A pilot study of telegenetics

Sir, In Wales we face the challenge of delivering highly specialized health-care services from the capital city, Cardiff, to remote clinical sites. Cancer genetics services, for example, are delivered from the Institute of Medical Genetics in Cardiff. However, the ‘hub site’ is off-centre and geographically distant from the population of North Wales (Fig 1). Furthermore, much of the population of Wales is rural and scattered, with poor travel links.

The demand for specialized cancer genetics services has increased dramatically in recent years, mainly because of heightened media and public awareness. Many genetics centres across the UK are experiencing increases in clinical commitment of up to 50% due to cancer genetics referrals alone (personal observation, HH). As a proportion of all referrals, cancer referrals to the North Wales region of our genetics service have risen from 3.9% in 1994 to 18% in 1997, representing about 1500 new families per year. Preliminary figures for 1999 suggest that it will have risen to over 35%. Over 1000 women with a family history of breast cancer have also been referred from all over Wales to a randomized trial in Cardiff.

Currently, it is impractical to increase the already extensive travelling time to North Wales undertaken by Cardiff-based consultants, but a balance needs to be sought between increasing local staff, maintaining centralization of resources and achieving a centre of expertise. We have therefore explored new approaches to service delivery that will allow us to expand our capacity to give information at sites distant to the main specialist centre, while maintaining the quality of service and information provided. Thus, we have evaluated tele-consultation in genetics—telegenetics. A pilot study was conducted in 1998 which explored the acceptability to patients and health-care professionals of telegenetics as a means of delivering medical genetics information from Cardiff to North Wales.

All genetics patients receive a standard work-up, which includes preliminary contact with a genetics nurse specialist. During the preliminary contact, eight patients gave informed consent to participate in the pilot project. Six had been referred owing to a family history of cancer and two for other genetic conditions. A baseline questionnaire assessing anxiety, illness-related worries and knowledge of genetics was completed by patients before the telegenetics consultation and immediately afterwards. Both patients and health-care professionals also completed a questionnaire about their satisfaction with the telegenetics consultation. The health-care professionals included four female genetics nurse specialists and two genetics consultants. An existing telemedicine link using ISDN at 384 kbit/s was made available for this study by the National Health Service offices in Mold, North Wales, and the Welsh Health Common Services Authority offices in Cardiff, a distance of approximately 300 km.

Although the small sample size precluded formal statistical analysis, trends in the questionnaire data were examined using descriptive statistics.

All the patients participating in the study reported high levels of general satisfaction with the telegenetics consultation. Fig 2 shows the trends to reduced anxiety and worry, and improved knowledge, as measured by standardized questionnaires used by our group for previous work on women at risk of familial cancer. General satisfaction reported by patients was higher than that reported by health professionals, in particular the genetics nurse specialists. Neither patients nor genetics consultants reported feeling nervous during the consultation, although some nervousness was reported by nurses. All patients reported that the telegenetics mode of

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communication had not made it difficult for them to understand the information conveyed by the consultant and all felt able to ask questions during the consultation. Patients and consultants tended to report that the telegenetics consultation was no different or preferrable to the usual face-to-face medical consultation, but the genetics nurses felt that it was very different and much worse.

Comments from patients indicated that they had a high level of satisfaction with both the affective and instrumental aspects of the telegenetics encounter (see Table 1). Initial feelings of unease were soon dispelled and the doctor’s attitude was important in determining patients’ attitudes to the encounter. Indeed, it would seem that the degree of rapport established with the doctor during the consultation is more important than the mode of communication. As one patient said, the telegenetics approach makes ‘little difference from speaking across the desk’.

Although genetics nurses acknowledged that patients found the consultation satisfactory, comments made by them appeared to show that they had the lowest satisfaction levels of all parties in the project. Their dissatisfaction was largely related to the changed dynamics of the consultation. The nurses felt less at ease during the sessions and also felt that they were superfluous during what seemed to them to be an exclusive one-to-one discussion between the consultant and patient. In addition, they felt less able to observe patients’ non-verbal behaviour.

