

REVIEW

NICE guidelines and the epilepsies: how should practice change?

C Dunkley, J H Cross

Arch Dis Child 2006;**91**:525–528. doi: 10.1136/adc.2005.080036

The care and provision for children and adults with epilepsy and their carers has recently been under scrutiny with a series of reports highlighting concerns and calling for change. The National Institute for Clinical Excellence (NICE) published recommendations for management of adults and children in October 2004. Although recommendations were often specific and practical they did not include precise details regarding their implementation. Key recommendations and their implications are discussed in this review.

order to ensure that recommendations were complementary while maintaining independence.

Although NICE recommendations were often specific and practical, they did not include precise details regarding their implementation. For example, the key involvement of specified health professionals who may not currently exist in local provision is described; waiting times for assessment and investigation are ambitious; and managed clinical networks, while implied, are not clearly defined. Since their publication there has been some published commentary. Ferrie and Livingston discussed the reliance on “expert opinion” as the basis for many of the recommendations and the need for a better evidence base for epilepsy management.¹⁰ There also remains concern about definitions and the implications should difficulties be encountered in guideline implementation. The NICE recommendations, however, imply changes not only in an individual’s practice but also a change to the model in which that practice is delivered.

Epilepsy is the commonest serious chronic neurological condition in childhood, with a prevalence of approximately 1 in 200 children. It is not a single condition; the term encompasses a group of disorders characterised by recurrent epileptic seizures. Diagnosis is based on clinical criteria; there is no single diagnostic test. Accurate diagnosis and subsequent classification of the epilepsy in an individual child is therefore often complex, and misdiagnosis common.¹ There is an increasing number of anti-epileptic drugs (AEDs) and other treatment options available and therefore decision making on ways forward can be problematic. In addition, appreciating the possible psychosocial and cognitive effects of epilepsy are fundamental to providing optimum care for the child and family. It is important to provide the patient and family information tailored to their specific situation.

THE CASE FOR CHANGE AND RECOMMENDATIONS

A series of reports on care for individuals with epilepsy have recently highlighted concerns and called for change.^{2–5} These resulted in the Chief Medical Officer Action Plan in February 2003⁶ followed by a response from the Royal College of Paediatrics and Child Health (RCPCH).⁷ Subsequently the National Institute for Clinical Excellence (NICE) published recommendations for adults and children in October 2004,⁸ shortly followed by the Scottish Intercollegiate Guidelines Network (SIGN) for children in April 2005.⁹ NICE and SIGN, although having some differences in remit and methodology, both reviewed the current evidence base for the diagnosis and management of childhood epilepsy in primary and secondary care and agreed practical recommendations. Joint Guideline Development Group Meetings were held to facilitate resource sharing and discussion in

WHO SHOULD MANAGE CHILDREN WITH EPILEPSY?

The “paediatrician with expertise”

The guidelines state that all children with a recent onset suspected seizure (or where there is diagnostic doubt) should see “a specialist” (NICE 1.4.1, 1.4.4C).⁸ The specialist is responsible for the diagnosis of epilepsy, the start of antiepileptic drug (AED) treatment, and regular review of management and withdrawal of treatment. The definition of the specialist is stated as “a paediatrician with training and expertise in the epilepsies”. This does beg the question “how ‘special’ the specialist?”. “Paediatricians with expertise”, “paediatricians with a special interest”, “link paediatricians”, and “paediatricians with responsibility” are other aliases emerging in discussions on this subject. A Consensus Conference held at the Royal College of Physicians in Edinburgh in 2002 agreed a definition of expertise, concluding that such should be able to demonstrate “training and continuing education in epilepsy, peer review of practice and regular audit of diagnosis” and that “epilepsy must be a significant part of clinical workload”.⁵ A similar definition was offered within the RCPCH submission to the Chief Medical Officer, also including liaison with neurologists via epilepsy clinics, participation in regional epilepsy interest groups, and maintaining links with education and social services.⁷

The role of this individual in the diagnosis and management of epilepsy is key to published

