The ME (my epilepsy) Project: an active learning approach for people with learning disabilities and epilepsy

Article · December 2010

1 author:

Mary Codling
Berkshire Healthcare NHS Foundation Trust

Publication with Pavilion publishing View project
chapter in a book View project
Monitoring Nurse Prescribing - Safe Practice or Intrusive Bureaucracy?

Nurse prescribing has been with us in one form or another since the 1990’s with progressively more scope for the prescribing of medicines. In May 2006 Nurse Independent Prescribers (NIPs) were given the freedom to prescribe from the whole of the British National Formulary (BNF) with a few restrictions surrounding controlled drugs, most of which have now also been removed. Not surprisingly, the Nursing and Midwifery Council (NMC) have produced standards for nurse prescribing (NMC, 2006). This lists comprehensive educational requirements in order to become a NIP and regulations governing the issue of prescriptions. It also highlights the requirement to prescribe within personal boundaries of knowledge and experience as well as keeping up to date with the relevant skills to enable safe prescribing. Furthermore, later NMC Guidance (NMC, 2008) highlights ways in which NIPs might maintain competence. However, it doesn’t provide a framework within which NIPs and Trusts can go about implementing this.

Earlier this year a question was sent around the Epilepsy Action Network asking for views about the continuing education and monitoring of the competence aspect of the NMC guidelines. A very brief description of a framework for continuing professional development and accountability was described and comment invited.

Quite a number of respondents felt that this was the responsibility of the individual NIP and that further enquiry into or restriction of prescribing by an individual’s employer was an oppressive move that should be resisted. Certainly, an individual’s prescribing is covered under the same “act or omission” rule of accountability as the rest of professional nursing practice (laid out in the NMC’s Code of Professional Conduct [NMC, 2008]). However, nurse prescribing (particularly independent prescribing) is still a relatively new concept and as such NIPs need to be mindful of not only prescribing appropriately, safely and within their sphere of competence, but also proving that they do so.

Aims and Scope
Epilepsy Care aims to help nurses and other professions allied to health keep abreast of developments in the field of epilepsy. It will review important topics and provide recent references from other journals on the same. It will provide a forum for professionals allied to medicine who want to disseminate information about their work in the field of epilepsy.
A number of respondents stated that their Trusts had adopted similar models to support nurse prescribing while others wished their Trusts had done so! So what was the approach? Some Trusts have constructed a simple framework that reflects the themes of the NMC guidelines.

All NIPs were required to submit a personal formulary of medicines they prescribe. This could include anything legally prescribable by a nurse. The formulary was to be discussed with the NIPs medical mentor and then signed off with copies held by both parties as well as the Non Medical Prescribing Lead for the Trust and pharmacy. The formulary had to be revisited annually but could be amended at any time, for example to reflect changes in practice or the availability of new medicines.

Bi-monthly Non Medical Prescribing meetings were set up to discuss changes in legislation, local policy, and prescribing issues and Medication and Healthcare products Regulatory Agency (MHRA) updates. A formal educational component was incorporated which was often peer led but might involve “expert” speakers covering particular areas of clinical practice. Attendance of a certain percentage of these meetings was mandatory. This empowered nurses to negotiate their working time with managers in order to facilitate attendance.

Perhaps most contentiously, an audit aspect was introduced with peer review of NIP issued prescriptions against the Trust’s Non Medical Prescribing Policy (which includes the process outlined earlier). The appropriateness of the prescription for the individual patient was assessed by the medical mentor who by definition was a senior doctor working within the NIP’s specialty.

So, is this sort of process too autocratic? NIPs need to ask themselves how they can explain their prescribing decisions if challenged. Can they show on-going professional development? How do they prove that they are working within their professional competencies? Likewise, Trust’s have a responsibility to ensure their NIPs are supported educationally. They will also want to minimise the potential for “maverick prescribing”. Certainly, there are many ways in which prescribing can be monitored, and NIP’s supported. Excellent educational opportunities are offered by epilepsy conferences such as those organised by the International League Against Epilepsy (ILAE) and the Epilepsy Nurses Association (ESNA) as well as numerous local meetings. Universities offer non medical prescribing update courses and these are supplemented by study days organised by professional bodies such as the Association for Nurse Prescribing. Add to this journals covering both epilepsy specific and generic prescribing topics as well as numerous on-line resources and the choice for ongoing education is indeed broad. The essential message has to be that the end of the Nurse Prescribing Course is the start of an ongoing professional journey and a well thought through plan of continuing education and supervision can nurture the fledgling prescriber towards “expert” prescribing practice.

