Why do women not return family history forms when referred to breast cancer genetics services? A mixed-method study

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Abstract

Background Personal and family data forms, completed by women referred to breast cancer genetics clinics, are valuable tools for verification and extension of family history, crucial steps in accurate risk evaluation. A significant minority of women do not complete and return these forms, despite reminders, even when completion is a pre-requisite for a clinic appointment.

Objective To facilitate access of women at increased familial risk of breast cancer to screening and counselling services by investigating reasons for non-return of the forms.

Participants and Design Based on a single regional 'breast cancer family' service in the UK, Analysis of quantitative data comparing women who did not return forms ($n = 55$) with those who had done so ($n = 59$), together with qualitative evaluation of potential barriers to form-completion through semi-structured telephone interviews with a random subset of 'non-returners' ($n = 23$).

Results Non-returners have higher proportions of the very young (below the age at which surveillance could be offered) and of women from lower social deprivation categories. Interviews revealed that the majority of non-returners are anxious, rather than unconcerned about their breast cancer risk and circumstances and attitudes contributed to non-compliance. Twenty-one participants confirmed that they would welcome an appointment at a 'breast cancer family' clinic, but nine did not attend for the appointment. They were significantly younger than those who attend, but were not at lower familial risk.

Discussion and Conclusions Many women who fail to complete and return a family history form would benefit from risk assessment and genetic counselling. Several steps are suggested that might help them access the relevant services.

Introduction

Around one in four women referred to a breast cancer genetics clinic in the UK do not return their Family History form.^{1,2} These forms, which tabulate information to generate a three-generation family tree, together with details (site, age of onset and outcome) of any cancers (particularly of breast and ovary) that have occurred among family members are widely used in the practice of breast cancer genetics.^{3,4} They are important because a family history of the disease is a recognized risk factor for breast cancer and familial cases tend to present at a young age.⁵ The UK and many other developed countries have, for many years, provided risk assessment, counselling and, where appropriate, regular mammographic screening and/or molecular genetic testing for women at increased genetic risk.⁶ Analysis of completed family history forms often serves as the 'gateway' to these services.⁷⁻⁹ Some centres have made completion and return of the form a condition of access to the breast cancer family clinic and women who do not comply, after a reminder letter, are referred back to primary care.^{2,10,11}

Since 1994, the NHS Tayside breast cancer family clinic (Dundee, Scotland) has offered a multidisciplinary regional service for a population of some 500,000. Women cannot self-refer to this clinic but must be referred (with consent) by their General Practitioner (GP) or by another NHS service. Family history forms have been used since the outset, but until 2005, all women referred were seen at the clinic even if they had not returned a completed form. It became apparent that around one quarter of referred women did not return the form in advance of their appointment, although some brought it with them when they attended the clinic.² An important purpose of the form is to enable the genetics staff to evaluate the woman's risk as accurately as possible by interrogating the Scottish cancer registry and public records of births, marriages and deaths before her first clinic visit (this being the best opportunity for individual risk and its management to be discussed in depth). Tayside appointment

policy was therefore changed (in line with several other centres, as cited above) to achieve a higher rate of form completion and return. From 2005, the explanatory letter accompanying the form stated that a clinic appointment could only be arranged on receipt of the completed form. The letter also made clear that if it was difficult to obtain the information requested or there were other problems in completing the form, clinic staff would be happy to assist. A telephone number was provided as a source of help. Similar notification was provided to GPs in the region (the source of some 75% of referrals) and to the staff of regional symptomatic breast services (who referred the remaining 25%). If a form was not returned within 3 weeks of issue, a reminder, with a second copy of the form, was posted and if, after a further 3 weeks, there was still no response, the GP was notified that no clinic appointment would be offered, although a fresh referral could be made if he/she felt it necessary.

On reviewing the situation some 18 months later, it was disconcerting to find that the rate of non-return of family history forms remained at 24% – virtually unchanged since introduction of the more strict policy. It therefore seemed appropriate to investigate the underlying reasons and then to consider how the procedures might be adapted in response. To do so, we set out to ask two separate, but possibly related, questions. (i) Do women who fail to return their forms share characteristics that distinguish them from those who do complete and return the forms? (ii) What are the barriers to completion and return of the forms as experienced by these women?