See end of article for authors’ affiliations

Correspondence to:
Dr J H Cross, Reader and
Honorary Consultant in
Paediatric Neurology,
Institute of Child Health,
The Wolfson Centre,
Mecklenburgh Square,
London WC1N 2AP, UK;
hcross@ich.ucl.ac.uk

Accepted 13 March 2006

proposals and adequate management of a complex disorder. Practising with expertise, professionally supporting an epilepsy specialist nurse (ESN), establishing useful links with neurophysiology and neurologists, auditing services, attending interest groups, and maintaining appropriate continuing professional development (CPD) are more difficult in services where care is widely shared; each paediatrician is seeing a small fraction of the epilepsy population with no lead for epilepsy. A lead paediatrician for epilepsy should be identified in each district, as is accepted for other chronic conditions such as asthma and diabetes. Paediatricians not wishing to diagnose or manage the epilepsies outside the acute setting should be supported and able to make this decision.

Epilepsy specialist nurses

Epilepsy specialist nurses (ESNs) should be an integral part of the network of care of individuals with epilepsy. The key roles of the ESNs are to support both epilepsy specialists and generalists, to ensure access to community and multi-agency services and to provide information, training and support to the individual, families, carers and, in the case of children, others involved in the child's education, welfare and well-being. (NICE 1.8.3)⁸

Every child with epilepsy should have easy access to a children's ESN. Their role could range from school liaison and family support to individual review clinics with the ability to prescribe.¹¹ Currently there are approximately 35 children's ESNs in the UK. Assuming 75 000 children in UK have epilepsy⁷ and a caseload of 250 children/nurse,¹¹ the projected UK need for children's ESNs would be 300. Epilepsy Action's Sapphire Nurse scheme is a potential source of funding for the first 12 months of a new post, providing there is a formal commitment to continued funding and there will be a nurse-led clinic service. Primary care trusts (PCT) need to take up this initiative, although it is imperative that individual nurses are linked into appropriate medical support.

Paediatric neurologists

There are currently insufficient paediatric neurologists within the UK.⁷ It is unclear to what extent they see appropriate children with epilepsy or conversely are seeing children who may be more appropriately managed at secondary care level. It seems likely that in the absence of appropriate secondary level expertise, centralised tertiary services could become increasingly burdened. NICE recommendations however should result in a rationalisation of tertiary involvement rather than necessarily an increase. Audits of tertiary care may need to explore this as a prompt to changing local referral practices or regional workforce planning. Satellite outreach clinics conducted by paediatric neurologists in the district setting, allowing clinical assessment and case discussion, are one practical way to facilitate regular communication between tertiary and secondary care, as proposed by the RCPCH submission.⁷

NEW WAYS OF WORKING

Managed clinical networks

The Children's and Long Term Illness National Service Frameworks both make reference to managed clinical networks as a potential model for service provision. Several regions (for example, Scotland, North Central London, and North-West England) have established such networks for epilepsy. It is difficult to imagine how NICE recommendations will be achieved without the support that such a network can provide. Management at regional level can

support organisation of meetings, communication between professionals, and websites with downloadable resources, coordinate audit and research, and develop guidelines, care pathways, and educational courses.

Scoping surveys are a simple method of identifying support and needs across a region as an aid to regional network development. Epilepsy Action is launching a spreadsheet based "PCT toolkit" which estimates each UK PCT's epilepsy population and likely impact on health services based on published epidemiological studies and population data.¹² A typical route might involve a scoping survey and mapping exercise, establishing a working group, holding a stakeholder's meeting, seeking funding, and then launching a network.

One such survey has been carried out in the Trent region using a questionnaire initially developed in the North Central London Epilepsy Network (NCLN). This was applied with the aims of determining the perspective of general paediatricians and to measure current provision against NICE recommendations. In December 2004, paper questionnaires were sent to all 70 general paediatricians in the Trent region, comprising five district general hospitals, two Nottingham city hospitals, community paediatric services, and tertiary services with two paediatric neurologists. Forty eight questionnaires were returned and analysed. Results are summarised in table 1.