Phil Tittensor (Co-editor)

References


The ME (My epilepsy) Project: an active learning approach for people with learning disabilities and epilepsy

Mary Codling, Epilepsy Nurse Specialist, Wokingham, Berkshire

Introduction

The impetus for this project was based on the findings from previous research that showed people with learning disabilities were not participating in their care despite having considerable knowledge about their epilepsy (Codling, 2008). Furthermore, there is limited research examining the participation of people with learning disabilities in the management of their epilepsy. Instead, much of the clinical information about their condition tends to be derived from parents, carers or professionals. The consequence for people with learning disabilities is that they feel disempowered and lack confidence in their ability to participate.

Aim of the project

Understanding the issues that prevent people with learning disabilities from participating became the driver for this project. The overall aim of the project was to enable people with learning disabilities and epilepsy to engage in learning about their epilepsy and hence, empower them to have a voice in their care.

Background

The intersection between information and engagement have been highlighted as key drivers for better management of long term conditions and self-care (Davies, 2009; Mooney, 2009; Savin & Pendleton, 2010). Taking into account the findings from previous research that people with learning disabilities did have knowledge about epilepsy, the findings suggest there was little intersection between the information they possessed and engagement (Codling, 2008). From a professional aspect, the ethical case to utilise the findings from research to improve engagement in care for people with learning disabilities and epilepsy is clear. According to McNally (2002), if changes do not occur as a result of information obtained from people with learning disabilities, then little will change. To translate the theory to practice, we decided to set up an educational support group for people with learning disabilities and epilepsy to enable them to participate and gain confidence in having a voice in their care. This project was funded and supported by the Queens Nursing Institute in 2009.

Supporting evidence

Epilepsy is often associated with learning disabilities. According to Espie & Paul (1997), there are few problems that present in people with learning disabilities as commonly and as persistently as epilepsy, and this is reflected in the comparison of its incidence to the general population (Forsgren et al., 1996; Airaksinen et al., 2000; Patja et al., 2000). The prevalence rate of epilepsy amongst people with learning disabilities is thought to be 22% compared to 0.4%-1% for the general population. In other words, epilepsy occurs 15-30 times as often in people with learning disabilities (van Schrojenstein Lantman-Valk, 2005; Espie et al., 2003a).

Historically, people with learning disabilities were viewed as being incapable of taking responsibility for their lives, or as not having a legitimate role in contributing to decisions made about them (Emerson et al., 1999). This is echoed by Beamer & Brookes (2001) who found there is a high risk of exclusion from decision-making for people with learning disabilities due to their perceived limited ability to engage socially, which is a factor that often arises due to their lack of literacy skills and communication difficulties. A further factor for lack of participation noted by Kerr & Espie (1997) is that people with learning disabilities do not fit well into established evaluative processes.

It could be argued that established processes which health professionals have become accustomed to when dealing with epilepsy could create a barrier to participation for people with learning disabilities. As Emerson et al. (1999) reminds us, approaches to interventions amongst people with learning disabilities are often symptom based or illness-based, and the more we get involved in trying to understand the nature of the person’s condition, the easier it becomes...
to lose sight of the person. This reiterates what Lovett (1996) stated some years previously that when we fail to take a person’s views into account, we lose the context to understand that person in a realistic way.

A number of authors have echoed the paucity of evidence demonstrating participation of people with learning disabilities, which further emphasises the importance of participation of this population group in issues about their epilepsy (Kerr & Espie, 1997; Espie & Brown, 1998; Clark et al, 2001). Furthermore, Lhatoo & Sander (2001) found that most large prevalence studies about epilepsy have seldom addressed subpopulation groups such as people with learning disabilities noting that this population group is under-represented. More recently, Beavis et al. (2007) echoed similar concerns and noted that despite the high prevalence of epilepsy in people with learning disabilities, intervention studies are relatively rare. Nonetheless epilepsy as a condition on its own is too often not socially accepted and therefore has a low profile (Stuttaford, 2003).

In contrast where research has explored issues around participation, the findings suggest that people with learning disabilities were prevented from participating in their own care due to the assumptions made by parents and staff that people with learning disabilities will not be able to handle information about epilepsy (Vallenga et al., 2006). According to Vallenga et al. (2006) the balance between risk and quality of life requires a systematic approach to risk management to avoid the over use of protective measures by care providers. Sometimes, these protective measures are used as a means to prevent an individual’s participation and person centred care (Vallenga et al., 2007).

