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GPs' views on their role in cancer genetics services and current practice

Alison Fry, Harry Campbell[a], Hafrun Gudmundsdottir, Robert Rush, Mary Porteous[b], Dermot Gorman[c] and Ann Cull

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Background. Increasing demand for cancer genetics services has necessitated an urgent review of how these services are organized and, in particular, identification of an effective role for primary care.

Objectives. We aimed to assess the views of GPs on their role in cancer genetics services and their confidence in performing that role; to assess their understanding of cancer genetics, current practice and referral behaviour; and to identify needs for information and training to enable GPs to play an effective role in these services.

Method. A cross-sectional questionnaire survey of GPs was conducted through general practices in SE Scotland; 397 (response rate 59.3%) GPs returned a completed questionnaire. Outcome measures were: responders' perceptions of their role in cancer genetics services; confidence within that role; understanding of cancer genetics; current practice regarding patients presenting with concerns about their family history of cancer; and perceived information and training needs.

Results. GPs identified their role to be: taking a family history; making appropriate referrals to specialist services; providing emotional support; teaching breast self-examination; and discussing need for screening. Lack of confidence within this role was reflected in low levels of understanding of cancer genetics and in inappropriate referral practices. Concerns were expressed about the increasingly specialist role demanded of primary care. A desire for referral guidelines and community genetics clinics was identified.

Conclusions. GPs readily identify a role for themselves in cancer genetics services, but admit to a lack of confidence in this area, calling for clear referral guidelines and specialist community support. Current inappropriate referral to specialist services results from a lack of confidence in estimating cancer risk, highlighting the need for the development of clear referral criteria. Given the rapidly increasing demand for cancer genetics services and the vital role of primary care, it is important to identify a model of these services that facilitates effective involvement of GPs without further increasing their workload.

Keywords. Cancer, family practice, genetics, primary health care.

Introduction

Demand for cancer genetics services has increased rapidly in recent years after a surge of public interest and media attention. At the Clinical Genetics Department in Edinburgh, the percentage of workload which is accounted for by cancer genetics has increased tenfold in the last 5 years. Currently organized on a regional basis, specialist services are struggling to cope with demand.[1] Between 30 and 50% of patients referred to these services are not at significantly increased risk of developing cancer,[2,3] but their presence can delay access to services

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Imperial Cancer Medical Oncology Unit, Western General Hospital, Edinburgh EH4 2XU, [a]Department of Public Health Sciences, University of Edinburgh, Medical School, Teviot Place, Edinburgh EH8 9AG, [b]Clinical Genetics Department, Molecular Medicine Centre, Western General Hospital, Edinburgh EH14 5JG and [c]Lothian Health, Deaconess House, 148 Pleasance, Edinburgh EH8 9RS, UK. Correspondence to: Dr A Fry, Department of Clinical Psychology, Outpatient Building, Western General Hospital, Crewe Road, Edinburgh EH4 2XU, UK.

for the remainder who are at moderate or high risk, to whom cancer risk management strategies should be targeted.

The organization of cancer genetics services is under review, and in particular the importance of primary care involvement is increasingly highlighted.[4–6] It has been suggested that as gatekeeper to specialist services, the GP must be able to identify and refer patients at increased risk while reassuring those at low risk,[2] to provide continuing support after genetic counselling and to clarify any advice given to the patient by a geneticist.[4] GPs are strategically placed to fulfil this role in that they potentially care for several generations of the same family.[7,8] They often know patients over long periods of time, so are able to provide counselling and support which is tailored to individual need.[4,9]

A number of obstacles to GPs fulfilling such a role can be identified. GPs' understanding of genetics and willingness to complement specialist services may be limited.[10] Case studies suggest wide variations in current levels of knowledge,[11] and most GPs have received little relevant training.[1,2,7] Enthusiasm to apply new advances in cancer genetics has allowed little time for development of clinical procedures, and consensus about how to manage patients is lacking even between specialist units.[12] Demands on primary care are already heavy,[13] and with an average surgery consultation lasting just 8.5 minutes[14] there is little time to explore complex genetic issues. By contrast, specialist genetic consultations last around 40 minutes and, if necessary, additional time is spent researching a patient's family history. Training needs and information requirements (in the form of referral guidelines or computer-assisted protocols) must be assessed for both GPs and other primary health care staff.[1,2,15]

Although there is a recognition in the literature that primary care has a significant role to play in cancer genetics services, it is not clear whether this is reflected in the attitudes of GPs themselves. The objectives of this survey were: to investigate how GPs view their role within cancer genetics services, how confident they feel within that role and how much time is available to fulfil it; to assess understanding of genetic issues and current practice; and to identify information and training needs that would assist GPs to play an effective role in cancer genetics services. The survey was undertaken prior to a randomized controlled trial of a new nurse-led community-based service in SE Scotland.