The current care of children with epilepsy is distributed among general paediatricians with most managing <5 children/month (44%, 21/48) in generic outpatient services. Nineteen per cent (9/48) did not manage children's epilepsy as an outpatient. Twenty nine per cent (14/48) of paediatricians defined themselves with either an "interest" or "expertise" in epilepsy and 21% (10/48) a wish to develop one. These results demonstrate that there are a proportion of paediatricians (31%, 15/48) managing children with epilepsy who, by their own criteria, have no interest or expertise in epilepsy and do not wish to get one. There was evidence of widespread support for the development of a regional epilepsy network (88%, 42/48).

The extent to which current services and practices meet NICE recommendations varies across the UK but has not been comprehensively assessed. Although several epilepsy networks have already developed in the UK there is little published audit measuring actual quality of provision for children.^{4 13-16}

Regional multidisciplinary epilepsy interest groups

These are an ideal method of engaging in clinical support, education, and service development. Often they will form the starting point for a managed clinical network. Epilepsy interest groups could be started where none exist; existing interest groups could consider look at extending their remit to include service development and clinical governance. Such groups allow clinical discussion and review of practice.

Designated clinics

Clinics run by designated paediatricians and epilepsy nurses, seeing new patients urgently after a first episode and following up those with diagnosed or suspected epilepsy, may offer a better way of organising outpatient services.¹⁷ There is no good evidence base yet for their role in epilepsy management,¹⁸ although there is evidence to support the role of designated clinics in other long term conditions in paediatrics.¹⁹ Young person's epilepsy clinics and transition clinics for selected children can facilitate tailored outpatient services with input from adult epilepsy professionals where appropriate.²⁰

Table 1 Results of the Trent Scoping Survey

	n = 48	
Setting for outpatient services	General paediatric hospital	28
	General paediatric community	15
	Designated epilepsy clinic	2
	Neurodevelopmental clinic	4
Number of paediatricians		
Declaring support for development of managed clinical network	42/48 (88%)	
Who manage children with epilepsy	39/48 (81%)	
Seeing an estimated number of children with epilepsy (children/month)		
	0/month	9/48 (19%)
	<5/month	21/48 (44%)
	5–10/month	14/48 (29%)
	>10/month	4/48 (8%)
Defining themselves as having “interest” or “expertise” in epilepsies	Yes	14/48 (29%)
	No	29/48 (60%)
Defining themselves as not having “interest” or expertise but wishing to develop one	10/48 (21%)	
Stating any relevant CPD	22/39 (56%)	
Able to identify names of current children with epilepsy under their care	21/39 (54%)	
Having contributed to any previous audit of epilepsy services	9/48 (19%)	
Having access to local tertiary “satellite” neurology clinic	12/48 (25%)	
Reporting use of NICE guidelines	29/48 (60%)	
Number of		
Epilepsy specialist nurses	3	
Other nurses identified as fulfilling aspects of the role of epilepsy specialist nurse	4	

ISSUES FOR SERVICE DEVELOPMENT

Waiting times

NICE made specific recommendations regarding waiting times which are often perceived as unachievable in the current climate of service provision and resources (“First outpatient assessment should be ‘urgent’ defined as 2 weeks; EEG and MRI should be ‘soon’ defined as 4 weeks”, NICE 1.6.3, 1.4.4, 1.6.21). Audit of outpatient, EEG, and MRI waiting times²¹ are relatively simple to perform and can provide useful evidence to aid restructuring and resourcing of services. Current waiting times make it clear that the availability of MRI for young children who all require sedation or general anaesthesia is inadequate.²² Seizure clinics with “urgent slots” and same day “fast-track EEG slots” for prioritised children are just one example of ways that services can be restructured to improve the patient journey.

