A study of GP referrals to a family cancer clinic for breast/ovarian cancer

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Objectives. The aim of this study was to investigate the appropriateness of primary care referrals to the Oxford Regional Genetics Service on account of a family history of breast and/or ovarian cancer and to explore GPs’ expectations following a referral.

Methods. Fifty consecutive GP referrers were sent a questionnaire post-referral, and their referral letters were reviewed.

Results. The study achieved a high response rate (94%) and showed that many GPs did not know which patients warrant referral to the genetics service and that they had unrealistic expectations of what happens at the clinic.

Conclusions. If GPs are to fulfil their gatekeeper role effectively, and possibly become more involved in the delivery of genetic services in the future, it is clear that they require further education in this area.

Keywords. Breast cancer, family history, ovarian cancer, primary care, referral guidelines, risk assessment.

Introduction

Over the past few years, the number of primary care referrals to genetics clinics on account of a family history of cancer has increased dramatically.1,2 Specialist genetic services are limited and unable to meet the current demand, and it is being suggested increasingly that primary care needs to become more involved in providing genetic services.3,4 National consensus is that the most appropriate management of those with a family history of breast/ovarian cancer first involves their categorization into low or moderate/high risk groups based on the degree of family history.5,6 The rationale is that whilst patients at moderate or high risk of developing an inherited form of cancer may benefit from referral to secondary care where they may be offered various prevention/early detection options,1 for low risk women it is argued that the most appropriate management is reassurance and advice in primary care.

Many of the patients referred from primary care have actually turned out to be at low risk of having an inherited predisposition to cancer,2 and some genetics centres have responded by developing guidelines for GPs advising them on which patients to refer.

Previous studies have shown that GPs are comfortable with the role of gatekeeper and see it as their responsibility to decide who should be referred on the basis of family history.7,8 However, as well as being able to make appropriate referral decisions, it is important that GPs have sufficient knowledge to be able to reassure low risk women effectively. It is also important that they have an understanding of what the genetics service is able to offer, so they can foster realistic expectations in patients they refer.

The main aims of this study were to investigate: GPs’ confidence in managing women concerned about familial breast and/or ovarian cancer risk; the appropriateness of referrals being made to the genetics service; and GPs’ expectations following a referral.

Background information on clinic policy

The Oxford Regional Genetics Service (ORGS) general clinic policy is that, following a referral, the patient is sent a detailed family history questionnaire to complete and return to the genetics service. Once received, the referred patient’s risk of carrying a cancer-predisposing gene, as well as their lifetime risk of developing cancer is assessed.
using the computer program Cyrillic 2.1.9 Those individuals deemed to be at low risk, defined as a <1 in 10 chance of carrying a dominant cancer-predisposing gene or a <3-fold increased risk (relative to a woman in the general population) of developing breast/ovarian cancer by the age of 50, are sent a letter of reassurance. The referring GP is also sent a letter explaining that the risk is low and hence the patient has not been sent a clinic appointment and reassurance is appropriate. Individuals at moderate or high risk of carrying a dominant cancer-predisposing gene (i.e. anyone who exceeds the level of risk described previously) are invited for a clinic appointment. The clinic verifies the information provided in the family history questionnaire as far as possible by obtaining histological confirmation of family cancers. This is usually done prior to the clinic appointment, and consent is always sought if the relative is still alive. If the relative is dead, information is sought from the cancer registry. At the clinic appointment, the family history information provided in the questionnaire is reviewed. The risk that the family history is due to a dominant cancer-predisposing gene and the individuals’ risk of developing cancer is discussed.

Management
At present, there is no strong research evidence regarding the effectiveness of any of the various management options for individuals with a familial risk.10 Nonetheless, there is a consensus view which most centres follow (with relatively minor regional variation). In Oxford, women at moderate or high risk would normally be recommended to begin regular mammographic screening from age 35. Clinical breast examination is sometimes carried out at the clinic or, more usually, a referral to the breast unit is made. Participation in research studies, e.g. the International Breast Cancer Intervention Study —‘the Tamoxifen Trial’, the National Multi-centre Study of Magnetic Resonance Imaging in patients at Genetic Risk of Breast Cancer or the UKCCCR Familial Ovarian Cancer Screening Study, is discussed with those patients fulfilling the entry criteria. Discussion of genetic testing and/or prophylactic surgery is usually only undertaken with the relatively small number of individuals found to be at high genetic risk. Use of hormone replacement therapy and the oral contraceptive pill may be discussed where relevant, although the extent to which these known risk factors for breast cancer interact with familial risk is not yet fully known.11

Methods
A short questionnaire (a single A4 sheet) was sent to 50 consecutive GP referrers to the Oxford Regional Genetics Service (ORGS) for familial breast and/or ovarian cancer, during June–September 1998. A covering letter from the consultant geneticist and a reply-paid envelope were enclosed. The questionnaire was sent within 2 weeks of the genetics clinic receiving the referral letter and asked a number of closed questions about the referral, use of guidelines and expectations of the genetics clinic. Responses were double entered and frequencies calculated using SPSS for Windows (v9). The corresponding GP referral letters were reviewed to assess whether or not they fitted the referral criteria specified in the local guidelines.

Results
The response rate was 94% (47/50 completed questionnaires received). In two instances, the referral was not related primarily to breast/ovarian cancer; hence, these cases were excluded from the analysis.

In 71% of cases (32/45), the patient had raised the issue of a family history of breast and/or ovarian cancer with the GP, and in 40% of cases (18/45) the patient had actually requested the referral. In 20% of cases (9/45), it was the GP who had first raised the issue, and in one instance it was another health professional. In three cases, both the patient and the GP reportedly had raised the issue.