Methods

An invitation to take part in the community service trial (of which this survey constituted a part) was sent to all general practices in the following SE Scotland health boards: Borders (24); Fife (54); and Lothian (125). Of these 203 practices, 169 (83.3%) agreed to take part, 23 declined and 11 did not reply. From an original 828 GPs across the three health boards, 720 were available for the survey. Fifty of these took part in a pilot study which resulted in minor changes to the content and format of the questionnaire. Their responses are not included here. The remaining 670 GPs (72 Borders, 160 Fife, 438 Lothian) were sent the revised questionnaire with a prepaid return envelope.

The questionnaire covered three areas: (i) perceived role of the GP within cancer genetics, confidence in performing that role and time available to fulfil it; (ii) current awareness and practice in the field of genetic counselling, including accuracy of risk assessment and referral practice for four simulated case histories of patients presenting with concerns about their family history of cancer (see Table 1); and (iii) ways in which GPs could be helped to deal with the increased workload associated with cancer genetics.

TABLE 1 *Case histories used in the survey*

In your opinion, what would be the risk of this woman developing breast cancer?			
Much higher than the general population	Somewhat higher than the general population	Same as the general population	Unsure

1. A 25-year-old woman whose maternal grandmother developed breast cancer at the age of 45 and whose maternal aunt developed breast cancer at the age of 47. No other relatives have been affected.

2. A 42-year-old woman whose mother developed breast cancer at the age of 61 and whose paternal grandmother developed breast cancer at the age of 63. No other relatives have been affected.

In your opinion, what would be the risk of this man/woman developing colorectal cancer?			
Much higher than the general population	Somewhat higher than the general population	Same as the general population	Unsure

3. A 24-year-old man whose mother died of rectal cancer, aged 39, and whose maternal aunt had previously had uterine cancer, aged 43. No other relatives have been affected.

4. A 64-year-old woman whose paternal aunt developed colonic cancer at the age of 74 and a maternal aunt who developed colonic cancer at 65 years. Her mother died at the age of 43 of myocardial infarction.

Results

The percentage of invited practices who agreed to take part in the survey was 87.5% for the Borders, 72.2% for Fife and 78.4% for Lothian. Participating practices were compared (using two-tailed *t*-tests) with all general practices in SE Scotland in terms of practice size (number of registered patients) and referral rate to the genetics breast cancer clinic. No significant differences were found. Within region, the mean social deprivation index[16] for participating practices in Fife and the Borders did not differ significantly from the mean for all regional practices. There was, however, a significant difference in deprivation index for Lothian, where participating practices served more deprived patients than the average for the area (t (406) = 2.81; $P < 0.01$).

Of 670 questionnaires sent out, 413 (61.6%) were returned. Of these, 16 were not completed: eight due to leave or relocation; 8 because of insufficient time. Results are presented for a final sample of 397 GPs (response rate 59.3%): 54 from the Borders; 81 from Fife; and 262 from Lothian. Most practices returned more than one questionnaire, although two of the smaller practices who had agreed to take part in the survey failed to return any. The maximum number of questionnaires received from any practice was 9.

Attitudes to genetic counselling and screening

Attitudes to the usefulness of genetic counselling and cancer screening in this context were generally positive. Over 60% of responders agreed or strongly agreed with the value of: genetic counselling for patients with a family history of cancer (88.8%); colorectal screening (84.8%); and mammography (80.5%).

Role of the GP in cancer genetics services

Eight statements about the role of the GP were presented, four relating to assessment of cancer risk and four to management of patients at risk. Responders rated their agreement with each statement on a 5-point scale ('strongly disagree' to 'strongly agree'). Responses are shown in Table 2.

Confidence in fulfilling their role

GPs were asked to rate their confidence in fulfilling each of these roles on a 5-point scale ('not at all confident' to 'very confident') (Table 3).

Time available

GPs rated the time they had available for each item on a 3-point scale ('no time at all/insufficient time/sufficient time'). A high proportion of responders (ranging from 48.6 to 68.4%) indicated that they had 'insufficient time' for most items. The two exceptions to this were "calculating the risk associated with a family history of cancer", where 55.7% of GPs responded that they had 'no time at all', and "teaching breast self-examination", where 53.6% responded that they had 'sufficient time'.

Case histories

Simulated case histories (Table 1) were used to assess GPs' degree of understanding of genetic cancer risk and their current referral practices when presented with a patient with concerns about their family history of cancer. The ability of GPs to categorize degree of cancer risk from a family history and their follow-up practice based on that risk were recorded. For each case history, GPs were allowed to select more than one follow-up option. Table 4 shows the distribution of GPs' risk assessments for each case history.

