any contact with an oncogeneticist. The questionnaire was a 150 closed-item questionnaire. It was first tested in an open and a semi-closed version on 40 consultees.

The referral pathways were described as: physician alone, family and physician, family alone, self-referral. The willingness to come to the clinics when referred by a physician was categorised as: coming only at physician's demand, being receptive to physician's proposal, wanting to come to the clinics very much indeed.

Expectations about the consultation were categorised in terms of the content of the information (risk, prevention, other) and the person for whom the information was needed (the consultee him or herself, children, parents, siblings, etc.).

Perception of risk was assessed in comparative terms involving the whole family ("Do you think your relatives may develop cancer more frequently than the members of other families?" and "If your family is at risk, do you think this risk may be attributable to your father's side, mother's side, or both?"). This question was also asked in comparative terms as regards the person him or herself ("In comparison with a person of your age and sex, do you think your own risk of cancer is: lower, equal, higher?").

Detailed sociocultural characteristics (age, sex, level of education, occupational field, number of children, religious practice, place of residence) were also collected.

Consultant's questionnaire

After every consultation, a two-page closed-item questionnaire was completed by the oncogeneticist about: the consultee's health, the medical reason for the consultation, details about any of the consultees' relatives affected by cancer, and the family and individual cancer risk estimations. The consultees' and geneticists' questionnaires were anonymous and only the consultee's birthdate and the time and place of the appointment at the clinics were specified.

Table 1. Degree of relationship with an affected parent among the sample (n = 206)

First-degree	Second-degree	Third-degree	Spouse	*n*	%
Yes	Yes	Yes	Yes	2	1.0
Yes	Yes	Yes	No	79	38.3
Yes	Yes	No	No	68	33.0
Yes	No	No	No	31	15.0
Yes	Yes or no	Yes or no	Yes or no	10	4.9
No	Yes or no	Yes or no	Yes or no	16	7.8

Statistical analysis

The effects of sociodemographic, cultural and familial characteristics on each dependent variable (referral categories, patients' expectancies, risk perception) were tested successively (chi-squared test, chi-squared test for trend in proportions, *t*-test, ANOVA) with the SAS statistical package. The statistical significance was defined, on the basis of a type I error, as lower or equal to 0.05.

RESULTS

Characteristics of the sample

Among the 209 cancer-free patients who attended the clinics during the study period, only 3 did not complete the questionnaire; 206 healthy consultees were therefore included in the analysis. The average age was 43.5 years (S.D. = 12.3) and women accounted for 91.3% of the sample. The overall and age-adjusted levels of education were significantly higher among the female consultees than in the reference population. On average, among the women in our sample, 40.8% had completed studies at more than high school level, as compared to 10% in the French population of the same sex in the same age groups ($P < 0.01$).

For the whole group, the degree of kinship with a cancer-affected relative is described in Table 1: 92.2% ($n = 190$) were first-degree relatives of an affected member of the family; only 7.8% ($n = 16$) were more distantly related. Among the 190 consultees with a first-degree relative affected with cancer (Table 2), one third quoted their mother and 18.4% a sibling as being the only affected relative; mother and sibling and

Table 2. Detail of first-degree relatives affected by cancer (n = 190*)

Father	Mother	Brother or sister	Son or daughter	*n*	%
Yes	Yes	Yes	Yes	2	1.1
Yes	Yes	Yes	No	7	3.7
Yes	Yes	No	No	34	17.9
Yes	No	Yes	No	8	4.2
Yes	No	No	No	7	3.7
No	Yes	No	Yes	1	0.5
No	Yes	Yes	No	29	15.3
No	Yes	No	No	63	33.1
No	No	Yes	Yes	3	1.6
No	No	Yes	No	35	18.4
No	No	No	Yes	1	0.5

*190 first-degree relatives out of the 206 cases.

both parents affected were therefore the most frequent pairs of affected relatives. Among the 35 whose sibling was only affected, it was a sister in 28 cases, a brother in 6 cases and both in one case.

The geneticist's consultation lasted on average for 51.7 min (S.D. = 21.4). It was about isolated breast cancer in 63.1% of the cases ($n = 130$), about breast and ovarian cancers in 1.5% ($n = 3$), and about cancers of the breast and other organs in 5.8% ($n = 12$). Isolated ovarian cancer was the site involved in 1.9% ($n = 4$) and isolated bowel cancer in 17.5% ($n = 36$). In the 10.2% remaining consultees ($n = 21$), the cancer which led to the consultation was located elsewhere (haematopoietic system, endocrine system, lung, brain, etc.).

