article

Factors influencing the referrals in primary care of asymptomatic patients with a family history of cancer

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Purpose: To describe the events and the reasoning that led UK general practitioners to make a direct referral to a genetics clinic for a family history of cancer. **Methods:** Asymptomatic patients with a family history of cancer and general practitioners who had referred them to a genetics clinic were eligible to participate. Semi-structured interviews incorporating a self-completed questionnaire were conducted with the general practitioners. Questions about the referral had to be framed in general terms as few general practitioners could remember the index case. Individual face-to-face interviews based on a topic guide were conducted with the patients. **Results:** Thirty-six of 54 eligible general practitioners and 71 asymptomatic patients with a family history of cancer completed the study. General practitioners adopted a reactive rather than proactive role in the provision of genetic services for asymptomatic patients with a family history of cancer. Most general practitioners favored cancer diagnostic clinics as a referral pathway, and made a referral to genetics only when patients or a hospital doctor specifically requested this. More idiosyncratic approaches to the referral decision were also encountered. Updating of skills and knowledge in genetics remained a low priority despite acknowledged inadequacies. **Conclusions:** Referral guidelines that are practicable in the context of a busy primary care clinic need to be developed if primary care practitioners are to play the major role desired for them in genetics. ***Genet Med*** **2008:10(10):751–757.**

Key Words: *Genetics, general practitioners, referral pattern, asymptomatic patients, family history of cancer*

Advances in genetics medicine have led to calls in the United States and Europe for an increased role for primary care in the identification and management of common multifactorial diseases such as cancer and diabetes.[1–5]

The attitudes, knowledge, perceptions of barriers and expectations of primary care practitioners regarding the provision of genetic services in primary care have been explored.[5–14] Referrals to genetics clinic have been studied,[15] and referral guidelines have been developed and evaluated.[16–21] New methods for taking family histories have been devised,[22] and computerized risk assessments have been developed[23] as an aid to decision-making. The research evidence about the specific ways in which primary care could make an effective contribution however still remains small.

The literature also contains some specific gaps. Most notably, very little is known about the ways in which primary care practitioners deal with genetic issues in their everyday practice. One possible reason for this lack of information is that spontaneous consultations involving genetics are still infrequent,[24] and hence, hard to study prospectively. Four prospective studies[22–25] were found in the United Kingdom, but three of them reported on the setting up and running of innovative "family history clinics" in primary care.[22,23,25] These clinics provided a full family history taking service and associated counseling, and were run by primary care practitioners as part of their practices. However, unlike ordinary clinics, they could be planned well in advance, so giving doctors and practice staff time to equip themselves with the necessary genetics knowledge, skills and tools needed to deal with the kinds of patients they had invited to attend. The extensive forward planning also enabled the researchers to conduct prospective studies, because they could organize data collection well in advance and also recruit the required numbers of participants in a manageable period of time. The remaining prospective study found in the literature on primary care genetics essentially just counted the numbers of GP consultations in which family history of breast cancer was discussed.[24] Most studies of everyday practice have either: asked primary care practitioners what they usually did,[7,8,12,14,15,26–29] or gathered information on genetics as part of a more generic data collection exercise.[6,5,9,11,14,17,22,23,26]

In the UK state health system, the primary care practitioner ("General Practitioner" or "GP") is gatekeeper to all clinical

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specialists: patients needing specialist genetic services have to be referred by their GP. Asymptomatic patients with a family history of cancer can be referred by their primary care practitioner either to the relevant cancer diagnostic clinic to have tests such as mammograms, or to the genetics clinic for risk assessment and counseling. There is no financial cost to the patient in either case, as both kinds of care are provided free at the point of delivery through the National Health Service, and there are no financial incentives or disincentives acting on the GP to encourage a referral to either one of these specialist services. In the United Kingdom, a minority of patients do have private health insurance, but not all specialists do private work, and private patients are very uncommon in cancer genetics.

Genetic services in the United Kingdom are organized into 25 regional centers which deal mainly with relatively uncommon inherited and congenital disorders, including familial cancer.[30] Each center is staffed by clinical geneticists and genetic counselors, and serves a population ranging from two to six million people,[31] with a ratio of 1 or 2 geneticists to one million people.[32] The center provides information, advice, genetic testing, and counseling to individuals and their families.