TABLE 2 *Perceived role of the GP in cancer genetics services*

The role of the GP is:	Percentage (%) who:		
	Disagree or strongly disagree	Neither agree nor disagree	Agree or strongly agree
Risk assessment:			
Taking a detailed family history from the patient	21.0	18.4	60.6
Calculating the risk associated with a family history of cancer	84.3	9.6	6.1
Counselling the patient on cancer risk	53.5	22.2	24.3
Deciding which patients should be referred to a regional cancer genetics clinic	8.9	13.2	77.9
Managing risk:			
Providing emotional follow-up support	2.5	7.1	90.4
Providing regular clinical examination	33.2	28.1	38.7
Teaching breast self-examination	10.8	18.2	71.0
Discussing the need for mammographic or colonoscopic screening with the patient	19.2	16.5	64.3

TABLE 3 *Reported confidence in providing aspects of cancer genetics services*

How confident do you feel about:	Percentage (%) who feel: A little or not at all confident	Moderately confident	Confident or very confident
Risk assessment:			
Taking a detailed family history from the patient[a]	25.5	35.6	38.9
Calculating the risk associated with a family history of cancer	95.2	4.5	0.3
Counselling the patient on cancer risk	77.0	18.2	4.8
Deciding which patients should be referred to a regional cancer genetics clinic[a]	29.7	43.3	27.0
Managing risk:			
Providing emotional follow-up support[a]	6.1	29.8	64.1
Providing regular clinical examination	26.6	34.3	39.1
Teaching breast self-examination[a]	8.9	24.3	66.8
Discussing the need for mammographic or colonoscopic screening with the patient[a]	32.5	35.0	32.5

[a] Item that more than 60% of responders identified as their role.

TABLE 4 *Distribution of risk assessments for each case history*

	Percentage (%) of GPs: Much higher than the general population risk	Somewhat higher than the general population risk	Same as the general population risk	Unsure
Breast cases:				
1. Somewhat increased risk	32.8	57.6[a]	5.4	4.2
2. Same risk	14.1	52.8	29.7[a]	3.4
Bowel cases:				
3. Much higher risk	21.9[a]	53.6	12.5	12.0
4. Same risk	8.2	35.9	40.6[a]	15.3

[a] Appropriate risk categorization, as agreed by three local genetic associates.

Table 5 illustrates the probability that a patient would be offered a particular service after being assigned a risk by their GP, irrespective of whether that risk categorization was accurate or not. For example, if a GP identifies a patient as being at 'somewhat higher risk', that patient has a 45.6% chance of being referred to specialist genetics services.

Information and training needs

Responders rated the usefulness of six items in helping them to handle the increase in workload associated with cancer genetics on a 4-point scale (not at all useful to very useful). Table 6 illustrates GPs' responses for each item.

Additional comments on this issue were made by 81 (20.4%) responders. A predominant concern was that primary care is increasingly expected to provide specialist services, in the absence of necessary expertise and sufficient resources to cope with the additional workload. A number of responders suggested that practice nurses may fulfil a valuable role in the provision of genetics services, but there were concerns that this may not be cost-effective given the small numbers of patients requiring these services within each practice.

Discussion

Participating practices were a representative sample of all general practices within SE Scotland for a number of key variables, in particular for prior use of breast cancer genetics services from which attitudes relevant to this survey might be formed. Sampled practices from Lothian, however, had a significantly higher deprivation score than the average for that region, and so the issues highlighted by this paper may be particularly relevant to GPs working in less-affluent communities. This is significant, since there are concerns about the equity of uptake in genetic counselling where more-educated patients are

TABLE 5 *Referral patterns based on risk estimate*

	Probability of being offered service (%)		
	Much higher than the general population risk	Somewhat higher than the general population risk	Same as the general population risk
Referral to specialist genetics services	67.1	45.6	5.4
Referral to other service	45.0	30.9	6.0
Referral for breast screening	57.8	44.6	20.3
Offer of clinical examination	61.3	61.8	56.2
Discharge	6.6	19.7	66.0

TABLE 6 *Training and information needs*

	Percentage (%) of GPs			
	Not at all useful	A little useful	Quite a bit useful	Very useful
Interactive computer program to link family histories to individual disease risk	16.6	33.1	34.5	15.8
Referral guidelines	0.8	9.7	44.6	44.9
Local clinics offering genetic counselling closer to the community	9.3	23.9	38.4	28.4
Direct access to medical genetic screening	13.4	27.4	41.4	17.8
Training for yourself in genetic counselling	23.1	41.6	26.0	9.3
Training for other primary care staff in genetic counselling	20.9	43.8	28.0	7.3

generally over-represented.[17] The response rate of 59.3% was similar to that of other postal surveys of GPs in the UK.[18,19]

There was variation between GPs in how they viewed their role in cancer genetics services, but a number of key points emerged. They accepted responsibility for taking a detailed family history and for deciding which patients should be referred to specialist services. A survey of general practice within Calderdale and Kirklees Health Authority[20] found a similarly positive attitude towards family history taking. There was less support for the idea that GPs should counsel the patient on their cancer risk, and a strong feeling that it was not their role to calculate the patient's risk of developing cancer. There was consensus that the GP has a role to play in managing increased risk of cancer once that risk has been established, including provision of emotional support, teaching breast self-examination and discussing the need for screening.