After this consultation, the oncogeneticists stated that 73% of their consultees' families had an increased risk of cancer. In 31.8% of all the 206 cases, a well-defined cancer family syndrome was probably involved, and 62.8% of these were a breast and/or ovarian cancer family syndrome.

Patients' referrals

The physicians were the most frequently mentioned source of information about the existence of oncogenetic clinics (53.7%), coming before relatives (17.8%), the cancer centres (16.3%), the media (13.3%) and friends or occupational circles (4.5%); 5.6% of the respondents mentioned more than one source of information. Among the 206 consultees, 68.9% were referred by a physician, 10.4% by a relative, 18.8% came of their own initiative and 2% were referred by the non-medical staff of a cancer centre. When referred by a physician ($n = 142$), 33.3% of the consultees declared that they wanted this consultation very much indeed and 54.8% that they had been receptive when the physician proposed the genetic referral; 11.9% only came to the clinic at the physician's demand. The physicians who had referred the patients were mainly gynaecologists–obstetricians (40.3%) and oncologists (18.7%). The remainder were mainly general practitioners (10.8%) and radiologists (7.2%).

The existence of a cancer family risk, as estimated by the geneticist, varied ($P = 0.012$) depending on the pathway of referral: self-referred consultees were less often at risk than consultees referred by a physician or by their family (Table 3). The consultees who perceived their family to be at risk of cancer prior to the consultation were also more highly motivated ($P = 0.03$) to attend the genetic clinic. Of this group, 41.2% were either self-referred or stated that when the physician proposed the clinic, they wanted the consultation "very much indeed", as compared with the group not perceiving their family as having an increased risk, in which only 25% gave these answers.

Sociocultural characteristics (age, level of education, occupational field, number of children, religious practice) and the degree of relationship with the cancer relative were not found to be significantly related with the consultees' paths of referral nor with their motivation to attend the clinics.

Patients' expectancies

Among the 206 consultees, 16.3% expected to be informed about the risk only, 33.5% about prevention only and 44.8% about both the risk and prevention. The interest in prevention increased with the consultee's level of education (chi-squared trend, $P = 0.001$). The patients' expectancies did not depend on other sociodemographic characteristics nor on their perception of the risk of cancer nor their degree of kinship with the affected relative. In 87.5% of all the cases studied, the consultees came to obtain information for themselves, in 50.5% for their children, in 25.8% for their siblings, in 9.1% for their patients and in 6.1% for their spouse.

Cancer risk perception concerning the family and the subjects themselves: consultees' and geneticists' perceptions

In 83.5% ($n = 172$) of all the cases studied, the consultees answered that they thought their relatives were more likely to develop cancer than the members of other families. The consultee's perception of risk in the family was not linked to sociocultural characteristics. It increased with the number of affected first-degree relatives, but not significantly ($P = 0.09$). The consultee's perception of an increased family risk prior to the consultation was confirmed by the geneticist in 74.3% of the cases (Table 4). Among most of those who did not feel their family to be at risk, the oncogeneticist concluded that an increased risk did exist (Table 4).

Among the respondents with at least one breast cancer among their relatives, who felt they had an increased family risk and in whom this risk was confirmed by the oncogeneticist ($n = 85$), the cancer risk was perceived to have arisen on the maternal side in 61.2%, on the paternal side in 20% and on both sides in 15.3%; 2.4% did not know. The overall proportion of agreement between the consultee's perception and the geneticist's estimation was 71.8%.

Among the consultees who thought they had a family risk, 49.1% said that they felt themselves to have an increased risk

Table 3. Referral and existence of a risk of cancer in the family assessed by the oncogeneticist (n = 197*)

	Presence of a cancer risk in the family according to the oncogeneticist					
	Yes		No		Don't know	
Referral	*n*	%	*n*	%	*n*	%
Physician ($n = 141$)	106	75.2	27	19.1	8	5.7
Family ($n = 21$)	17	81.0	3	14.3	1	4.8
Self-referred ($n = 35$)	18	51.4	14	40.0	3	8.6

*197 out of 206 cases: nine missing values.