Participants and procedure

The two components to our approach were as follows: (i) a comparison of women who did or did not return their forms, using quantitative data on age, deprivation category and perception of individual breast cancer risk and (ii) an exploratory qualitative assessment of personal reactions to the family history forms reported

by non-returners, through a semi-structured telephone interview with a random subset of them. The full protocol was approved by the NHS Tayside Medical Research Ethics Committee.

We first identified all referrals where no family history form had been returned (despite a reminder letter) over the 18 months since introduction of the 'no form, no appointment' policy. There were 80 such cases, but 17 of these were excluded on closer analysis; one was male and the others had either been seen at a family history clinic or had telephoned the clinic staff and received counselling from them. For the remaining 63 women, a letter was written to their GP, explaining the purpose of the study and requesting permission to contact their patients for a semi-structured telephone interview. Replies were received in respect of 55 of these women (response rate 87%).

A control cohort of women who had returned their family history forms over the same period was generated for simple demographic comparisons by selecting, for each of the 'non-form-returners', the next case in (dated) referral sequence. On the advice of their GPs, we excluded eight patients from the 63 'non-returners' (one had died from causes unrelated to cancer, one was clinically depressed and six were known or believed to have moved away). Control subjects for four of these had already been selected before the GP responses were received and since no bias could be introduced by retaining them, the control cohort numbered 59, while the 'case' series was restricted to 55.

In addition, we made use of data on breast cancer risk perception collected earlier (with ethical approval and patient consent), by questionnaire, from 143 women on their first attendance at our clinic and before they had received any counselling.¹²

For each member of the case and control cohorts, age at time of referral was derived from the Community Health Index (CHI) number and deprivation category from their home postcode, using an update of the

Carstairs and Morris index¹³ as applied to the 2001 census data (Information and Statistics Division of NHS Scotland).

A semi-structured telephone interview protocol was prepared (see below). We aimed to enrol a random subset (50%) of the 'non-returners' in this element of the study. GPs had given consent for 46 patients to be contacted in this way, and current telephone numbers were obtainable. An initial telephone call was made by a member of the team (MS) to these potential participants, in random order, to explain the nature and purpose of the study, to ask whether they would be willing to participate and, if so, to arrange a convenient time for the interview. None of those contacted declined to take part and recruitment stopped when the first 23 women (i.e. half of the cohort) had been enrolled. Participant information about the study was then sent to each of them, and written consent was returned to the investigators.

One member of the study team (KAH) conducted all the interviews over a 2-week period. The interviewer was a mature medical student, and she was trained in interview techniques by a health psychologist member of the team (GO). The topics covered were as follows:

1. Recall of the circumstances of her referral to the clinic.
2. Reactions to the family history form and accompanying letter.
3. Experiences of attempting to complete the form.
4. Extent of interaction with the wider family regarding familial cancers and the form.
5. The woman's own perception of her lifetime breast cancer risk, expressed as percentage ('What do you estimate your lifetime risk of breast cancer to be on a scale of 0 to 100%?').
6. Level of worry about cancer during the preceding month using questions from the Lerman cancer worry scale.¹⁴ During the past 1 month, how concerned were you about getting cancer? Would you say, not at all, sometimes, often, a lot?)

7. Suggestions for improvements in the referral process.
8. Any further comments that the interviewee wished to make.

Each participant was asked whether she still wanted an appointment at the breast cancer family clinic, and, if so, specific arrangements were made to suit her. The outcomes of these appointments (including whether women attended or failed to attend and professional evaluation of familial cancer risk) were recorded.

All interviews were audio-recorded (with the participants' consent), and the transcripts content analysed by a health psychologist (GO). Themes for further analysis were identified in discussion with a consultant clinical geneticist (MS) and another member of the team with extensive clinical research experience (FS).

For quantitative data, between-group comparisons were made using Fisher's exact test (two-tailed) for categorical variables and Student's *t*-test for continuous variables. Calculations were carried out via the on-line statistical package 'Graphpad' (www.graphpad.com).

Results

Quantitative data

Comparing the demographic features of the control and 'non-returned' cohorts (Table 1), it was noted that the latter included many more women under the age of 35 at the time of referral. There were also more women whose home

addresses placed them in lower social categories among the 'non-returned'. Both these differences were statistically significant.