Education

Initial and continuing education for all those involved in the childhood epilepsies is vital in order to develop and maintain expertise. The British Paediatric Neurology Association (BPNA) has initiated a national educational programme of Paediatric Epilepsy Training at three levels.²¹ PET 1 (level 1) is aimed at health professionals who anticipate clinical contact with children with suspected epileptic seizures. PET 2 (level 2) is for paediatricians and specialist nurses who will provide clinical management and are developing further expertise in epilepsy; and PET 3 (level 3) is for those with tertiary or quaternary level responsibilities. The plan is for standardised courses to be “rolled out” nationwide allowing participants to obtain appropriate and continuing training. Clinical attachments to tertiary or quaternary epilepsy clinics could be arranged as another supplement to professional development. The BPNA (child neurology) and Sheffield (neurodisability) distance learning courses both contain paediatric epilepsy modules. As in other areas of medicine the issues surrounding competency remain problematic and will need to be tackled in due course.

Audit and performance indicators

Meaningful audit of suspected epilepsy is difficult, partly because the epilepsies are heterogeneous and children are spread across services. What is appropriate management for

one patient may be inappropriate for another. Audit must attempt to measure the quality of diagnosis and management rather than just describe practice. NICE guidelines now identify such standards against which audit should be conducted. The BPNA audit group is developing audit tools and performance indicators to enable easier, meaningful, and standardised audit. There is an urgent need for the development of information technology resources on a national level to aid with this. Use of such technology would allow sharing of data (including national audit of practice), guidelines, and patient information. “First Attendance” and “First Year” audit tools with instructions are available from the BPNA website.²¹

Patient information resources

The range of different epilepsies and available treatment options make epilepsy an “information-heavy” subject. Despite multiple sources of written patient information, in practice it can be a challenge to get the right information to the right patient. Services should develop, pool, and make appropriate resources, tailored to the child, young person, and family, easily available at a local level.

The child and family

The media and voluntary organisations have both made reference to NICE epilepsy guidelines.²³ Published guidelines included a document written specifically for the public.²⁴ Expectations or “demands” on health services are likely to change; for example, “lobby packs” are being produced by Epilepsy Action.²⁵ Working with epilepsy organisations and support groups and seeking patient representation on network working groups, are examples of ways in which positive engagement may be sought.

CONCLUSIONS

The NICE guidelines provide a framework on which to base practice and ensure that equal standards of care are set across all areas in the UK. However, recommendations may be relatively easier to write than achieve; and an increase in resource allocation is unlikely to be forthcoming. The individual general paediatrician seeing children within a general outpatient setting is likely to find it difficult to make sufficient changes in order to fully meet the NICE recommendations. However, diagnosing and managing children

with epilepsies should not remain the responsibility of the general paediatrician without expertise. There needs to be wider discussion among those currently providing local services to children with epilepsy as to how changes can be effectively implemented; this will require support and planning at regional and national level. Training is an imperative requirement and available through the BPNA.²¹ Developing the evidence base for different types of service delivery through collaborative working should be realised centrally as an urgent requirement and addressed. NICE and SIGN should not just be seen simply as “bookshelf reference guides” for “best practice” but as an urgent prompt for restructuring of services for children with epilepsy.

ACKNOWLEDGEMENTS

We acknowledge the NCL Epilepsy Network for Children and Young People and the BPNA Audit Group for development of the scoping questionnaire. We thank William Whitehouse, Senior Lecturer in Paediatric Neurology, Queen’s Medical Centre, Nottingham, for help in organisation of the scoping questionnaire and providing Trent data.

Authors’ affiliations

C Dunkley, Department of Paediatrics, King’s Mill Hospital, Sutton-in-Ashfield, UK

J H Cross, Neurosciences Unit, Institute of Child Health and Great Ormond Street Hospital for Children NHS Trust, London, UK

Competing interests: J H Cross was the paediatric neurology representative on the NICE Guideline Development Group