The comments from the genetics consultants suggested that the degree of rapport established with the patient was an important influence on their level of satisfaction with telegenetics. One consultant, however, reported that the unanticipated presence of relatives made it difficult to conduct the session effectively. The consultants’ comments reflected those made by patients in suggesting that satisfaction with the consultation was largely dependent on the extent to which the patient was relaxed. Previous studies of doctor–patient communication have shown that the rapport between the two is important, but it may be of special relevance to telemicine, which may compound any difficulties in establishing rapport.

Clearly there are limits to the generalizations that can be made from such a small sample, but the results of this pilot study suggest that telegenetics may be an acceptable method of communicating genetic information to patients. We recognize that response bias and acquiescence are potential problems in measuring satisfaction, and suggest that this be limited in future research by measuring pre-consultation expectations as well as post-consultation satisfaction. Large-scale evaluation studies need to be conducted and these should incorporate both quantitative and qualitative methods. While controlled trials would allow evaluation of the impact of telegenetics on a variety of patient outcomes, qualitative research would enable exploration of the process and dynamics of the telegenetics encounter, which may influence these outcomes. Processes that should be evaluated include style and content of communication, as well as non-verbal interactions between health-care professionals and patients. Little is currently known about the process of face-to-face genetics counselling and the addition of a televisual component adds a new dimension of complexity to research.

This is the first attempt we are aware of in the UK to explore the potential offered by videoconferencing to deliver a genetics service to patients at a distance. In the UK there are the often opposing drives to develop centres of expertise, such as the newly defined regional cancer centres, and the need to keep care local. In Wales we were ideally placed to explore telegenetics as a potential means of surmounting these difficulties, for two reasons. First, the referral rate—especially in relation to breast and

### Table 1 Examples of comments from patients, genetics nurses and genetics consultants

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<th>Group</th>
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| Patients             | I found the experience very reassuring and would certainly recommend this method.  
                      | [I was] made to feel very welcome…[the consultation was] informative, clarified certain issues I was unsure of…left me with a definite way forward.  
                      | Initially you were aware of the TV but afterwards forgot about it.  
                      | Apart from the initial few minutes of getting used to talking through the medium of a screen, I felt completely relaxed and at ease.  
                      | I would not mind if I had a discussion with a doctor face to face or on television—it was the rapport that I had with the doctor that mattered.  
                      | As TV is a medium which I am used to it is quite usual to receive information from the television.  
                      | I do prefer this method of consultation as I do not like going to hospitals and sitting in overcrowded waiting rooms with many sick people for an indeterminate length of time.  |
| Genetics nurses      | I felt that I had very little to contribute… and the patient was ‘transfixed’ to the screen and therefore there did not seem to be any input from myself… I felt redundant!  
                      | [The patients] were already very much at ease—they did not seem to need me!  
                      | I felt I had little to contribute during the consultation.  
                      | It is very difficult to pick up non-verbal cues when sitting directly beside someone. It was difficult to position myself so that I could focus on the patient and the telly screen at the same time.  |
| Genetics consultants | [I had] difficulty relating to the family as a whole… and could not establish rapport with [the] father and son. A family that would have been challenging in a normal clinic situation [was] made worse by telemicine.  
                      | This second family was…easier than the first as I sensed they were more comfortable.  
                      | [I initially felt a little uncertain how to explain things. [It was] difficult to introduce oneself, difficult to close the consultation.  
                      | [The patient was] easy to talk to… very chatty, clear agenda.  
                      | [It] helped that the patient was experienced in filming.  |

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ovarian cancer—is steadily increasing. Second, we already have the infrastructure to allow telegenetics to be a natural extension of our service, with no change in skill mix or information content. As part of our all-Wales service, we have genetics counsellors who can be present during clinical genetics consultations. In addition, the Institute of Medical Genetics provides one of the few remaining all-Wales clinical services from a base site in Cardiff through satellite clinics in district general hospitals. We believe that telegenetics is an innovative and potentially cost-effective means of increasing contact with distant sites that require genetics services.

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References