Most primary care practitioners report that they usually refer asymptomatic patients consulting about a possible family history of cancer to the relevant cancer diagnostic clinic for investigations and as a result, seldom refer to a genetics clinic.[6,8,26] In one study[26] about 20% of practitioners did report that they had referred at least one patient in the past to the genetics clinic for a genetic evaluation for familial cancer risk, but in this study, as in others, doctors' reasons for departing from their usual practice in these specific cases were unclear. Studies[6,8,15,17,28,33] based on routine data collection can throw little light on primary care practitioners' reasons for making the referral decisions that they do, and responses to questions about usual or preferred referral patterns also provide little information about exceptions to that rule.

The aim of the present study was to describe as accurately as possible the events and the reasoning that led UK primary care practitioners to make direct referrals to a genetics clinic for a family history of cancer. Were these doctors different from the majority who never made such referrals in terms of their attitudes toward initiation of discussion of family history of cancer and referral pathways? What motivated them to use the genetics clinic? And is it possible to learn lessons from these doctors about the effective delivery of genetic services in primary care? Both patients' and doctors' accounts were used to address these questions. Only patients who were asymptomatic were included in the study, because the focus was the early detection of patients at increased risk of developing cancer, rather than the early detection of patients with cancer. Patients' accounts, it was noted, were largely absent from the existing literature.

MATERIALS AND METHODS

Design

The approach adopted was to identify GPs who had referred asymptomatic patients to the genetics clinic, and then to ask the GPs and the patients to describe the events and the thinking that had led to the referral. The limitations of such a retrospective approach were recognized, but a prospective study of such infrequent events was beyond the resources available for the study.

To collect detailed accounts and explanations of events, semi-structured interviews were required. It was recognized that this would limit the number of referrals which could be studied, but alternative methods such as self-completion questionnaires would not have generated data at the level of detail necessary to address the study aims. The study was approved by the Local Research Ethics Committee.

Sample and data collection

The selection of GPs was based on the objective to investigate their reasons for making a direct referral of an asymptomatic patient to the genetics clinic, given that the majority of GPs only ever refer such patients to cancer diagnostic clinics. Therefore, only GPs who had referred at least one asymptomatic patient to the genetics clinic were eligible to participate. Recruitment of the GPs was carried out in parallel with the recruitment of patients they had referred (Fig. 1).

The genetics service involved in the study area was the Yorkshire Regional Clinical Genetic Service (YRGC). The YRGC received 150 referrals from GPs during the period of this study. All 150 patients were sent an invitation to participate in the study by the Service staff. Patients were asked to provide their telephone contact if they were interested in study participation. Seventy-five patients responded with their telephone contacts. Seventy-one (47%) patients completed the study; nine patients withdrew before the start of the study and three patients were later excluded because it was found that they had been referred from secondary care. Patient interviews were carried out with the use of a topic guide to explore among other things, the factors motivating asymptomatic patients to consult the GP, their expectations of the consultation, the amount of family history information collected by the GP, and the amount of genetics and referral information given by the GP.

To collect information about the specific circumstances leading to a referral to genetics, only GPs whose patients participated in this study were recruited. The names and contact details of the GPs who referred the 71 patients were taken from the referral letters. Only 64 GPs were identified through the letters, because there were seven GPs who referred at least two patients from the same family to the YRGC. Patients were then asked to confirm whether these were the GPs whom they consulted and who had referred them to the genetics center; consequently four GPs were excluded. A further six GPs were excluded as they no longer worked in the same practice. As a whole, 54 GPs were deemed eligible to participate in the study and they were contacted by telephone. Seven GPs declined the invitation, whereas 11 could not be reached. Not <50 attempts were made to contact each of these 11 GPs before and after their surgery sessions and they were also left with messages to return the call, but these attempts failed. At the end, only 36 of 54 (64%)

