Reactions of GPs to a triage-controlled referral system for cancer genetics

Glyn Elwyn, Rachel Iredale and Jonathon Gray


Background. The demand for genetic services is increasing as public awareness about ‘predictive’ tests increases and commercial marketing initiatives develop. In the UK, genetic services vary widely between regions. To manage demand, an all-Wales cancer genetics service based on telephone triage and referral guidelines was designed and implemented.

Objectives. The aim of this study was to examine the reactions of GPs to a cancer genetics service controlled by referral guidelines and a triage system, and the perceived impact genetics will have on general practice.

Methods. We conducted a structured qualitative study in primary care using sequential focus group discussions with 14 GPs, representing 12 practices divided into two groups (service providers and educationalists). The doctors were introduced to the ‘new’ genetics, briefed about the service and the referral guidelines and given an outline of the topics to be discussed. All discussions were recorded, transcribed and analysed.

Results. The GPs in this study had not considered how they and their teams would handle the practical implications of the ‘new’ genetics. They had no major objections to a triage system as a means of regulating access to a scarce specialist service, but were concerned about two issues. First, that an insistence on the completion of a postal questionnaire as a means of obtaining an initial assessment could disadvantage some individuals and, secondly, that it was not clear to either the GP or the patient that the risk assessment would be undertaken by a telephone interview. Although there was some concern about yet another set of referral guidelines, participants accepted that the potential demand for cancer genetics services had to be regulated.

Conclusion. The acceptance by GPs of this triage system represented a reluctant acknowledgement that primary care, in its present organizational form, cannot provide high quality genetic counselling. However, the realization that this represented a relinquishment of the normal generalist role led to the emergence of ambivalence and a wish to consider how best to accommodate this new need in primary care.

Keywords. Cancer genetics, general practice, referral guidelines, triage, Wales.

Introduction

The demand for genetic services is increasing as the public becomes aware that predictive tests are available and are being marketed commercially in many countries. Cancers are the first of an anticipated host of common diseases to be investigated genetically. These initiatives pose challenges to both specialists and generalists about how best to deliver counselling and risk assessment services, as well as ethical issues for society at large.

There is little consensus about the delivery of cancer genetics services, and differing geographical arrangements and referral patterns exist in the UK, with wide variation in access and quality. Many regional centres have been supported within academic institutions, funded from research grants, and have essentially developed on an ad hoc basis. Yet it is known that problems relating to cancer genetics constitute 15–20% of referrals to breast and gynaecology clinics, delaying access for patients who are waiting for ‘usual’ services and handled by clinicians who are likely to be ill equipped to discuss the issues involved.
As a result of a report for the Chief Medical Officer in 1998, proposals to set up an all-Wales cancer genetics service were considered. There was concern that setting up a ‘traditional’ specialist-led service for a large geographical area based exclusively in a tertiary centre (Cardiff) would be both inequitable and become rapidly overwhelmed by demand. A novel system was therefore designed which was based on the concept of distributed clinics (Swansea in West Wales, Bodelwyddan in North Wales and Cardiff in South East Wales) coupled with protected entry to specialist expertise. The service was commissioned in July 1998 when three genetic counsellors (two with nursing backgrounds) and one consultant were funded to provide a cancer genetics service for Wales (population, 2.9 million).

The three-stage triage system (see Box 1) first requires referred patients to return a detailed pedigree questionnaire. The referral is not taken further unless the questionnaire is returned. The arrival of this information leads to a telephone call by one of the genetic counsellors who uses the family history information to calculate a genetic cancer risk assessment, so that patients can be divided into low-, moderate- and high-risk categories. Using breast cancer concerns as an example, the guidelines define an entry threshold to the cancer genetics service. Patients with less than three times the age-specific lifetime risk are designated ‘low’ risk, advised over the telephone and referred back to primary care. Patients who meet the referral criteria are assessed in more detail and the probability that they have the breast cancer gene is calculated. This allows categorization into ‘moderate’ and ‘high’ risk groups. Those at ‘moderate’ risk levels are invited, over the telephone, to attend a breast clinic and managed according to local guidelines. Those at ‘high’ risk are counselled over the telephone and offered an appointment with the cancer genetics specialist (JG), in addition to an invitation to attend a breast specialist. At the end of the first year of the service (1999), there were ~800 new referrals, and >250 ‘low risk’ patients were returned to their GP for further support.

