



A qualitative study of GPs' views on modern genetics

Laurence Bathurst

GradDip, MA, is a research assistant, School of Health Information Management, the University of Sydney, New South Wales.

Qi Rong Huang

MBBS, PhD, GradDipHIM, is Lecturer, School of Health Information Management, the University of Sydney, New South Wales. j.huang@fhs.usyd.edu.au

BACKGROUND

With rapid advances in genetics and increased public awareness of genetic testing for many hereditary diseases, the demand for genetic services may increase. We wondered how developments in genetics have impacted on general practice and the position general practitioners have taken in practising the new genetics.

METHODS

A qualitative study using semi-structured interviews conducted during 2003–2004 with 15 GPs practising in Sydney (New South Wales) and the Australian Capital Territory.

RESULTS

General practitioners reported that genetic services had minimal impact on their practice and the number of consultations related to genetic conditions was insignificant. They felt they were often not included in the 'referral loop' of such patients. Their knowledge of advances in genetics was limited. They were wary of the possible costs of testing and the time taken to provide genetic counselling.

DISCUSSION

General practitioners' attitudes toward modern genetics seems to be disengaged, and they are ambivalent toward the role they now play, or will play, in genetic services.

Advances in genetics, particularly at the molecular (DNA) level, are developing rapidly. This may mean the demand for genetic testing and counselling will increase in general practice as information enters the public arena.^{1–3} Our understanding of how general practitioners perceive their attitudes to, and role in, modern genetics comes from early overseas studies.^{2–9} That is, few GP consultations for genetic conditions; limited knowledge by GPs of molecular genetics; reservations about their role in delivering genetic services; and any impact on general practice. These findings are confirmed by Australian studies that recommend education for GPs in genetics.^{10–12}

We revisited genetic services in general practice, exploring GPs' experiences and views.

Methods

We adopted qualitative methods and conducted in depth interviews with GPs using semi-structured questionnaires (rather than focus groups) to allow discussion around sensitive areas such as those involving professional knowledge, self efficacy and ethics.^{12–16}

Subjects were recruited from members of the General Practice Computer Groups (GPCG) and the Western Sydney Division of General Practice (WSDGP) who participated in an earlier survey on genetics in which they had agreed to take part in further surveys. Out of 129 GPs in the first survey, 15 were interviewed between July 2003 and February 2004. Most were members of WSDGP. Their practices were located in metropolitan Sydney (the inner west, western suburbs and northern region) and the ACT. Informed consent was obtained and interviews conducted face-to-face with most GPs at their practices (four preferred the telephone). A checklist of questions was compiled, but was only used to prompt discussion rather than influence respondents' measures of what was important. Data were categorised into common themes and analysed accordingly.

Results

Several themes emerged from the interview data (*Table 1, 2*).

Familiarity and experience with genetics

The GPs were not familiar with modern genetics. Their knowledge of it was limited to Mendelian diseases (eg.

cystic fibrosis, muscular dystrophies and thalassaemia) rather than multifactorial or polygenic diseases. Nor were they confident about which conditions could be tested for, and how. Consultations with a genetic component were rare, and so often they were not in the referral-follow up loop.

Impact on practice in the future

The GPs thought it inevitable they would be involved in counselling for and managing genetic disorders, if only as referral agents.

Barriers to providing genetics services

The most important barrier was limited knowledge, especially by older GPs. Limited time for proper consultation for the attendant counselling was another barrier.

Training and education

Although there was a need for education for genetics, it should be easily accessible. The rarity of patients with genetic conditions would not deter the GPs, although an increase in such patients would motivate them more, as

would personal interest in any topic. There was a current lack of relevant education in genetics. The GPs already used the internet and medical journals for information.

Ethical and moral issues

Litigation was at the forefront. This centred on the accuracy of tests, ability to interpret results correctly, and disclosure and confidentiality in relation to inherited positive or carrier status for genetic diseases. Termination of pregnancies for genetic diagnoses, eugenics, and the use of genetic information to discriminate against afflicted people were not issues for these GPs.

