The genetics liaison nurse role as a means of educating and supporting primary care professionals

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Background. Previous research with primary health care professionals has demonstrated consistently that education, training and support are necessary before there should be any expansion in primary care genetics. The genetic liaison nurse role has been suggested as one means of providing this education and support.

Objective. The aim of this study was to evaluate GP responses to the genetics liaison nurse role as a means of supporting community-based genetics services.

Methods. A self-completion postal questionnaire in primary care was sent to GPs working in Nottingham. Main outcome measures were assessment of potential usage of a genetic outreach professional in terms of time, roles and support for a pilot scheme

Results. A total of 182 (55.0%) of 331 GPs working in Nottingham returned a questionnaire. Although 54% did not believe that the genetics liaison nurse role would be useful in the present, most believed that such a role would definitely or probably (64%) be useful in the future. The most valued contribution was as a source of advice when genetics problems arise in a consultation. Providing education on specific genetic disorders and on clinical skills relevant to genetics were also seen as important. Many GPs would also use a liaison nurse to see patients prior to their attending an out-patient clinic with a clinical geneticist. Respondents suggested that each nurse should spend ~3 hours a month in each practice and be attached to between 10 and 20 practices.

Conclusions. GPs appreciate that there may be limited genetics services provided in primary care at present, but this is likely to change in the near future. The genetics liaison nurse role should be evaluated as a means of providing genetics specialist outreach support for service delivery and to facilitate education.

Keywords. Genetics, liaison nurse, primary care.

Introduction

There are concerns in a number of countries about the ability of specialist genetics services to meet existing demand for genetic services. Genetic services will need to be provided at the primary care level, even in those countries where primary care does not have a traditional gatekeeper role. Demands on GPs' time are high, and most doctors have received little, if any, training in genetics, and what knowledge or skills that they may have could be out of date. Despite this, they are already being consulted for family history risk.

Previous research has demonstrated an acceptance by GPs that they have an increasing role to play in genetics, but lacked confidence in their ability to do so because of limited skills and knowledge of clinical genetics. Emery et al. conducted a systematic literature review exploring the role of primary care in delivering genetic services. Educational programmes, referral guidelines and computer decision support have all been suggested as potential methods of supporting primary care in the provision of genetics services. Genetic nurse specialist outreach clinics were also identified as a useful method of supporting primary care genetics. This approach has been used or suggested in other service contexts and countries.

The study reported in this paper asks GPs about the usefulness of genetic outreach and how they would use a
genetics liaison nurse if one was attached to their practice. As far as we are aware, this is the first study to assess this.

Methods

In January 2000, a postal questionnaire was sent to all 343 GPs in Nottingham. A follow-up questionnaire was sent to non-responders 4 weeks after the first mailing.

Details of date of birth, gender and qualifications of GPs were obtained from a publicly available list supplied by Nottingham Health Authority. The list contained full data only for those GPs working in a Nottingham practice in 1997. Thus data were missing on 36 (10%) of GPs in the sample.

Subjects were asked how useful would it be for a genetics liaison nurse to be attached to their practice at the moment and in the future; and whether they would be interested in being part of a genetics liaison nurse pilot scheme. They were also asked how they could envisage using a peripatetic genetics liaison nurse attached to their practice. Five possible roles were proposed which had been suggested during previous qualitative research. Subjects were asked about their preferred learning style and the number of GP principals in their practice, as a marker of practice size.

The relevance of needing support for genetics in primary care was assessed by measuring the anticipated usage of nurse time, estimated via GPs’ opinion on the average amount of time per month allocated to the practice and the number of practices that each genetics liaison nurse should cover.

Data were analysed using SPSS for Windows version 9. Probability of obtaining results by chance (P) was measured using a chi-square test.

Results

Questionnaires were sent to 343 GPs. However, 12 were returned marked ‘retired’, ‘dead’ or ‘not working at that address’. Completed questionnaires were returned by 183 (55.3%) of the remaining 331 GPs.

Respondents were similar to non-responders for age, sex, size of practice and holding the DRCOG or DCH, but were more likely to be members of the Royal College of General Practitioners (56.5% versus 42.2%, chi-square = 6.01, d.f. = 1, P = 0.01).

Seventeen respondents (9.6%) thought that there would definitely and 64 (36.0%) said there would probably be a role for a liaison nurse at present. Ninety-seven (54.5%) definitely and 86 (48.3%) possibly thought that there would be a role in future. The majority said they would probably (100, 58.1%) or definitely (28, 16.3%) be interested in participating in a pilot scheme. There were no significant statistical associations between any of the above variables and the number of partners in the practice.