All but two interviewees indicated that they would welcome a further appointment at the breast cancer family clinic at a convenient time. The offers were made in writing and followed up by a telephone call from a genetics nurse specialist to establish a convenient time for each woman, to provide information on the clinic's functions and how it operates and to assist with completion of the family history form if requested (although attendance, in this instance, was not dependent on completion and return of the form). If a woman did not attend this specifically planned appointment, another was offered, but despite this, nine of the 21 women still did not attend. Five of these were under 35, compared with none of the 12 who did attend ($P < 0.01$ by Fisher's exact test, two-tailed). Based on the family histories obtained at interview (by telephone or face-to-face), three of the 21 were judged to be at 'high' familial risk according to NICE criteria,⁵ 12 were at 'moderate' risk and 6 at 'average' risk. This distribution is in line with the overall pattern of referrals to our clinic,⁹ and the importance of categorization is that enrolment in a special surveillance programme is offered to those at moderate or high risk, while those at 'average' risk are discharged with reassurance, advice on how to be 'breast aware' and information on 'lifestyle' measures believed to reduce breast cancer risk. The nine who did not attend the appointment arranged for them included only one assessed as 'average' risk, six as 'moderate' and two as 'high' risk.

Interviewees reported very high perceptions of cancer risk both in absolute terms and compared with patients who had attended the clinic. The relevant information was not recorded in the notes of our contemporaneous controls, but it was available for a sample of 143 women attending our clinic for the first time a few years previously. Using the same question ('what do you estimate your lifetime risk of breast cancer to be on a scale of 0 to 100%?'), the mean figure for the 23 in the

Table 1 Age and deprivation category comparisons of control and 'non-returned' cohorts

	Control group (<i>n</i> = 59)	'Non-returned' (<i>n</i> = 55)
Mean age (SE)	44.95 years (1.55)	41.91 years (1.75)
Number (%) under 35	9 (15.3)	18 (32.)*
Number (%) in deprivation categories 4–7	8 (13.6)	15 (27.3)*

*Difference significant ($P < 0.05$ by Fisher's exact test, two-tailed).

current study was 61.7% (SEM 5.23) compared with 50.4% (SEM 1.79) for the 143¹² ($t = 2.222$, $df = 164$, $P < 0.05$).

Six interviewees (26%) reported concern about cancer in the past 'often' or 'always', and 13 participants reported concern 'sometimes' in the past month.

Qualitative data

One of the 23 interviewees did not recall ever having received the family history form. She had moved addresses around the time of her original referral and thought it had been lost in the post. Table 2 summarizes the reasons given by the remaining 22 women for not completing or returning the forms (most cited more than one reason).

On analysis of the content of interviews, it is evident that not completing and returning a family history form generally reflects interactions between a pre-existing high level of anxiety about cancer risk and personal/family circumstances and attitudes towards finding out breast cancer risk. The latter can be considered further under the headings set out in Table 2.

Reactivation of cancer worry

Nineteen of the 22 reported that receiving the form had made them think more about their personal risk of developing breast cancer.

It puts it in the forefront. You tend to put these things at the back of your mind, although it never goes away (Participant 16, age 38)

Filling in the form made me feel very scared (Participant 3, age 41)

When they ask about your family history – especially when a lot of your own family on your

mother's side have died of cancer – then you are thinking is it going to be worse? – am I going to go the way they went? It just turns like a wheel (Participant 10, age 52)

Ambivalence about proceeding with referral

A theme that emerges from comments made by nine interviewees and which may underlie the responses of several more is a degree of ambivalence about referral to the breast cancer family clinic and fear of what referral might mean for their risk of cancer.

If I am going to get cancer, I don't want to know and I would not get treatment (Participant 2, age 71. This interviewee said that her family disagreed with her attitude and were encouraging her to follow up her referral to the clinic)

I did not want there to be any tests I had to go for or go to hospital for routine check-ups. It was something I just wanted to put to the back of my mind (Participant 7, age 24)

In some ways it's the fear of the unknown. Part of me – if I go down that line maybe they'll find something – if I don't, maybe they won't. It's not very logical or intelligent but I do think about it from time to time. The responsible thing to do, especially if you have a family, is to use these resources as much as possible – so that hopefully they will help you in the long run (Participant 16, age 38)