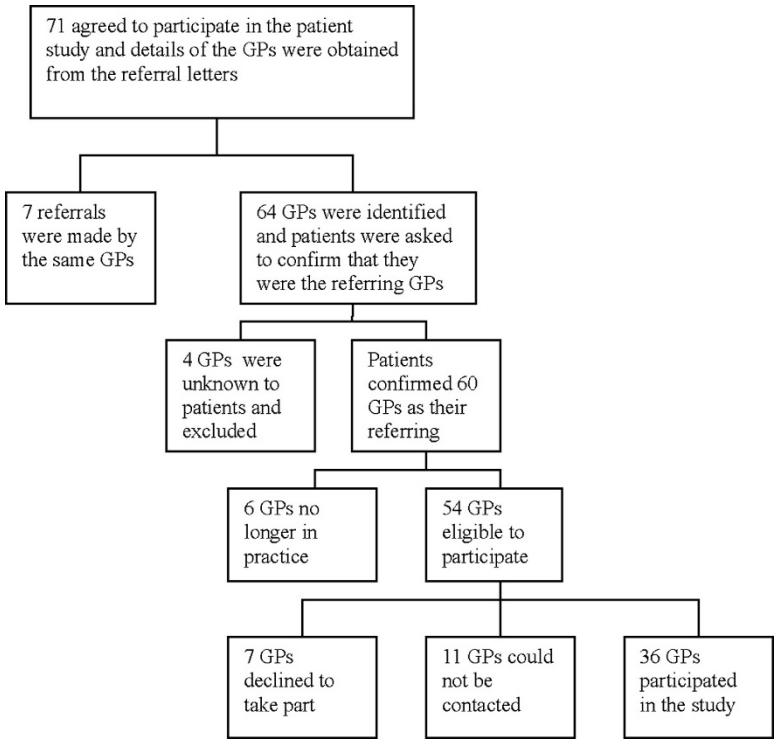

Fig. 1. GPs' recruitment process.

eligible GPs participated in the study as a decision was taken to stop the recruitment process due to time constraints.

To keep the length of the GP interview to a minimum, participating GPs supplied some factual information in advance, by completing a short questionnaire. The interviews were semi-structured and a topic guide was used to collect information on: factors that led to the discussion of family history of cancer with a patient, GPs' behavior and attitudes regarding appropriate referrals, GPs' attitudes and knowledge about genetics and genetic services, and GPs' plans regarding the provision of primary care genetic services in the future. It soon emerged that few of the GPs could remember the index patient, so questions that had been designed to probe the specific circumstances of that referral had to be recast in terms of how the GP would respond in those kinds of circumstances.

Data Analysis

The GP and patient interviews were tape-recorded and transcribed. Two researchers coded and developed the themes according to the method recommended by Moser and Kalton[34] for summarizing survey data. A coding frame was devised which coded for the presence, or absence, of responses predicted from the literature, and incorporating the respondents' own chosen terms of reference. This allowed frequencies of particular responses to be measured. Although the main purpose of the analysis was to characterize the types of views and explanations expressed by respondents, summary percentages were calculated to assist interpretation, and to place the findings in the context of the existing literature.

RESULTS

GPs' demographic characteristics

Of the 36 GPs who completed the study, 19 were women and 17 were men. All the GPs worked in group practices. Most of them had more than 6 years of working experience. Only one had any further education in genetics. Table 1 shows the demographic characteristics of the respondents.

Patients' demographic characteristics

A majority (92%) of the 71 patients who completed the study were women, referred for an assessment of family history of breast and ovarian cancers, whereas the rest were referred for bowel, throat and liver cancers. The majority of participants were 30 to 50 years old (65%); 18% were under 30 and 17% were over 50 years old.

Attitude of GPs toward initiating discussion of family history of cancer

Even though all GPs in the present study had referred at least one asymptomatic patient to the genetics clinic, none ran their own family history clinics or initiated consultation about genetics by any other means, and not all would proactively initiate a discussion of family history of cancer in the course of other consultations. Over one-third (14) of the GPs thought that they would initiate a discussion if they knew that the patients had a significant family history of cancer, and a further 23% (12) said they probably would, but 28% (10) said they would not initiate a discussion of family history with their patients.

Table 1
Demographic characteristics of GPs

Characteristics	No. GPs
Gender	
Male	17
Female	19
Time since qualification	
<5 yr	3
6–10 yr	7
>10 yr	26
No. partners in practice	
Single	0
Two	0
>Three	36
Further education in genetics	
Yes	1
No	35
Total GPs completed the study	36

For those GPs who would initiate a discussion of family history of cancer, an established doctor-patient relationship seemed to influence this behavior. For the other GPs, concern over unnecessary anxiety, lack of time and resources, and the ethical and fear of legal implications of genetics hindered them from adopting a proactive role in initiating discussion about family history of cancer.