Fewer female GPs (24.6%) than male GPs (41.5%) thought that such a nurse would have a limited role in the future (chi-square = 7.01, d.f. = 2, P = 0.03). Younger GPs were also more supportive of the genetics liaison role. Almost half (48.8%) of the GPs aged 50 or older thought that there would be limited value in the future compared with 42.9% of the 45- to 49-year-olds, 23.7% of the 40- to 44-year-olds and 18.9% of the GPs aged under 40 years (chi-square = 14.78, d.f. = 6, P = 0.02). There were no significant associations between support for the role and additional qualifications.

Respondents were most keen for the genetics nurse to provide education about genetic diseases and to have a service delivery role (Table 1). Other suggested ways of utilizing a genetics liaison nurse included education and update of developments in genetics for the primary care team; involvement with pre-conceptual and antenatal care; raising public awareness; counselling; building links with genetic specialists and patient support groups; and advice on specified diseases.

More GPs (40, 23.4%) preferred vicarious learning (e.g. through discussing actual cases and observing the genetics liaison nurse) than formal educational approaches.

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<th>Definitely</th>
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<td>n</td>
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<td>To provide education on specific genetic disorders</td>
<td>77</td>
<td>45.0</td>
<td>47</td>
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<td>To provide education on clinical skills relevant to genetics</td>
<td>62</td>
<td>36.0</td>
<td>47</td>
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<tr>
<td>To provide a service in assessing family history and genetic risk</td>
<td>82</td>
<td>47.7</td>
<td>52</td>
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<td>To act as a source of advice when potential genetics problems arise in a consultation</td>
<td>92</td>
<td>53.2</td>
<td>48</td>
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<td>To see patients who you refer to a clinical geneticist prior to them attending an out-patient clinic</td>
<td>51</td>
<td>29.5</td>
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conducting risk assessments, acting as sources of advice, etc. Fewer than a tenth thought that genetics was not a priority for continuing medical education. Respondents thought that a genetics nurse should cover 20 practices, spending ~3 hours (one session) per month in the practice.

While nurses could cover more practices with this time commitment to each, it will be important for the nurse to spend part of the working week at the specialist genetics centre in order to keep up to date with technological developments, whilst remaining accessible to provide effective care at the primary level.

Contact with the genetics liaison nurse during the care of patients would also provide education via vicarious learning. While formal education meetings on genetics within postgraduate programmes may have a role to play, such approaches have been shown to be less effective than vicarious learning. Most GPs said that they liked to learn via such a mechanism. Such an approach can be less threatening than education in more formal settings and is more tangible when related to specific cases.

The genetics liaison role has not been evaluated hitherto, other than by Modell et al., in a project with haemoglobinopathy screening which used educational sessions led by a nurse facilitator to raise referrals from primary care. Modell et al. recognized the importance of outreach and ongoing support to enhance and maintain any educational interventions.

It may have been difficult for subjects to answer the questions posed since they may not previously have considered the impact of genetics on primary care and may be uncertain about the skills of the person who may be appointed to the role, and hence the benefits to the practice. However, Nottingham GPs may be better placed than GPs elsewhere to comment on responses to genetics provision in primary care due to the fact that they have been encouraged to think about genetics through involvement in previous research and a community-orientated clinical genetics service.

While this study evaluates a potential response to primary care support needs in the UK, the underlying problem and the proposed solution is pertinent in other countries. Studies in The Netherlands, Belgium and the USA, for example, have shown that primary care professionals are being consulted by patients concerned about familial risk, questioned whether they will be able to respond adequately and have evaluated potential solutions to the consequent educational and support needs in primary care. The organization of UK specialist genetics services is also typical of other countries, where there are also concerns about the scarcity of specialist genetics counselling to meet existing, let alone future, demand for genetics services.

Pilot studies are urgently needed to assess the roles and numbers of genetic nurse specialists required in primary care to help guide development of service response to the ‘New Genetics’ as more services become ready for.

### Discussion

Half of the respondents did not think that a genetics liaison nurse would be useful at present, which is not surprising since mass genetic screening programmes currently are not feasible. However, two-thirds did think that there may be a role for such an individual in future and most had some level of interest in being part of a pilot in the near future. Most thought that they definitely would use the nurse in the roles that were suggested. While there was a recognition that a genetics liaison nurse would have an educational role, the main input to the practice seemed to be in active service delivery,
to go ‘on-line’. This survey has provided an indication of the likely level of nurse support that will be needed. In the short term, the nurse could assist with existing community-based genetic screening (e.g. for cystic fibrosis, haemoglobinopathies and phenylketonuria) and family history risk for cancer. However, part of the evaluation will be to assess the nature and quantity of current and future work.

The term ‘genetics liaison nurse’ has been used in this study, because GPs may be more accustomed to nurses filling such an outreach role in other disease settings. An evaluation could test whether genetic associates with other professional backgrounds could also fulfil this genetics outreach role.

While this research has been based in the UK, the need to improve the knowledge and skills of health professionals participating in genetic screening is a concern in North America and Europe. We therefore believe that this approach to supporting primary care-based genetics will have international utility.

References