

BPNA Audit and Guidelines

NOV 1999 ①

An audit of children referred with suspected epilepsy

A twelve item check list to interrogate, a hand written note and a clinical letter from a child's first outpatient appointment, developed by Richard Appleton of the BPNA.

Although feedback from the BPNA was sought little was forthcoming and few clinics have actually used the instruments so far. The combined results of three centres from around the UK (50 patients in all) were published last year (Appleton et al Seizure 1998;7:489-495). Although there are limitations to this kind of study, principally to what extent has been written in the notes got to do with the quality of service given, I think it is an important start and I think it would be valuable to conduct the audit in some other centres. It could be used as a SpRs audit project for example. In Birmingham we are going to compare patients attending general paediatric clinics at a DGH with those attending a 'seizure clinic' at the Children's Hospital. An interesting variation on this theme would be to compare case notes entry audit (as published above), with, for example, a face to face interview or telephone interview of the family's perception of the consultation between 2 to 7 days after the consultation. Notwithstanding deficiencies in the instrument itself, there is great power in using the same

instrument at different places at different times at different sorts of clinics and for different patient groups. If any other people are interested in using the instruments and helping co-ordinate this kind of data and publishing the results, please get in touch with me or Helen Cross (Great Ormond Street Sick Children's Hospital, London; 0171 405 9200; email h.cross@ich.ucl.ac.uk).

Treatment guidelines for status epilepticus in children

Following our consultation exercise with the BPNA membership earlier this year and with the APLS trainers, the current draft guideline has been well received. There is a good chance that it is going to be published in the next APLS course book. A copy is enclosed with the newsletter. This guideline is just the beginning of more work: both audit studies and clinical trials of the management of acute seizures and status epilepticus in children are being planned.

Members interested in pursuing joint audit projects or finding out more about proposed trials could contact me, Tim Martland (Booth Hall Children's Hospital Manchester M9 7AA 0161 741 5044)

or Richard Appleton (Alder Hey Children's Hospital, Liverpool L12 2AP 0151 252 5851).

Child's Glasgow Coma Scale

The current draft of a GCS for children is also enclosed with this newsletter. This has evolved from adaptations to Jennett & Teasdale's 1977 GCS version by James & Trauner (1985) and then Janet Eyre and Peta Sharples and their paediatric nurse colleagues in Newcastle and the North East and then by myself, paediatric intensivists and paediatric intensive care nurses in Birmingham over the last few years (Tatman et al, Arch Dis Child 1997;77:519-521). The reliability has been measured to be satisfactory, (see the Tatman paper) and Janet Eyre et al have good data indicating validity by outcome on an almost identical scale (soon to be published). Janet Eyre and Fennella Kirkham are producing a very brief clinical guide to accompany the scale and we hope next to produce a brief guide and diagnostic aid for brain hemiation syndromes in children. This proposed Child's Glasgow Coma Scale has identical criteria to the Paediatric Coma Scale adopted by the (British) National Paediatric Neuroscience Bench Marking Group, which is a paediatric ICU nurses group and so may be the coma scale currently in use on your PICU if not in your local A&E department already!

We were keen for as simple and straight forward a scale as possible for use by unfamiliar doctors and nurses in DGH's and

so deliberately omitted the 'Grimace Scale' from this version. The Grimace Scale seems to be a useful surrogate for the verbal scale in intubated patients on PICU and is included in the 'Paediatric Coma Scale'.

Ketogenic Diet

A small but highly motivated network of doctors and dietitians interested in the KGD has met over the last two years. The group meets once a year, provides clinical support, shares expertise, uncertainties and experience. It is developing an audit tool for the assessment of nutrition and biochemical as well as clinical consequence of the diet. We are also producing information sheets and guidelines.

For more information contact me or Ruby Schwartz
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Future projects

Anyone wanting to join in development of some multi centre audit or guideline or care path projects is welcome to contact me. Future ideas of the BPNA include development of the care path and care guidelines for management of Guillian Barre in children, guidelines and an audit of treatment for idiopathic (benign) intra cranial hypertension in children, audit of management of refractory prolonged status epilepticus on PICU

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A National Sentinel Audit into epilepsy-related deaths.

People of all ages with epilepsy have an increased mortality risk of approximately two to three times that of the general population¹. Some of these deaths may be due to a complication of a seizure (eg: head injury, drowning), convulsive status epilepticus or a related underlying condition including a neurodegenerative disorder or severe cerebral palsy. There remain a number of people with epilepsy whose death cannot be adequately explained and it is to this group that the syndrome of sudden, unexplained death in epilepsy (SUDEP) has been attached. The syndrome is almost certainly under-recognised by health-care professionals and in children, SUDEP has been compared to sudden infant death (SID).

The Royal Colleges (of Paediatrics and Child Health, Physicians, Psychiatrists, General Practitioners, Pathologists and Nursing) have been asked to undertake a prospective National

Sentinel Audit investigating the circumstances of all epilepsy-related deaths. The audit is being co-ordinated by the charity 'Epilepsy Bereaved' and funded by the Department of Health through the National Institute for Clinical Excellence (NICE). It will audit the type and severity of epilepsy, ante-mortem primary and secondary care services and the post-mortem examination and certification of deaths. Audit criteria, standards and tools are currently being developed for health professionals, pathology departments and coroners' services and the audit is due to commence in late 1999 for a 12 month period.

It is hoped that the results of this National Sentinel Audit will clarify not only SUDEP as a phenomenon, but also identify risk and importantly, possible preventable deaths.

¹ Cockerell OC, Johnson AL., Sander JWAS, Hart YM, Goodridge MG, Shorvon SD. Mortality from epilepsy: results from a population based study. *Lancet* 1994; 344: 918-21.

Richard E. Appleton Helen Cross

This has the support of the RCPCH: 'On behalf of the Royal College of Paediatrics and Child Health, I would like to confirm that the College gives its wholehearted support to this proposed project. It is a subject of great interest to paediatricians and parents of children with epilepsy. I can assure you that we will do all we can to ensure its success. Prof. Richard Cooke, Vice-President and Director of Research Division.'