The patient interviews confirmed these findings. As well as initiating all of the consultations in the present study, 63 of the 71 (89%) patients reported that they had initiated the discussion of cancer family history which had led to their GP making a genetics referral. In the remaining eight cases, the GP had raised the issue of family history of cancer when the patient consulted about hormone replacement therapy or other medication.

A recent event in the family was the most frequently quoted reason that motivated patients to visit their GP: 47 (66%) patients said they became concerned after a family member had a recurrent cancer, a recent diagnosis, or there was a death in the family due to cancer. More specifically, 29 (41%) patients said the specialists or hospital consultants looking after their relative(s) advised that they should consult the GP. Twelve (17%) patients said they became worried when reaching the age at which their relative(s) contracted or died of a common cancer. Eleven (15%) patients said they were worried that medication they were taking and its symptoms might be related to cancer. Nine (13%) patients consulted the GP because they were worried for their children or were pressurized by their children. Media had the least influence as only five (7%) patients said they had consulted the GPs after watching or reading material on a related topic.

Referral pathways

When asked about their usual pathway of referral of asymptomatic patients, more than two-thirds (69%) of the GPs in the present study said a diagnostic clinic was their usual choice. Only 11 (31%) GPs said they would usually refer such patients to the genetics clinic. The following findings show that in terms of knowledge and skills in genetics and usual referral patterns, this sample of GPs, chosen on the basis that they had referred an asymptomatic patient to the genetics clinic, were in fact very similar to the literature descriptions of the majority of GPs who only ever refer such patients to diagnostic clinics.

Factors influencing a referral to diagnostic clinics

In a systematic review, Suther and Goodson[35] found that GPs perceived a number of obstacles to providing routine genetic services in primary care: a lack of knowledge about existing genetic services, and how to take a family history, a lack of appropriate referral guidelines, and a lack of confidence. Many GPs in the present study reported similar obstacles.

GPs' lack of knowledge about genetic services

Even though all GPs in the present study had referred asymptomatic patient(s) to the genetics clinic, 92% admitted to not knowing, or knowing very little, about their local genetics center and the services it provided. Patients' accounts agreed: 87% (62) did not recall being given any information about genetics and genetic services by the GP. Only six (8%) patients recalled being given some information on what to expect from the genetic center and one patient could not remember. As a result, as many as 21 patients reported that they were surprised to receive in the post a pedigree form from the geneticist, and some said they were shocked at being contacted by the genetic center.

GP's lack of knowledge and confidence in taking an accurate family history

The family history or pedigree is the central diagnostic tool in the evaluation of hereditary conditions and identifying those who need management. Therefore, as gatekeepers to specialist services, including genetics, GPs should be taking a detailed and accurate family history. Table 2 shows the type of

Table 2
GPs' accounts of their family history taking (not mutually exclusively)

Family history details	No. GPs (N = 36)
Diagnosis/type of cancer	19 (53%)
Age of the affected	18 (50%)
Who is affected	16 (44%)
Number affected	12 (33%)
Patients' concern/worry	8 (22%)
Ask about parents and sister and other first degree relatives	7 (19%)
Any other symptoms	4 (11%)

information GPs in the present study reported that they asked or elicited from the patient's family history, and the number of GPs who asked for these types of information.

GPs in this study seemed to enquire about only the most basic aspects of the family history and even so, not all the GPs asked for this information. Only 19 (53%) GPs asked about the diagnosis or type of cancer when consulted by asymptomatic patients, only half asked about the age of onset of cancer and fewer than half asked about who was affected and the number of affected relatives.

Patients' accounts of the type of family history information that had been taken confirmed that GPs had inadequate skill in carrying out this task. Forty-three (62%) patients thought that their GP either just noted what they said or only asked about a few details. Ten (14%) patients said the GP already knew their family history and member(s) of their family and therefore did not ask any questions or took only a few details. Only 14 (20%) patients said the GP asked a lot of details about family history.

