Neurological networks

With only a limited number of paediatric neurologists serving the population, the question arises as to how to ensure that every deserving family has access to the rare expertize and investigational resources they offer. Paediatric neurologists tend to be concentrated in regional centres with the result that a 'distance-decay' effect may occur whereby the greater the distance from a regional centre the worse the care is likely to be.

Access to specialist care in the UK is usually through an informal clinical network. This depends on relationships between health care professionals which determine referral patterns and patient flows. In some areas this would mean no more than a series of referrals with phone contact and occasional meetings between the doctors involved at professional or social gatherings. In other areas the network is better defined by a series of outreach clinics at which tertiary centrebased neurologists can sit in consultation with general paediatricians from a large geographical area. These consultations allow paediatricians to share the clinical problems troubling them most. The advantage of this arrangement is that joint consultations allow general paediatricians to learn from the visiting neurologists (and vice versa). The knowledge acquired can then be applied locally, allowing a child's care to be focused as near to the family's home as possible as well as helping other children in the area with similar conditions. The disadvantage of this system, however, is that lack of resources often means that some health care districts have no joint clinics. This may result in families being adversely affected by the eccentric ideas of the young tyro or the older paediatrician with set ways or eccentric ideas, poorly supported by diagnostic resources and free of peer review.

The notion of formalizing the structure and role of clinical networks as a basis for improving health care delivery is currently being addressed and developed in the UK. 1,2 Clinical networks are not another distracting structural change in our health care delivery system but, rather, they represent the fine-tuning of what is already in existence, informally and successfully, in many places. It is an idea that can be embraced enthusiastically in many settings worldwide.

The basis for the network should be a common disorder. For example, a clinical pathway can be defined for a child with epilepsy from the moment of presentation to primary care services through to selection for a curative surgical programme (in the minority of patients who do not respond to medication). At each stage in the pathway, guidelines can be defined along with appropriate intervention. This in turn allows health care professionals to make best use of scarce resources, standardize care, and improve access to specialist care. Once the communication channels are defined and opened – not only between the district centre and the regional centre but also on a locality basis, involving educational, social, and medical services - they can be used to good effect for the benefit of children with rare disorders. The possibilities of this

type of network in relation to rehabilitation following acquired head injury can be seen in the paper by Pam Tomlin and colleagues.3

Clinical networks will require management, which in turn will facilitate a multiregional, if not national, audit and enhance the potential for research collaboration between centres. An audit will allow the development of a guideline template with a sound evidence-base. The best approach will then become the national approach, with less chance of rogue performance. It is important, however, that any template is flexible enough to accommodate local geographical or organizational circumstances.

The time for this idea to be implemented has probably come. As it unfolds it can be strengthened by two developments. The first is ready internet access.⁴ Dedicated websites can provide easy reference for all those within the network who will be able to check information on pathways and the criteria for investigations and management at each stage. The UK Wanless report⁵ recommended the doubling and 'ring fencing' of communication technology spending (2.2 million pounds by 2003/2004) with a focus on infrastructure, patient records, admissions, patient Smart cards, 'tele-medicine', and training. This investment will allow unprecedented access by health care professionals and families to information and guidance. The second development is extending the role of nurses⁶ which will allow information that is given to families to be clarified and consolidated, feedback on the wanted and unwanted effects of drugs to be facilitated, and will enable liaison with other services, particularly social and educational services, to be improved.

Once the benefits of a clinical network with its clinical pathway for a common condition such as epilepsy are felt it is likely that the benefits will be reaped in other areas of practice. Communication pathways and a better standard of liaison will be consolidated. 'Distance-decay' and eccentric practice will become things of the past. It will be interesting to see the extent to which any given template, having established its national worth, can become an international tool.

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