This method of controlling access is new and it was not known how GPs would react to a referral system that was constrained by guidelines (see Fig. 1) and managed by a telephone triage process, although studies have explored the appropriate role of GPs in the new genetics. Generalists have the advantage, it is suggested, of familiarity with families, the ability to provide continuity of care and, in the NHS at least, access to lifelong clinical records. However, the novelty of new genetic developments inevitably means that generalists feel some uncertainty. Limited research exists on generalist attitudes to cancer genetics; one study in Scotland identified a desire for clear referral guidelines and the introduction of community genetics clinics. Two recent evaluations show limited adherence to referral criteria, significant overestimation of predictive testing and the possibility of clear guidance regarding interventions.

We were therefore interested in examining the reactions of GPs to the existence of a triaged all-Wales cancer genetics service. Were they aware the service existed? Did they feel that it was appropriate to refer all ‘at risk’ patients to such a service, or act as first line advisers? In short, we wanted to know their views about a service that worked on the premise that GPs would be required to manage patients categorized by the triage system as ‘low risk’. To gauge their reactions, we conducted a number of focus group discussions.

Box 1 The cancer genetics service in Wales

The service is for those individuals who are concerned that the existence of relatives with cancer may increase their genetic predisposition to cancer.

Stages

1. Postal questionnaire

Questionnaire is sent to the patient asking for a detailed family history and other baseline information. Step 2 is dependent on this questionnaire being completed and returned. Failure to return the questionnaire results in one postal reminder. An initial risk assessment is made on the basis of the family history received.

2. Telephone assessment

A trained genetic counsellor conducts a telephone consultation from one of three sites in Wales (Cardiff, Swansea and North Wales) in order to confirm the family history. The patient is informed of their risk category, i.e. ‘high’, ‘moderate’ or ‘low’ risk, and triaged to different pathways. It is estimated that approximately 30% of patients will be ‘low risk’ and will be discharged after the telephone assessment.

Differentiated management of risk categories

Low risk: clients are reassured that they are ‘population risk’ and told that extra surveillance is not required.

Moderate risk: ongoing management between primary care and appropriate specialist is recommended.

High risk: in addition to suggesting the involvement of other specialist surveillance, this group will be offered a genetic clinic appointment.

3. Triage decision

Once the consultant has reviewed the case notes, the referring clinician and patient are given information on risk grouping. Patients designated to be at ‘low risk’ are sent an information leaflet and asked to attend their GP if they have further enquiries. The GP is sent a ‘discharge’ letter.
Methods

A pair of sequential focus groups was held to explore the reactions of GPs to the triage system and associated referral guidelines. The participants were provided with reading material about cancer genetics and the service. Existing studies had revealed that GPs were not acquainted with this clinical area and we chose to ensure that the participants became better informed over time and had the opportunity to think about the issues covered. It is recognized that initial reactions are often unrepresentative, and we therefore designed a method where information provision and group interaction facilitated insights which were the outcome of a reflexive process. We selected this approach in preference to obtaining the views of individuals who are new to the subject or to seek data by predetermined categorizations inherent in surveys.

Participants and focus group meetings

Over three-quarters of the Welsh population live in urban areas. Practitioners from Swansea and neighbouring areas were chosen for this study because the city represents an urban population that is distant from a tertiary genetic specialist centre. At the time of the study, the majority of referrals had come from hospital specialists, and few GPs had used the service; it was therefore not practical to compare users with non-users.

We therefore convened two groups of GPs: one consisted of purposively selected doctors who had part-time educational roles in a university-based department of postgraduate education (age range 38–54 years). We chose this sample in order to represent the views of practitioners who had responsibilities for maintaining the professional development of their colleagues and an increased motivation to monitor the impact of clinical developments. All seven eligible individuals in the area were invited, and six attended.

The second group of practitioners was selected randomly from a list of all those who worked in the area, providing they had no academic or educational roles: 12 were invited by letter and eight attended (age range 31–55 years). In total, 14 doctors (eight men and six women) participated, and 10 of the 12 practices represented urban districts. These groups were re-convened on three consecutive occasions, between July and November 1999. Prior to their attendance at the focus groups, and at the end of the series, each participant was asked to complete a short questionnaire which assessed their views on genetics generally and specifically on the new cancer genetics service.

Each participant was given reading material in advance of every meeting which contained background articles on cancer genetics. During the focus groups, participants engaged in case study discussions, and were given risk information, assessment tools and examples.
Data collection and analysis

The interviews were tape-recorded, transcribed and analysed. RI studied the transcripts repeatedly, explored meanings and ascribed the main themes. It is generally accepted that it is the moderator (RI) who knows the material in depth, the transcripts were also read by GE, and by another independent researcher. The moderator checked the themes with each of those independently and obtained agreement by discussion. The main themes included the impact of changes in primary care, including those brought about by advances in genetics; understanding basic principles of cancer genetics and the increasing importance of assessing family histories; how to convey complex risk information; the role of the generalist and other colleagues in primary care; and the principles governing future service provision. Participant validation was achieved in three ways: first, the moderator regularly summarized the key issues during subsequent focus groups and, secondly, a report was sent to the participants after each focus group describing the process and listing relevant transcript excerpts under emergent themes. Thirdly, by postal consultation, agreement was achieved that this account represented an accurate analysis of the discussions. This paper reports data on the themes that are relevant to our stated aims: that of assessing the clinicians’ reactions to the new service and associated referral guidelines, and the perceived impact genetics will have on general practice.