In the present study, lack of knowledge in genetics and confidence in taking family history details were given by GPs as reasons for not taking a proper family history. Responses such as ". . . I want to hear a reasonable family history . . . I don't think age enters into it for me . . ." indicated that some GPs did not know the right type of information to collect. Some GPs expressed their lack of confidence in performing this task because they were not up to date with the rapid advances in genetics. "I ask about age of onset, whether they're alive or dead . . . But I suppose because the fact that everything changes, is changing rapidly, that you think, maybe I don't know, so I would generally say there's a lot that I don't know." Another GP said, ". . . but there are so many new (genetic) investigations and things that I feel I don't really know much about that would concern me."

GPs also reported problems in eliciting information from patients, which led to inadequate details of family history of cancer being collected. GPs said, ". . . the patients do not know the type of cancer in the family; they can be remarkably unspecific . . .," and ". . . it is also difficult to get the actual details of the relative or whoever is presented with it . . . ."

Despite acknowledging the gaps in their knowledge and skills, few of the GPs had plans to rectify the problem: only 12% intended to seek further education in this specialized area. A further 29% thought they probably would seek additional education, but 59% had no intention of doing so. Low demand for genetic services in primary care was given as the main reason for the lack of interest in further education in this specialist area. Over 90% (33) of the GPs recalled less than one consultation on average per month on family history of cancer, and only three GPs reported more than one consultation on average in a month. This is compared with an average of 348 clinic consultations per month.[36]

Factors influencing a referral to the genetics clinic

GPs offered a number of reasons why a direct referral to the genetics clinic might sometimes be made. In most cases, these kinds of referrals were said to be initiated by patients, which corroborates the accounts, reported earlier, that patients themselves had given.

Specific request by patients and relatives

Although GPs' first choice of referral was usually the diagnostic clinic, a direct referral to the genetics clinic was made if the patient and/or their relatives specifically requested the referral. This was reflected in responses such as ". . . I usually refer to the breast clinic. But I would do straight referral to the geneticist if they (the patients) wanted me to . . .," ". . . I refer them to the surgeon, but if they ask me to refer them to genetics, I will do that instead . . .," and ". . . I have referred a couple to genetics on request from the family. (For) rectal and ovarian cancers, we would refer to the specialist (diagnostic) clinic."

Patient interest in knowing more about their risks prompted some GPs to refer patients to the genetics clinic. This is indicated by responses: ". . . Some people come and say 'Can I be referred to find out more?' And that's what they want. So then it's quite hard to say no . . .," ". . . I ask about family history and if they want to be referred to the genetic center, they get what they want," and ". . . if they are just asking about their risk, then I would refer them to genetics if they want to go."

Patient enquiries and interest in genetic testing was also reported to be the motivational factor for some primary care practitioners to provide genetic counseling and carry out genetic testing in the United States.[8,9]

Patients' anxiety and concern

GPs' responses indicated that patients' anxiety and concern could influence a referral decision to genetics. GPs said, ". . . I might refer in circumstances where there is an area for concern rather than family history. They are usually very concerned to have come to see you in the first place." and ". . . sometimes I refer because the patient is extremely anxious . . . ."

Specific request by hospital doctors

As was already clear from the patients' accounts, the decision to refer patients to the genetics clinic was also influenced by specific requests from hospital doctors/consultants. One GP said, ". . . I have a couple of patients where the hospital suggested that genetic screening may be needed, and those I have directly referred to genetics." Another said, ". . . and one on request from the surgeon looking after the affected relative . . . ."

Type of cancer in the family

For some GPs, their referral pathway was determined by the type of cancer in the family history.

Some GPs said they would use the genetics clinic if they discovered that the patient had a strong family history of breast cancer. One GP said, ". . . with breast cancer, if there seemed to be a lot of female members within the immediate family, I might refer to genetics . . . ." This is consistent with other studies, in which a family history of breast cancer was found to be the single most common reason for a referral to the geneticist.[6,37]

Other GPs emphasized a distinction:

" . . . if it is ovarian we tend to refer to gynecology. If it is strong family history of breast cancer, we might refer to genetics"

Others followed different rules:

" . . . it's not common. If there was a strong family history of breast cancer then I would refer to the breast clinic. If it was ovarian cancer I would refer to genetic. I can't ever remember referring to both"

" . . . Breast cancer, I would refer to genetics or breast clinics. Ovarian and colonic cancers I would generally refer to a surgeon. So, it depends on the type of cancers, even if it is asymptomatic . . . ."