Table 4. Comparison between the geneticists' and consultees' estimations of familial risk (n = 201*)

	According to the geneticist					
	Yes		No		Don't know	
Familial risk is increased	*n*	%	*n*	%	*n*	%
According to the consultee						
Yes ($n = 167$)	124	74.3	34	20.4	9	5.4
No ($n = 25$)	16	64.0	6	24.0	3	12.0
Don't know ($n = 9$)	5	55.6	0	0.0	4	44.4

*201 out of 206 cases: five missing values.

Table 5. Comparison between risk perception as regards the family versus themselves (n = 192*)

	"Do you think your relatives may develop cancer more frequently than the members of other families?"			
	Yes		No	
	n	%	*n*	%
"Compared to a person of your age and sex, do you think your own risk of cancer is:"				
lower:	11	6.6	1	4.0
equal:	40	24.0	9	36.0
higher:	82	49.1	7	28.0
don't know:	34	20.4	8	32.0
Total	167	100.0	25	100.0

*192 out of 206 cases: 14 missing values.

of cancer (Table 5) as compared to 28% of those with no perception of an increased family risk ($P = 0.04$). The perception of personal risk varied ($P = 0.042$) depending on whether any first-degree relatives were affected (Table 6) and was the highest when one of the consultee's parents was affected. The effects of both parents having cancer on the perception of personal risk was not any higher than the effect of having one affected parent only.

DISCUSSION

Cancer genetic clinics are a recent application of genetic knowledge to clinical medicine. To our knowledge, the only studies published on the themes investigated here, i.e. referral pathways, patients' expectations and risk perception in patients attending cancer genetic clinics, have concerned risk knowledge before and after counselling [5, 6].

Our sample was selected so that it would be geographically representative of the national genetic clinics, and included approximately 20% of all the consultations carried out in France during the study period [7]. Since this practice was developing at the time of the survey and since some centres have special recruitment characteristics, our sample may have underestimated some of the reasons for consulting such as colorectal cancer. However, the outcome of our study, i.e. patients' expectations, their cancer risk and the pathways of referral, should be valid whatever the type of cancer involved. The healthy consultees studied here were volunteers: they had special characteristics, particularly a high level of education and a very high proportion of women attended the clinics because breast cancer ran in their families. Women were also more often involved when cancers of other kinds were the reason for consulting. The effects of sociodemographic characteristics on risk perception should be handled with caution, since they may not apply to the source population as a whole.

Table 6. Affected first-degree relatives and perception of personal cancer risk by the patient (n = 200*)

	Personal risk perceived to be increased			
	Yes		No	
	n	%	*n*	%
No first-degree affected ($n = 15$)	6	40.0	9	60.0
Only sibling affected ($n = 34$)	10	29.4	24	70.6
Only mother or father affected ($n = 68$)	39	57.4	29	42.6
Only mother and father affected ($n = 33$)	17	51.5	16	48.5
≥2 first-degree relatives (both parents alone excluded; $n = 50$)	18	36.0	32	64.0
Total ($n = 200$)	90	45.0	110	55.0

*200 out of 206 cases: six missing values.

The first objective of this study was to determine whether the target population attending cancer genetic clinics was the appropriate population in terms of cancer risk. From the medical and the public health point of view, the first target population at these clinics can be defined as those people who felt they have a family risk and who expressed their need for medical advice. We report here that most of these people were right in thinking, prior to the consultation, that they had an increased risk of cancer in their family, but that some may have been under the false impression of an increased risk of cancer. Because of their risk perception, this first target population may have adopted screening practices which were not really suitable in view of their medical condition. In this case, the genetic consultation may have helped them to adapt their screening practices to the current state of medical knowledge. The authors of several studies [8, 9] have pointed out that the preventive behaviour of cancer family members differs from that of the general population. A cancer risk defined by a professional based on exact knowledge of the family background may be the best assumption on which to base preventive behaviour. Still with the same objective of defining an effective strategy for cancer screening and prevention, the second target population of the oncogenetic clinics can be said to consist of those who do not think they have a genetic risk when actually they do have one. If one looks at the target population dealt with in our study in the light of these two definitions, namely (1) people who think they have a family risk and (2) people who do not think they have a family risk when they actually have one, we can calculate that 94% of the present sample fulfilled these criteria (Table 4). Our results show that referral by physicians or family members was more effective in guiding the at risk target population towards the oncogenetic clinics than self-referral. This confirms what has been mentioned in previous studies [2, 10] about the potential drawbacks of publicity via the media informing people who do not need to be warned. In our study, the physician's decision to refer patients left the patient freedom of choice in most cases; only 11.9% of those referred by a physician said that they attended only at the physician's demand but were not opposed to it. This proportion could be further decreased if the practitioner explained the reasons for the referral more clearly.