Sixty-nine percent of GPs (31/45) said they felt either confident or very confident about their management of the referred patient; 31% (14/45) did not feel very confident; and 44% of GPs (20/45) felt they needed more information on the topic of familial breast/ovarian cancer. GPs’ expectations of the referral to genetics are presented in Table 1.

Approximately half of the respondents (23/45) recalled receiving referral guidelines (which had been mailed by the local Health Authority to GPs in 1996; see Appendix 1

<table>
<thead>
<tr>
<th>Expectation</th>
<th>Proportion of GPs who responded likely or very likely (n = 45)</th>
</tr>
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<tbody>
<tr>
<td>Pedigree construction</td>
<td>71% (32)</td>
</tr>
<tr>
<td>Accurate assessment of risk of developing disease</td>
<td>80% (36)</td>
</tr>
<tr>
<td>Accurate assessment of risk of carrying breast cancer gene</td>
<td>53% (24)</td>
</tr>
<tr>
<td>Breast examination</td>
<td>31% (14)</td>
</tr>
<tr>
<td>Early breast screening recommended</td>
<td>62% (28)</td>
</tr>
<tr>
<td>Genetic testing</td>
<td>31% (14)</td>
</tr>
<tr>
<td>Discussion of tamoxifen use</td>
<td>36% (16)</td>
</tr>
<tr>
<td>Discussion of prophylactic surgery</td>
<td>27% (12)</td>
</tr>
<tr>
<td>Discussion of ovarian cancer screening</td>
<td>36% (16)</td>
</tr>
<tr>
<td>Advice on use of hormone replacement therapy/oral contraceptive</td>
<td>67% (30)</td>
</tr>
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in accompanying paper by Lucassen et al.\textsuperscript{2}) and, of these, 70% (16/23) reported actually using the guidelines for this referral.

Forty-one GP referral letters were available in the clinic notes for an assessment of whether or not the referral met the locally agreed referral guideline criteria. Forty-six percent (19/41) of these letters met the referral criteria (i.e. reported family history suggestive of moderate/high risk), 29% (12/41) did not meet the criteria (i.e. reported family history suggestive of low risk), and in 24% (10/41) of cases there was insufficient information in the letter to know whether or not the criteria had been met. Fifty-three percent (8/15) of referrals where the GP reported using guidelines met the referral criteria, compared with 42% (11/26) of referrals where the GP did not use guidelines (chi square = 0.465, \( P = 0.495 \)). In the nine referrals where the GP had raised the issue of family history, only one-third (3/9) actually met the referral criteria.

Discussion

Although this study is relatively small, the survey achieved an unusually high response rate and some interesting findings emerged. We believe the high response may reflect an acknowledgement by GPs that cancer genetics is being recognized as a potentially important new area for primary care.

The study demonstrates that many GPs need more help with recognizing which patients to refer to the family cancer clinic, with more than one in four referrals of patients with a low risk family history. If GPs are to act as efficient gatekeepers, it is important that they know which patients are likely to benefit from referral and which patients are at low genetic risk and for whom it would be more appropriate to offer reassurance and advice at the primary care level. It has been shown that guidelines can improve GP referrals\textsuperscript{12,13} and there is evidence that referral guidelines for familial cancers have improved referrals at least in the short term.\textsuperscript{2} However, there are real problems in general practice of guideline overload,\textsuperscript{14} and in this study only half of the GPs recalled receiving referral guidelines circulated 2 years previously. If guidelines are to remain effective, it appears that they need to be updated regularly. It is also disappointing to note that a quarter of GPs did not include sufficient information in their referral letters. Bearing in mind the pressure on cancer genetics clinics and the potential anxiety to women knowing that they have been referred, this needs to be addressed.

This study also demonstrates that many GPs have unrealistic expectations of the services offered by the family cancer clinic and the options likely to be available to their patient. For example, many more GPs thought early breast screening would be recommended than was the case. Thirty-one percent of respondents thought genetic testing would be performed and around 27% thought prophylactic surgery would be discussed, both of which happen only relatively rarely, with high risk patients. Many GPs believed their patient would be given advice on use of hormone replacement therapy or the oral contraceptive pill, yet probably very few are aware that as yet there is no good evidence on the interaction of these risk factors with family history on which to base advice to patients.

We found that most often it is the patient who raises the issue of familial cancer. However, it is interesting that in 20% of cases it was the GP who had raised the issue, and in these instances the referral often did not meet the recommended referral criteria. Given the unnecessary anxiety which may result from referring low risk women to secondary care, and the lack of strong research evidence for the effectiveness of any of the available interventions for those at moderate or high risk,\textsuperscript{10} it does not seem appropriate for GPs to be proactive in relation to raising the issue of familial risk at this time.\textsuperscript{15}

In summary, despite expressing confidence in their management of women who are worried about their family history of breast and/or ovarian cancer, we found that many GPs are unsure which patients warrant referral to the genetics service and also have misperceptions of what happens when they do refer a patient. A recent study of women with a family history of breast cancer concluded that GPs could play an important role in advising women on what to expect from referrals, gene testing and mammographic surveillance (A. Andermann, submitted for publication), and qualitative studies with GPs have shown that they lack knowledge in this area.\textsuperscript{7} This study provides further evidence that GPs require education and information on the topic. We subsequently have developed an information package (which contains updated referral guidelines) and an accompanying educational session for GPs on familial breast and ovarian cancer which currently is being evaluated in a randomized trial.

Acknowledgements

We would like to thank Lindsay Briggs and Tracy Edwards for administrative assistance, and the CRC for funding this study.

References

15 Emery J. Principal role of primary care is not to seek out those at increased risk. Br Med J 2000; 320: 186.