

Clinical networks in epilepsy in children

Geoff Lawson

Abstract

Clinical networks are important in paediatrics. They are particularly important where single paediatricians provide sub specialty services in district general hospitals (DGHs). Training courses, regional special interest groups and audit through Epilepsy 12 all contribute to the development of strong clinical relationships between paediatric neurologists, general paediatricians and epilepsy specialist nurses which in turn enhances the care offered to children and their families. This article discusses how clinical networks have developed to assist the delivery of care for children with epilepsy.

Keywords clinical networks; epilepsy in children; standards of care; training

Introduction

Medicine continues to make rapid progress. This has been paralleled by distinct changes in the way in which we practise, evident even during my own medical career which began when I qualified in 1977. Thirty years ago self-styled practice was the norm and was seen as a strength. Professional education was mainly accomplished through individual endeavour by attending the occasional educational meeting, providing a lecture for one's colleagues, and reading a journal from time to time. However we now live in an age of clinical governance, appraisal, revalidation, multidisciplinary teams, and the internet. There has been an introduction of pathways of care and a focus on providing a service of excellence for patients which encourages their active participation and is responsive to their views. All of these factors have encouraged the development of clinical networks.

In 2000 the NHS Scotland plan, Our National Health, defined managed clinical networks as: *'linked groups of health professionals and organisations from primary, secondary and tertiary care working in a co-ordinated manner, unconstrained by existing professional and existing [organisational] boundaries to ensure equitable provision of high quality effective services.'* This discussion paper also suggested that *'Networks are a potentially powerful way of improving services, standardising care and unlocking clinical creativity'*. I would hope to argue that this model of service for children with epilepsy has emerged in the UK and is entirely appropriate. I would also hope to successfully argue that sound training and the development of networks are inextricably linked.

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How many children does this affect?

Before discussing the merits of clinical networks I will first describe the typical workload within a typical DGH in the UK. To appreciate the dimensions of the prevalence of epilepsy, in a population of 300,000 one could expect approximately 3,000 births per year and 65,000 children below the age of 18. Epidemiological studies would suggest that between 50 and 150 new cases of epilepsy should be seen for every 100,000 children giving epilepsy a prevalence of between 300 and 600 patients per 100,000 children. Few children, if any, are seen in general practice without the involvement of a paediatrician and yet the vital initial referral of children with epilepsy and the continuing prescription of most anticonvulsants remains in primary care. About 150 General Practitioners who could each expect to see one new case of epilepsy in children and take care of another three or four known cases each year serve this hypothetical population. At the other end of the spectrum of care in a tertiary care setting more challenging problems with epilepsy are considered by a limited number of paediatric neurologists (100 across the UK at present). Sitting between primary and tertiary care there are 3000 general paediatricians most of whom work in groups of 8–10 in District General Hospitals, with two or three perhaps taking a special interest in epilepsy.

Already one can see that the network of care required is extensive and requires thorough communication and understanding if a safe and consistent service is to be provided for children with epilepsy and their parents.

The diagnostic challenge provided by epilepsy

Though the diagnosis of seizures and epilepsy can be straightforward, it can also be one of the greatest clinical challenges. An adequate diagnosis requires differentiation between seizures and other causes of transient neurological disturbance and collapse, differentiation between acute symptomatic and unprovoked truly epileptic seizures, and, in children with epilepsy, classification of the disorder and identification of the cause so as to optimise treatment and offer prognosis. The phenotypic presentations of epileptic seizures are varied and there are many imitators, ranging from convulsive syncope through to psychogenic events, so a wide spectrum of conditions needs to be appreciated to allow an accurate diagnosis to be made.

After the initial history and examination have been undertaken appropriate investigation needs to be considered. Unfortunately fainting is probably the single commonest reason for requesting an electroencephalogram (EEG), which in 20% of the normal population will reveal non-specific abnormalities open to misinterpretation. Given that most requests for EEG's emanate from non-specialist settings and are often reported by neurophysiologists without great experience of epilepsy in children and its management, there is considerable potential for misdiagnosing faints as seizures.

Cardiac syncope can cause immediate loss of consciousness, tonic stiffening of body and limbs, and often myoclonic jerking. Testing with a tilt table and electrocardiographic monitoring may be needed to identify a specific cause and avoid the erroneous diagnosis of epilepsy. Fever in children and alcohol in adults are the commonest causes of acute symptomatic seizures. Recognition of non-epileptic seizures prevents unnecessary antiepileptic

drug treatment and avoidance of the provocative factor or treatment of the underlying cause. It can also facilitate the safe return of the individual to normality, which for children is often physical activity and school attendance.

Another frequent reason for referral for an EEG is when children are observed to have vacant spells. The most basic differential diagnosis lies between daydreaming or pre-occupation and absence epilepsy. A useful clinical distinguishing feature is distractibility as those with absence epilepsy cannot have a vacant spell terminated by external stimuli. However as vacant spells can be very brief lasting between 5 and 20 seconds assessment of distractibility can be difficult. EEGs are often extremely useful in such situations as they are rarely normal in children with true absence epilepsy.