The second aim of this study was to examine clients' expectations prior to the cancer genetic consultation, since cancer genetic clinics are a new form of genetic counselling.

This consultation is obviously different from reproductive genetic counselling, since at the moment of the consultation, in the case of the healthy consultees, the question involves the consultee him/herself. It is also generally different from predictive testing for neurological disorders, since preventive behaviour can be recommended, although this has not yet been proven to significantly reduce the chances of the disease occurring [11]. However, in the case of some rare cancer genetic syndromes such as the Li–Fraumeni syndrome, the medical surveillance which is possible seems to be so demanding and to impose such a psychological burden, with no rational proof for its efficacy, that in this context, similarities have been described with Huntingdon's disease [11].

The expectations observed in our study confirm that prevention is perceived as being a patient's main reason for attending the cancer genetic consultation rather than the need for information about the risk, and this interest in prevention increases with the level of education. Prevention is known to attract more interest from better educated people, particularly in the field of cancer screening [12]. Our results also confirm this trend in the case of oncogenetic clinics, since the consultee's general level of education was higher than that of the reference population and they showed greater interest in prevention.

Very few studies [5, 6] have dealt with what the relatives of women with breast cancer know about the risk of cancer and the effects of cancer family counselling on this knowledge. Their results show how poor this knowledge was before the consultation and the usefulness of the consultation in this respect. Risk perception and its effects on subsequent behaviour has been extensively studied for more than 15 years in the field of reproductive genetic counselling [13, 14]. Information is gradually becoming available about the effects of risk framing [14, 15], the relationship between the percentages or numbers given to express risks, and their transcription by the consultees into perceived frequency of the event [16–18]. Our results show the gap that may exist in the patients' minds between their perception of the risk to their relatives and their perception of the risk to themselves. Even if risk perception as regards the consultee him/herself is determined by his/her perception of the family risk, as mentioned in previous studies [19], it seems important to point out that these two risk perceptions do not completely overlap. People do perceive their risk factors and susceptibility to a disease in the light of their family histories [19], particularly in the field of cancer [9], but there also exist other determinants. Even if the perceived risk of developing a disease is believed to be an important determinant of health-related behaviour [20], this is not always the rule [21]. Cancer genetic risk is becoming a biological issue owing to the dynamics of the genetic discoveries made over the last few years, paticularly in the field of breast and bowel cancer [22–24]. This biological testing, towards which the attitudes of the public seem to be very positive [25, 26], should not hide the fact that prevention is really part of cancer genetic counselling. The present uncertainty surrounding the effects of preventive strategies is similar to what Lippman observed in parents faced with reproductive genetic counselling, i.e. that decision-making can often consist of patients' responses to uncertainty and that which goes on during the deliberative process will be an effort to circumscribe uncertainty as far as possible, and from this position to determine a course of action [27]. With cancer genetic counselling, uncertainty arises not only about the risk estimation step (clinical or biological estimation) but also about the efficacy of the possible preventive strategies. The case of breast cancer, with options such as chemoprevention [28], preventive surgery [29, 30] or screening, which have such different psychosocial consequences, shows that the need to acquire scientific knowledge in the field of prevention must be a priority during the years to come.