I know I initiated it [the referral process] but I just did it on the spur of the moment. Then I realised it was perhaps a little too much to cope with at the time. So I backed off from it (Participant 20, age 54)

Family unable or unwilling to help

Three interviewees had either been adopted themselves or were the child of a mother who had been adopted; hence, they had only limited

Table 2 Reasons reported by interviewees ($n = 22$) for not completing/returning forms

	Cancer worry	Ambivalence rereferral	Family unable or unwilling to help	Bad timing	Form complicated	Letter unclear	Practical issues
Number reporting (number aged <35)	19 (5)	9 (1)	9 (4)	8 (4)	12 (3)	17 (3)	2 (0)

access to family history. That was also the case for those whose affected relatives were of an earlier generation and had either died or could no longer recall relevant details. More, however, found it difficult to approach other family members for information because:

The family doesn't like to talk about things like this (Participant 6, age 55; and very similar comments from Participant 7, age 24; Participant 19, age 60)

I don't get along with other members of the family (Participant 12, age 40)

How do you get records when there's nobody around? If you have an old fashioned family, nobody necessarily wants to discuss what, where, when and who died...it's a stumbling block (Participant 13, age 49)

Some were inhibited from broaching the subject with family members for fear of their response:

I can't go to my auntie who is in her 70's and ask her about her sister's death from cancer. Emotionally it is a no-go area. I thought, how am I going to get this information? What have I done? Oh no – nosey parker again – she wants to find out things – open a can of worms that we will emotionally have to put away (Participant 13, age 49)

Form too complicated

For the 12 who found the form complicated, most problems appeared to reflect interpretation of the statement 'no clinic appointment can be offered without a completed family history form' as meaning that answers to all the questions (e.g. dates and hospital addresses for any cancer diagnoses in relatives) are mandatory to receive an appointment. The word 'daunting' was used by several, mainly referring to the difficulty in finding out the family history that the form requested. The physical aspects of the form seemed less of an issue although one participant mentioned that 'The boxes need to be a bit bigger to allow for more information'. Another participant found the form difficult because she was dyslexic.

More commonly, responses took the form of:

A lot of information was needed. I put off filling in the form as I did not know some of the answers (Participant 3, age 41)

I thought I am not going to be much help so I abandoned it (Participant 4, age 63)

I didn't know where to start. It just felt too big (Participant 10, age 52)

The form I had to fill in – quite a big form and the stumbling block was that I could not answer all the questions. It just sat there and sat there. In the end it did not go any further (Participant 16, age 38)

The form layout was no problem – very easy – but the contents were very difficult to find (Participant 19, age 60)

Poor impact of accompanying letter

Seventeen respondents specifically cited uncertainty about 'what happens next' – that is, what would be involved in attending the breast cancer family clinic, despite relevant information being provided in the accompanying letter. Only nine of the interviewees could recall the content of that letter – or even having read it.

I needed to know what would happen after you fill out the form – do you have to go into hospital for routine checks? (Participant 7, age 24)

I wish someone had phoned me just to explain what was involved (Participant 12, age 40)

Reading the letter now – if I could not find the information I could have contacted you and perhaps taken it further. However I fell at the first hurdle and just saw that insurmountable. I did not read and make myself aware that I could proceed without all the information (Participant 13, age 49)

Form arrived at a 'bad time'

For eight women, the request to provide family details had come at a particularly bad time because of concurrent medical or other issues.

One, for example, had just been admitted to hospital for surgery (unrelated to cancer), while for several others, a close relative had very recently been diagnosed with cancer or had suffered a recurrence.

Practical issues

Only two participants (ages 44 and 49) mentioned practical difficulties as obstacles to attending a clinic. For both, the problem was related to 'being very busy at work' rather than child care or other domestic ties.