The management of children with neurodisability deserve special mention. Epilepsy can often be part of the complex clinical challenge presented by such children, which has led to many secondary care neuro-developmental paediatricians developing an expertise in neurology in general and more specifically in epilepsy. Epileptic events must be separated from other paroxysmal attacks whenever possible and when appropriate the impact of the epilepsy and its treatment carefully considered. This is most successfully achieved by a multidisciplinary team approach which should network with paediatric neurologists when needed. Taken from another perspective paediatric neurologists are such a relatively scarce resource that they could not provide a comprehensive neurodisability service without the support of secondary care paediatricians, this emphasising the mutual benefit and support which a clinical network provides.

Significant numbers of children can be easily wrongly ascribed as having epilepsy when they do not, and the converse when they do have epilepsy and the correct diagnosis overlooked. This is less likely to occur when assessment is made by those with greater experience of the epilepsies of childhood. The acquisition of the skills and knowledge to provide a clinical service to children with epilepsy is clearly greater than that which can be offered by an education in general paediatrics. It was therefore important that education and sharing of expertise in this area was made more widely available. The circumstances by which this occurred was a not uncommon feature of the NHS whereby progress was made after a crisis point had been reached.

Background events during which networks have developed

Fifteen years ago the Clinical Standards Advisory Group (CSAG) was composed of a wide spectrum of assessors including GPs, Hospital Doctors, Social Workers and a significant patient representation; it reported on epilepsy in 2000. It identified (amongst other issues) the need for epilepsy services to children, which they suggested should be delivered by clinicians with specific expertise in epilepsy. However despite this sound advice little effective action was evident following this report. Two years later in 2002 the Leicester inquiry revealed the vulnerability of an isolated Consultant Paediatrician who was misdiagnosing epilepsy and overtreating many of his patients. In 2003 the Sentinel Study revealed information on sudden unexpected death in epilepsy (SUDEP) and called for more expertise in the delivery of information to patients and carers in epilepsy.

I would suggest that the antithesis of a clinical network was demonstrated in Leicester where the dangers and pitfalls in the diagnosis and management of epilepsy were exposed. It was found that a paediatrician taking care of children with epilepsy had become geographically and professionally isolated, and in the analysis of this consultant's clinical practice it was shown that just over a third of the children diagnosed as having epilepsy did not have epilepsy, and just under a third were thought to have been over treated. This episode graphically illustrated the potential consequences of the shortcomings identified in 2000 by the Clinical Standards Advisory Group in its report on epilepsy services in the United Kingdom.

As a response to the Leicester inquiry the Chief Medical Officer (CMO) asked the British Paediatric Neurology Association (BPNA) for their advice as to how these problems should be overcome. The response from the BPNA was to suggest that paediatric epilepsy training (PET) should be established on a formal basis. The CMO agreed with this suggestion and asked the BPNA to work towards this objective. To achieve this the BPNA charged a sub-group of the Association known as the Epilepsy Interest Group (EIG) to develop a plan for training/CPD in epilepsy. A core group of paediatric neurologists within the EIG was established and developed links with paediatric epilepsy specialist nurses and general paediatricians with an interest in epilepsy. A plan was developed for PET courses with the following underlying principles:

- the courses were to meet the needs of all clinicians (medical and nursing) to provide high quality training in epilepsy, appropriate for their needs
- materials to be developed such that courses could be run up and down the country without local organisers needing to develop their own materials, thus ensuring consistency
- the quality of the courses to be underwritten by adhering to established educational principles by providing specific training (Train the Trainers) to those responsible for delivering local courses

It was therefore in 2003 that a process of designing, creating and delivering a 3-tiered paediatric epilepsy training package was begun. Level 1 training was principally aimed at paediatricians in training, Consultant Paediatricians with an interest in epilepsy, Paediatric Specialist Nurses, and A&E Doctors. Levels 2 and 3 were created principally for Consultant Paediatricians with a developed or developing expertise in paediatric epilepsy. Finally further events were designed to meet the needs of Paediatric Neurologists who require a tertiary, specialist knowledge in the paediatric epilepsies. Each of these courses was created to improve the knowledge base of epilepsy and expand the understanding of the service needs of those who diagnose and manage children with epilepsy.

From the outset the objective was to produce enjoyable, interactive training courses. To do this and yet reach the significant number of clinicians seeing children with epilepsy meant that courses needed to be developed which Paediatricians and Paediatric Neurologists could deliver although they had not necessarily written the original course material. Although written by relatively few individuals many contributed to the editing of the drafts of this material and even more contributed to the collection of precious and rare videos of children and young people having seizures, their EEGs and MRIs. A picture writes a

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