Discussion

The study has shortcomings: the sample was small, and we may have introduced observer bias in eliciting questions. Nonetheless there were some interesting findings. Even though there has been extensive media coverage of rapid developments in genetics (especially around the Human Genome Project), and 'DNA' has moved into the popular vocabulary, the impact of genetics in general practice is still minimal.¹⁷

What is the reason? The barriers we identified – lack of knowledge or expertise and uncertainty about roles – were similar to previous research from both Australia^{10–12} and overseas.^{2–9} We also found concern about the costs of providing such care.

Whether GPs' perceptions of themselves as 'gatekeepers' will extend to genetic services is unclear. Clearly GPs need to establish links and develop referral guidelines to genetic clinics.^{3,11,18} More research is needed to establish a model of integrated delivery of services involving GPs, genetic counsellors and specialists, and also to examine how the costs of providing such services at primary care level can be addressed.

Implications for general practice

What we already knew:

GPs are poorly

- engaged in modern genetics, and
- prepared for any possible increase in demand.

What this study shows:

GPs feel

- barriers to engaging genetic services include lack of

Table 1. Interview data

Familiarity and experience with genetics practice

'I feel quite familiar with the basics of genetics and I am really interested in that branch... but don't take me as a role model... I don't think other GPs know about genetics that well because it's a complex area' [Dr A]

'I know nothing about it' (when commenting on molecular genetics) [Dr B]

'Where the knowledge is, is in the genetic clinics [and] it's the genetic clinics who want and will want [GPs to be involved]... They are the people who will want a population of knowledgeable GPs so they can send their ordinary patients back to (them)... in the knowledge that those patients won't fall through the cracks' [Dr C]

Perceived impact on practice and GPs' role in the future

'This depends on the level of advice you have to give because I am sure those tests aren't across the board for each different cancer... I would be happier to have access to someone with expertise' [Dr D]

'I think we could play a very important role here; I mean, if we are aware that there are certain tests available for these types of conditions at least we can advise the patient a little bit more and give them more information or make them aware and give them at least some news about their risk of getting all these conditions' [Dr E]

Barriers to providing genetics services

'I will give [the patient] time, but not an hour or 2. I've got other people [to see]. Now this [genetics] does not lend itself to 6 minute medicine... and anything more than 20 minutes, you're losing. Simple economics, it doesn't pay, end of story' [Dr F]

'The problem with counselling is the time factor, because with this sort of problem, you might have to have more consultations, not just one single consultation... now how much time did you spend with the patient? Is it a C consultation or a D consultation? You know the insurance commission cannot pay you that much money; [queries] why are you doing long consultations? So that is a barrier' [Dr G]

'Patients in western Sydney want to know if they are going to pay money or not... and we don't know if Medicare pays for it or not... the cost could be 300, 400. That's a big issue, we need all [such] information' [Dr I]

Training and educational needs

'[For] most GPs, their understanding of genetics would be similar to mine, even the young doctors... There are so many different areas that we're supposed to be expert in... they've probably got a more packed course [nowadays] than when I did medicine' [Dr D]

'It also means that people who are making the educational materials also hear what people are doing in real life and may well find out that we think it's really great and technically its fantastic information... but if nobody is using it because it just takes too long or the graphics are too small or it doesn't print out [well] on a black and white printer... feedback is what people really need' [Dr G]

Table 2. Interview data**Perceived opportunities arising from the advance of the new genetics**

- More testing available for patients
- A wider role in providing genetic services made available to GPs
- Early intervention and better management
- More relevant and accessible support (eg. online)

Perceived barriers to being actively engaged in genetic counselling

- Not familiar or knowledgeable enough
- Should be left to the experts and be happy to remain in 'gatekeeper' role
- Not clear about the role of GPs within the network of those already providing services
- Education and information not easily accessible to GPs
- Cost to patients and possible lack of reimbursement by Medicare
- Time constraints

- knowledge and skills about modern genetics
- time for genetic counselling, and
- cost of tests
- a need for further education in modern genetics.

Conflict of interest: none declared.

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