REFERENCES

- 1 **Ferrie CD**. Preventing misdiagnosis of epilepsy. *Arch Dis Child* 2006;**91**:206–9.
- 2 **CSAG (Clinical Standards Advisory Group)**. *Services for patients with epilepsy*. London: Department of Health, 2000.
- 3 **Joint Epilepsy Council**. *National Statement of Good Practice and Care of People who have Epilepsy*. Joint Epilepsy Council, 2002.
- 4 **Hanna NJ**, Black M, Sander JWS, *et al*. *The National Sentinel Clinical Audit of Epilepsy-Related Deaths: Epilepsy—death in the shadows*. The Stationery Office, 2002.
- 5 **Consensus Conference on Better Care for Children and Adults with Epilepsy**. Final Statement, Royal College of Physicians of Edinburgh, 2002. *J R Coll Physicians Edinb* 2003;**33**(suppl 11).
- 6 **Department of Health**. *Annual Report of the Chief Medical Officer 2002*. Department of Health Publications.
- 7 **BPNA**. A national approach to epilepsy management in children and adolescents. Submission by Royal College of Paediatrics and Child Health to Chief Medical Officer for England, July 2002. www.BPNA.org.uk.
- 8 **NICE**. *The epilepsies: diagnosis and management of the epilepsies in children and young people in primary and secondary care*. National Institute for Clinical Excellence (NICE) Clinical Guideline 20, October, 2004.
- 9 **SIGN**. *Diagnosis and management of epilepsies in children and young people*, Scottish Intercollegiate Guidelines Network (SIGN), 2005.
- 10 **Ferrie CD**, Livingston JH. Epilepsy and evidence-based medicine: a vote of confidence in expert opinion from the National Institute for Clinical Excellence? *Dev Med Child Neurol* 2005;**47**:204–6.
- 11 **Royal College of Nursing**. A competency framework and guidance for developing paediatric epilepsy nurse specialist services. Royal College of Nursing, 2005. www.rcn.org.uk/publications.
- 12 **Epilepsy Action**. Epilepsy toolkit—what epilepsy means for your PCT. Epilepsy Action. www.epilepsy.org.uk.
- 13 **Appleton R**, Besag F, Kennedy C, *et al*. An audit of children referred with suspected epilepsy. *Seizure* 1998;**7**:489–95.
- 14 **Wilde M**, Haslam C. Living with epilepsy: a qualitative study investigating the experiences of young people attending outpatients clinics in Leicester. *Seizure* 1996;**5**:63–72.
- 15 **Stewart H**, Matthews T, Foley M, *et al*. An audit of care provided for children with epilepsy in the South Tees area. *Child Care Health Dev* 1998;**24**:185–94.
- 16 **Dunkley C**, Albert D, Morris N, *et al*. A population audit of first clinic attendance with suspected epilepsy. *Seizure* 2005;**14**:606–10.
- 17 **Hindley D**, Ali A, Robson C. Diagnoses made in a secondary care “fits, faints, and funny turns” clinic. *Arch Dis Child* 2006;**91**:214–18.
- 18 **Mar S**, Dunkley C, Al-Ansari I, *et al*. Comparison of a dedicated children’s seizure clinic to mixed general paediatric clinics. *Child Care Health Dev* 2005;**31**:597–602.
- 19 **Bloomfield S**, Farquhar JW. Is a specialist paediatric diabetic clinic better? *Arch Dis Child* 1990;**65**:139–140.
- 20 **Smith PE**, Myson V, Gibbon F. A teenager epilepsy clinic: observational study. *Eur J Neurol* 2002;**9**:373–6.
- 21 **British Paediatric Neurology Association (BPNA)**. www.bpna.org.uk.
- 22 **Healthcare Commission**. Acute hospital portfolio: radiology, July 2002. www.healthcarecommission.org.uk.
- 23 **Epilepsy Action**. The epilepsies: you, epilepsy and the NICE Guideline. Epilepsy Action. www.epilepsy.org.uk.
- 24 **NICE**. *The diagnosis and care of children and adults with epilepsy. Understanding NICE guidance—information for people with epilepsy, their families and carers, and the public*. National Institute for Clinical Excellence (NICE), October, 2004.
- 25 **Campaigning for Better Epilepsy Services**. Epilepsy Action. www.epilepsy.org.uk.