Discussion

This study has been a pilot exercise in a previously neglected area. It was limited in scale and telephone rather than face-to-face interviews may have limited the development of the personal relationship for obtaining better quality results. Nevertheless, clear and consistent findings have emerged. Levels of cancer worry were somewhat high among our study group, and these have been shown to correlate with perceived breast cancer risk.¹⁵ Given that they had not been tested for BRCA1/2 mutations and none belonged to a family known to carry such a mutation, the actual individual lifetime risk of breast cancer must be substantially less than 50% in all cases,¹⁶ yet the mean figure for their perceived risk was over 60%. Most of these women could expect to gain considerable benefit from attending a breast cancer family clinic to evaluate and discuss their personal risk of cancer.^{10,17,18} Our study thus adds to the existing body of evidence that anxiety can inhibit positive responses to health threats.¹⁹

It is unfortunate that for this group, the apparent complexity of the family history form, particularly the excessive demands it was perceived to make, has conveyed the wrong message. Instead of encouraging co-operation with the clinic staff in order to provide a service tailored to the personal circumstances of each patient, it has actually served as a deterrent.

Many (perhaps most) women with a family history of breast cancer welcome the

opportunity for professional risk assessment, counselling and, above all, access to early and regular mammographic screening.^{10,12,17,18,20} Nevertheless, almost all will have personal experience of the disease as it has affected close family members so that a degree of ambivalence about proceeding with investigation of their own possible genetic pre-disposition to breast cancer is to be expected. In this setting, it is understandable that the requirement to complete a comprehensive family history form can represent a major obstacle, particularly to anxious patients with a high perception of their own cancer risk.

Future research might profitably go into greater depth, employing larger numbers of participants, posing more open questions and applying intentional theoretical sampling (according to age and risk category, for example) to gain a clearer understanding of the difficulties encountered by individual women facing the issue of genetic cancer risk.

We reviewed all our findings to see what changes in organization of our clinical service might reduce the numbers of women who do not return a 'family history' form and thereby enhance the effectiveness of our outreach to affected families.

The accompanying explanatory letter was intended to reassure patients that the purpose of the family history form is to enable clinic staff to provide a precise estimate of individual risk and to base recommendations for future management on that estimate. Families were encouraged to 'do their best', but there was no requirement to complete all sections of the form where information was not obtainable through inaccessibility (or non-co-operation) of family members. The letter clearly failed to achieve its purpose. Most of the patients interviewed could not recall its content. As already noted, several of the 'suggestions for improvement' invited from our subjects focused on the lack of clarity in that letter. One (participant 21, age 52) commented 'it would have been more helpful if it had been in English!' – a salutary reminder of the well-known phenomenon that professional communications, crafted with care

and with the best of intentions, can be incomprehensible to the recipient. Others would have preferred a telephone contact initiated by the clinic, ahead of attendance, to help with completion of the family history form and, importantly, to explain what would happen at the clinic.

The excess of women under the age of 35 and of those from more deprived socio-economic groups among the 'non-returners' and also within the subset who failed to attend individually arranged clinic appointments may be a rather specific illustration of the 'inverse care law' which states that 'the availability of good medical care tends to vary inversely with the need for it in the population served'^(21, p. 405). While we do not normally consider initiating active surveillance (including mammography) before age 35, we do offer initial counselling and risk assessment to younger women if they request it (through their GP), with a view to enrolling them in due course, if appropriate in view of the familial risk. Non-attendance at the stage of initial referral can therefore mean inadvertent exclusion from the surveillance programme. The difficulty for younger women, with child care responsibilities for example, was suggested by several of the GPs as an explanation for the failure of at least some of their patients to engage more fully with the breast cancer family service. However, this did not feature among the reasons articulated by our interviewees, five of whom were under 35.

Conclusions

Both qualitative and quantitative findings from this study clearly identify changes that should be made to our clinic procedures although there is a need to confirm the findings with a larger sample of participants. These include redesign of the family history form, making it easier to complete, clarifying its purpose and more explicitly relieving respondents of responsibility for information that is difficult to obtain; preparing (perhaps as a 'frequently asked questions' leaflet) a comprehensive

account of what a family history clinic visit entails, including the information that mothers can bring young children with them; making that leaflet available at the sources of referral (primary care and symptomatic breast clinics) in addition to including it with the family history form when the family history service responds to a referral; greater use of telephone contacts, particularly for those under age 35 and/or from socially deprived backgrounds, and closer liaison with primary care when someone referred does not complete and return the family history form. Continued monitoring of the rate of 'non-return' of the revised forms should establish the success or otherwise of these measures and perhaps their applicability to cancer genetics services generally.

Evaluation of familial risk will be an increasing element of oncological practice, so this study's experience and findings may serve as a reference in other contexts.

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Conflict of interests

None.

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