Levels of confidence in delivering genetics services were low, even for tasks that GPs thought should be their role. Available time for these tasks was reported as limited, reflecting general frustrations felt in primary care about increasing workload imposed by recent changes to health care policy and by rising consultation rates.[13,14,21–23]

Even at the very basic level of categorization required by this survey, there were high numbers of inappropriate risk estimates given for the case histories. GPs readily placed patients into the moderate or high-risk category, but were less inclined to assign a risk equivalent to that of the general population. Once a risk assessment had been made, referral patterns based on that risk appeared to be appropriate. These data suggest that only 5% of patients judged to be at the same risk as the general population would have been referred to specialist cancer genetics services. The ability of simulated case histories to predict physicians' actual behaviour has been queried,[24] and on the basis of published figures we know that in reality between 30 and 50% of patients referred to specialist services are not at significantly increased risk of cancer.[2,3] In order to explain the discrepancy between our simulated referral patterns and those reported in the field, it is suggested that current high rates of inappropriate referrals result from GPs' lack of confidence in assigning cancer risk based on a patient's family history of the disease.

The need for referral guidelines was identified by a high proportion of responders. Given the strong feeling that it is not the GP's role to calculate cancer risk and the

low levels of appropriate risk categorization achieved in the case histories, referral criteria should be based on a patient's family history alone. Risk criteria based on family history are already available in the form of a Cancer Research Campaign patient education leaflet, which could potentially be made more widely available in general practice. The idea of an interactive computer program to link family history to disease risk was endorsed by 50% of responders, and could provide an efficient means of supporting GPs in their referral decision. Such a system is currently being developed through collaboration between the Cancer Research Campaign and the Imperial Cancer Research Fund's Advanced Computation Laboratory and General Practice Research Group.

There was resistance to accepting training in genetic counselling either for GPs themselves or for other primary care staff. There was a preference for support in the form of community genetics clinics offering counselling locally. Strong concerns were expressed about the increasingly specialist role that primary care is expected to play in the absence of sufficient resources.

This survey was undertaken as a precursor to introducing a trial of a new nurse-led community-based genetics service in this region, with an intention to review GPs' attitudes at the end of the trial period. Developing primary care is at the heart of the government's commitment to the NHS in Scotland and is essential to the development of an effective and efficient system of care. Furthermore, developing partnerships between different parts of the NHS in an attempt to integrate care and provide patients with "seamless service" is a current policy objective of the NHS. If there is to be encouragement of effective integration of services at the interface between primary and secondary/tertiary care in the field of cancer genetics then it is vital that the views of GPs are explored so that appropriate developments can be planned. It is essential that the design of services across this interface should properly reflect the contribution that the primary and secondary care sectors can make. Obtaining the views of a wide range of GPs supplemented by further GP consultation and involvement in planning should be an integral part of the design of any new development in cancer genetics.

Although a number of GPs suggested a role for their practice nurse in providing cancer genetics services, there were concerns about the cost-effectiveness of such an approach in view of the small numbers of patients requiring these services within each practice. In the model for cancer genetics services now under evaluation in SE Scotland, support for GPs is provided through genetics nurse specialists who are based in a regional genetics centre but provide counselling and follow-up services in locality clinics.[6,12,25] It is likely that in future the genetic investigation of many more common disorders will be possible, thus increasing the number of patients who come to their GP for advice. It is vital that the NHS addresses now the issue of how to provide these services effectively and efficiently before the need for them escalates further in the coming years.

Conclusions

GPs perceive their role in cancer genetics services to be taking a detailed family history, deciding whom to refer to specialist services, providing emotional support at follow-up, teaching breast self-examination and discussing the need for screening. Their confidence in carrying out this role, however, is low. Estimation of cancer risk based on family history is an unreliable method by which to expect GPs to make appropriate referrals to regional services. Referral guidelines are required that provide clear criteria based on family history alone. GPs do not see training for themselves in this field as a priority, but would welcome support from specialist community clinics. It is vital that a model of future genetics services be identified that facilitates primary care involvement without making unrealistic demands on the GP.

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