Results

It was clear that the GPs in this study modified their views as they learnt more about the new genetics, the proposed triage system and the implications for their future practice. The results are therefore reported in this sequence. The pre-group questionnaire revealed that participants were already aware of a range of ‘increasingly important’ issues and mentioned their concerns about ‘screening’, ‘inherited disorders’, ‘inadequate knowledge’, ‘patient anxiety’ and ‘where do I refer?’ Post-group responses were noticeably different, with participants citing ‘the importance of communication to patients’, ‘risk assessment’, ‘family history’, ‘philosophically challenging’, ‘knowing who and how to refer’ and the ‘future is exciting but uncertain’.

Acceptability of the triage system and referral guidelines

Although there was some unease about yet another set of referral guidelines, participants realized and accepted that the potential demand had to be regulated. The views of the 14 participants were summed up by the statement, “the service should be applauded for being so forward thinking. I wish other services would do the same thing so that we don’t have these horrendous waiting lists . . . its all about educating us about what’s an appropriate and inappropriate [use of the service].”

One comment, echoed by the majority, revealed the degree of comfort with the referral guidelines, “On two or three occasions now, I have shared this [guideline] with the patient. I’ve found it easier to get the point across [that referral is not always necessary].” A few participants took the idea of printed referral guidelines a stage further and suggested the implementation of a feedback system that reported both the number of patients referred to the service and their ‘appropriateness’, advocating, in effect, a quality monitoring system. It was also emphasized that the referral guidelines should be included with discharge letters from the cancer genetics service so that GPs were reminded regularly of the referral criteria. As the participants became more aware of their potential roles in this area, hopes emerged that one day information about local services would be available electronically.

Unease was voiced when it was realized that a referral did not automatically lead to a specialist opinion. A referral is usually regarded (by both the GP and patient) as a process that leads to a consultation with a ‘specialist’ invested with the institutional trappings. As one doctor said, “that’s fine, but obviously someone has to tell these women that they may not get to see somebody in a white coat”. The need for patients to complete detailed questionnaires before they obtained a telephone assessment

FIGURE 2  Discussion topics

1st focus group
- Impact of the ‘new’ genetics on general practice
- The new all-Wales Cancer Genetics Service

2nd focus group
- The referral guidelines
- Who should manage patients at ‘low risk’?

3rd focus group
- How acceptable is the triage system?
- How should the service provide information to primary care?
was questioned. Many clinicians felt that patients with low literacy levels or who might be resistant to completing ‘official’ documents were going to be clearly disadvantaged. Doctors working in areas of high socioeconomic deprivation worried that some patients would have difficulty discussing their ‘family history’ over the telephone.

Managing the ‘new’ genetics in primary care

Although we had supposed that educationalists might have a greater awareness of new developments in medicine, we found that there were no significant differences of views between the two groups. Some participants reported an increase in demand for genetic tests for cancer, especially in the past year, “particularly about the risks of breast cancer and ovarian cancer”. They confirmed a clear gender distinction bias and mentioned the influence that “magazine articles or seeing TV programmes” had in triggering presentations about the breast and ovary. The participants were alarmed to hear that genetic tests could be purchased, and were concerned that patients would soon expect ‘counselling’ after private tests. They were unaware that cancer genetic services had been commissioned in Wales since mid-1998, or that a genetic counsellor had been appointed at a clinic in Swansea a few weeks before the focus group meetings. One participant recalled a recent patient who was “absolutely terrified because her sister and her mother had died of breast cancer at an early age”. His advice had been that there were “no services available”.

Participants expressed concern about another potential service being required of primary care, without any planned professional development or additional resources. “Even if the counselling is done in what is now secondary care, patients will still come back to us with their letter and ask to have it interpreted . . . it will always end up back with us . . . the main pressures for us to take on counselling is going to come from the patients because if a patient is sitting in front of you and wants an answer, you feel obliged to do your best to supply what they need.” They drew parallels with HIV testing, which was conducted initially in specialist clinics but “it has moved gradually into primary care. I think the same thing is probably going to happen for genetic diseases.” The main concern was the feeling that they wanted to “do genetics properly”, to assess genetic risk well and conduct family counselling sensitively. This wish was tempered consistently by a sense that this was unrealistic in the prevailing system and time frames, and they rejected the notion that it could be done by using interactive computer programs because of the constraints imposed by current workloads.