1. Hoskins IA. Genetic counseling for cancer patients and their families. *Oncology* 1989, **3**, 84–92.
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. Sobol H, Mazoyer S, Narod S, *et al.* Genetic heterogeneity of early-onset familial breast cancer. *Hum Genet* 1992, **89**, 381–383.
4. Hodgson SV, Maher ER. *A Practical Guide to Human Cancer Genetics*. Cambridge, Cambridge University Press, 1993.
5. Evans DGR, Blair V, Greenhalgh P, Hopwood P, Howell A. The impact of genetic counselling on risk perception in women with a family history of breast cancer. *Br J Cancer* 1994, **70**, 934–938.
6. Lerman C, Lustbader E, Rimer B, *et al.* Effects of individualized breast cancer risk counseling: a randomized trial. *J Natl Cancer Inst* 1995, **87**, 286–292.
7. Sobol H, Bignon Y-J, Cuisenier J, Lyonnet D, Noguès C, Eisinger F, et le 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. Kash KM, Holland JC, Halper MS, Miller G. Psychological distress and surveillance behaviors of women with a family history of breast cancer. *J Natl Cancer Inst* 1992, **84**, 24–30.
9. Vernon SW, Vogel VG, Halabi S, Bondy ML. Factors associated with perceived risk of breast cancer among women attending a screening program. *Breast Cancer Res Treat* 1993, **28**, 137–144.
10. Green J, Murton F, Statham H. Psychosocial issues raised by a familial ovarian cancer register. *J Med Genet* 1993, **30**, 575–579.
11. Vasen HFA. Screening in breast cancer families: is it useful? *Ann Med* 1994, **26**, 185–190.
12. Bostick RM, Sprafka JM, Virnig BA, Potter JD. Knowledge, attitudes, and personal practices regarding prevention and early detection of cancer. *Prev Med* 1993, **22**, 65–85.
13. Evers-Kiebooms G, Van Den Berghe H. Impact of genetic counseling: a review of published follow-up studies. *Clin Genet* 1979, **15**, 465–474.
14. Wertz DC, Sorenson JR, Heeren TC. Clients' interpretation of risks provided in genetic counseling. *Am J Hum Genet* 1986, **39**, 253–264.
15. Shiloh S, Sagi M. Effects of framing on the perception of genetic recurrence risks. *Am J Med Genet* 1989, **33**, 130–135.
16. Sorenson JR, Wertz DC. Couple agreement before and after genetic counseling. *Am J Med Genet* 1986, **25**, 549–555.
17. Wertz D, Fletcher JC. Interpretation of genetic and environmental risks. *Sci Technol Hum Values* 1987, **12** (3/4), 60–66.
18. Edwards AWF. Probability and likelihood in genetic counselling. *Clin Genet* 1989, **36**, 209–216.
19. Weinstein ND. Optimistic biases about personal risks. *Science* 1989, **240**, 1232–1233.
20. Gochman DS. *Health Behavior: Emerging Research Perspectives*. New York, Plenum Press, 1988.
21. Weinstein ND. Why it won't happen to me: perceptions of risk factors and susceptibility. *Health Psychol* 1984, **3**, 431–457.
22. Miki Y, Swenson J, Shattuck-Eidens D, *et al.* A strong candidate for the breast and ovarian cancer susceptibility gene BRCA1. *Science* 1994, **266**, 66–71.
23. Futréal P, Liu Q, Shattuck-Eidens D, *et al.* BRCA1 mutations in primary breast and ovarian carcinomas. *Science* 1994, **266**, 120–122.
24. Fishel R, Kolodner RD. Identification of mismatch repair genes and their role in the development of cancer. *Curr Opin Genet Dev* 1995, **5**, 382–395.
25. Lerman C, Daly M, Masny A, Balshem A. Attitudes about

genetic testing for breast–ovarian cancer susceptibility. *J Clin Oncol* 1994, **12**, 843–850.
26. Hietala MHAA, Arja R, Niemela P, Peltonen L, Aula P. Attitudes toward genetic testing among the general population and relatives of patients with a severe genetic disease: a survey from Finland. *Am J Hum Genet* 1995, **56**, 1493–1500.
27. Lippman-Hand A, Fraser FC. Genetic counseling: parents' responses to uncertainty. *Birth Defect* 1979, **15**, 5C, 325–339.
28. Nayfield SG, Karp JE, Ford LG, Dorr FA, Kramer BS. Potential role of tamoxifen in prevention of breast cancer. *J Natl Cancer Inst* 1991, **83**, 20, 1450–1459.
29. Mulvihill JJ, Safyer AW, Bening JK. Prevention in familial breast cancer: counseling and prophylactic mastectomy. *Prev Med* 1982, **11**, 500–511.
30. Vogel VG, Yeomans A, Higginbotham E. Clinical management of women at increased risk for breast cancer. *Breast Cancer Res Treat* 1993, **28**, 195–210.