In summary, a referral to cancer genetic services in the present study was not necessarily a sign that the referring GP was actively engaged in primary care genetics.

DISCUSSION

This study has limitations because of the small sample size of GPs. Countless efforts were made to recruit GPs into the study but to no avail. The lack of interest of GPs in participation in research is not unusual[38,39] and a response rate ranging between 22% and 43% is also common for this type of study.[7,8,9] Despite this limitation, the evidence from the patients and the GPs who participated in the present study confirmed previous findings in the United Kingdom[14,15,26,27] and United States[6,9] that most GPs tended to adopt a reactive rather than a proactive role in the provision of genetic services for asymptomatic patients with a family history of cancer.

More specifically, the present study showed that referring to a genetics clinic is not itself evidence that a GP is more proactive about identifying those who may be at an increased risk of cancer and require management. All the patients in this study initiated the consultation with the GP and most of them initiated the discussion of family history. Their GPs confirmed that they preferred not to initiate discussion of family history with their patients, and they were also concerned that adopting a proactive approach might arouse unnecessary anxiety and contravene patient's confidentiality. Fear of the legal implications of genetic advances was also mentioned as a reason for being reactive in discussing family history with patients.

The GPs' preference for a reactive role meant that their skills and knowledge in genetics would only be used infrequently and unpredictably; this in turn meant that updating of skills and knowledge in genetics was a relatively low priority. The result, as in other studies, was that GPs in the present study lacked knowledge and skills related to genetics and therefore lacked confidence in managing these patients. Many GPs in this study did not, for example, take a detailed family history for the purpose of genetic risk assessment. Their family history taking was similar to that found in previous studies,[14,15,37] in which GPs were found to take some type of family history, but one which was often short and lacking in adequate details. It has also been reported that GPs have a tendency to collect and use family history information more as a social history; information collected was inadequate for genetic risk assessment[14] and led to inappropriate referral.[37] In another study,[10] GPs said they carried out this exercise to gain insight into the possible psychological and social impact the disease had on family members, and not to find out whether patients were at risk of cancer.

Lack of knowledge of the genetics center and its services also contributed to making genetics an unusual choice of referral pathway in the present study, and had implications for GPs' ability to provide information to patients about genetic services. Most GPs favored diagnostic clinics as a referral pathway, and made a referral to genetics only when patients specifically requested this or when requested by a hospital consultant or surgeon. More idiosyncratic approaches to the referral decision were also encountered.

In 2003, the UK government published the Genetic White Paper, "Our Inheritance, Our Future- Realizing the potential of genetics in the National Health Service,"[4] giving prominence to the role that could be played by primary care practitioners in genetic medicine. To help their patients benefit from the new genetic knowledge and technologies, the Genetic White Paper encouraged GPs to adopt an expanded role in genetics: identifying genetic conditions, assessing and managing risk, screening, testing, managing patients' concerns and expectations, and providing long-term care. Official guidelines issued in 2006 on the care of women at increased risk of familial breast cancer[40] state that GPs should take a family history that includes aunts, uncles, and grandparents when they are making decisions about the management of a patient presenting with breast symptoms or who has concerns about relatives with breast cancer. These guidelines draw GPs' attention to the existence of computer packages and questionnaires that have been devised to assist them with family history taking.

Unfortunately, as was pointed out earlier, the evidence base for using computer packages and questionnaires was developed in a proactive primary care context, not a reactive one. Evidence is not available to inform primary care practitioners how to respond to patient initiated discussion of cancer genetics in the context of an ordinary primary care consultation. This is an important omission, because recommendations shown to be practicable in the context of a busy primary care clinic are essential if primary care practitioners are to play the major role desired for them in identifying individuals who, because of family history, might be at increased risk of cancer.[1,4,32] Fresh approaches, such as those that involve specially trained nurse counselors,[41–43] may also be required if the Genetics White Paper's vision of primary care genetics in the United Kingdom is to be realized.

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