Although delegation to practice nurses or nurse practitioners was considered, it was in terms of examining the range of skills needed to undertake genetic risk assessment and counselling rather than in relation to any broader debate about the future of nursing in primary care. This, however, was one area where views were markedly different, as this sequence illustrates:

“This is a very complex area . . . you have to understand statistics you have to understand Mendelian inheritance . . . you have to understand DNA, all this sort of stuff. On top of that you need to be able to communicate and I think, perhaps I am defending my own profession here . . . I think doctors need to do this . . .” (Group A, participant 2)

“I don’t think we need doctors necessarily. I think the nurses can do it. There’s some super nurses about . . . but I agree with you they should have some [scientific] background . . .” (Group A, participant 6)

Occasionally there was a marked ambivalence about delegating the task to others: “if you’ve got nurses doing the testing and the initial counselling . . . and are willing to see those patients all the time, then fine, but I can’t see that happening. In the end it’s going to be the GPs who pick the pieces . . .” Balanced against the opinion that existing workload made it impossible to provide genetic counselling in primary care was the view—which strengthened as the groups reconvened—that the essence of general practice was to quell false expectations by managing patients at ‘low risk’ and avoid generating either unnecessary anxiety or false hope: “They are really searching for certainty aren’t they and we can’t give them that . . .” Another stated: “One of the problems is that patients ‘say’ they would like to know what the risks of things and go and get tests . . . but what they really want is a negative test. They want to be reassured . . . once they are told that they ‘do’ have a risk then they have great difficulty . . .”

Discussion

The GPs interviewed had not considered how to handle the implications of the ‘new’ genetics. They had few objections to a counsellor-led triage system as a means of regulating access to a scarce specialist service, but questioned the use of a questionnaire and telephone consultation as means of controlling access. This acceptance was part of a reluctant acknowledgement that ‘primary care’ was, in its present organizational form, unable to provide high quality genetic counselling.

These findings echo Kumar’s and Gantley’s work. Emery and others are developing innovative software that may enable genetic risk assessment to be undertaken in primary care, yet there seems to be a reluctance to contemplate any extension of role and workload, and GPs have been reported as having neither the knowledge nor the skills to manage these problems. At one level, these doctors were also resistant to accepting a role
in the provision of genetic advice but, after considering the issues in depth over 5 months, ambivalence emerged and they appreciated that the referral guidelines would help them refer patients appropriately, and avoid generating undue anxiety or false expectations. In effect, the GPs, whilst accepting controlled access to a specialized counselling service, wanted to retain their role as ‘gatekeepers’, provided they receive accurate, useful information (e-mail advisory services and interactive web pages were suggested). Their prime concern was to support patients confused and anxious by another facet of predictive technology and there was a gradual acceptance that genetic risk assessment could occur in community settings.

The strengths of this study are the deliberative use of sequential focus groups that revealed the reflexive view of the participants. The study was part of the evaluation and implementation of a novel service and assisted the all-Wales cancer genetics service to design and provide information to colleagues in primary care. The referral guidelines have been refined and have been issued to every GP in Wales. This study was not designed to assess the views of practitioners in remote rural areas: their views may well differ. A further study is evaluating the experience of consumers and practitioners after using the service. We cannot claim that these reactions are fully representative, but nevertheless they add to our understanding of the way generalist practice could work with the inevitable new developments in genetics.

This study reveals that telephone triage-controlled systems seem to be acceptable in niche specialities (e.g. cancer genetic testing), but only to a certain point. Telephones themselves do not constitute barriers to access (language disabilities excluded) and could well herald ways of managing other areas, such as follow-up appointments. It is important, however, not to impose other obstacles which could skew participation, such as a requirement to respond to postal questionnaires, or complex telephone questioning involving difficult terminology.

The novelty of cancer genetics services begs complex ethical questions about the imposition of risk awareness. Where is the wisdom of alerting individuals to high and moderate ‘risk status’ when the evidence for effective interventions is either unknown or equivocal in many situations? Is offering advice about genetic risk akin to offering ‘choice’ or is it more to do with (covertly) prescribing action? It is clear that the NHS has to provide patients with advice about these issues, and a ‘managed’ referral system seems a reasonable and acceptable solution, provided it does not de-skill primary care. Nevertheless, the underlying assumption is that the benefits of predicative services outweigh the potential harms—a starting position that may be correct but one that should not be accepted without considering the complexities that underpin these policy decisions.

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