Key policy drivers

Participation of people with learning disabilities in issues about their care has become an important topic in recent years. There are two main reasons for this. First, the Government introduced ‘Valuing People’ a White Paper for people with learning disabilities for which there is an explicit requirement for user participation and incorporating the principles of choice, rights, inclusion and independence (DH, 2001). Key policy drivers for long-term conditions echoes similar principles with the emphasis on promoting self-care (DH, 2005; 2006a). Additionally, “Our health, our care, our say” (DH, 2006b) promotes choice and control for service users to be achieved through various developments and innovative practice.

The second reason relates to the growing body of evidence surrounding inequalities in the provision of health care for people with learning disabilities (DRC, 2006). The lack of participation of people with learning disabilities in issues about their care was accentuated by the report ‘Death by Indifference’ (Mencap, 2007) where people with learning disabilities died because they were not included in decision making relating to their treatment. “Equal treatment: Closing the Gap” (DH, 2007) called on services to treat people with disabilities as equal and not to discriminate against people because of their disabilities. Although policies are in place to promote empowerment and self-awareness, people with learning disabilities may not have direct access to this information and it is therefore paramount that staff create opportunities for individuals to engage in their care. This project is an example of innovative care aimed at realising that objective.

Method

The My Epilepsy project was very much based on a design and build approach using a group method to support people with learning disabilities and epilepsy to understand the nature, experience and management of their condition. There is evidence that this approach has proved successful for engaging people with learning disabilities in other issues relating to their health (Goodman, 1998; Cambridge & McCarthy, 2001; Fraser & Fraser, 2001).

The studies that have utilised a group approach report this as an effective method for conducting exploratory research with adults who have learning disabilities. For instance, Goodman (1998) used focus groups of people with learning disabilities to assess their understanding of the complaints procedure and found a lack of awareness of the system together with a very limited understanding of the concept of complaint. Cambridge & McCarthy (2001) found that people with learning disabilities were able to raise their concerns and views about services in focus groups. Fraser & Fraser (2001) also conclude that the use of focus groups proved to be an appropriate method for understanding the level of knowledge held by people with learning disabilities about health promotion. The use of group work is further supported by the growing literature surrounding self- advocacy groups, where people with learning disabilities have taken part in service evaluations (People First, 1994; Whittaker, 1997; McNally, 2002).

About the ME (My Epilepsy) groups

Before commencing the groups two introduction days were set up for the purpose of mapping need. People with
learning disabilities and epilepsy were invited to find out what the groups were about and to ask people what they would like to get out of the group. There was a good response to the introductory days for which people with learning disabilities requested information on different seizure types, medication and risk. When asked where they would like the group to meet, they specifically asked not to use a health setting. We therefore decided to hold the group meetings in a hotel as we felt this would be free of any potentially negative connections people may have with health services.

Two groups consisting of ten participants each were held on a weekly basis in two localities within Berkshire for a period of ten weeks. All participants attending the groups had the capacity to consent to attend. The framework chosen to structure and inform the group was PEPE, an electronic psycho-educational programme about epilepsy for people with learning disabilities (National Society of Epilepsy, 2007). PEPE was originally designed by Dr. Bernd Huber in Germany and was then translated into English at the National Society for Epilepsy. The PEPE programme is a multi-media course offering a holistic approach to teaching about epilepsy from seizure types to medication, risks, employment, leisure, housing and relationships. Despite the development of this programme there have been relatively few initiatives that attempt to measure the effectiveness of this resource.

Each week the group followed the format of the PEPE programme alongside a number of other creative methods for teaching such as group discussions, role-play, and group interactions. We also used a video to make recordings of role-play consultations with participants about going to the doctor that was played back to the group for discussion. Pictures of medication were used to discuss participants’ medication and inform them of how to take medication, compliance and side effects. Different seizure types were discussed and participants shared their own experiences about their seizures and described what happens to them. Other topics covered as outlined in the PEPE programme were investigations, risks associated with epilepsy, how people felt about having epilepsy, being looked after by carers, living arrangements and relationships.

A repeated measure design was used to compare knowledge before and after the group intervention so that we could evaluate any changes. We used a questionnaire to test knowledge that was included in the PEPE (National Society of Epilepsy, 2007) electronic psycho-educational programme about epilepsy for people with learning disabilities. We also used flip charts pre group intervention to find out what knowledge participants had about their epilepsy and repeated this exercise post group intervention to enable us to compare changes in knowledge and understanding following the sessions.

Self-reporting of seizures was achieved by keeping a diary of seizure occurrence during the ten weeks and comparing seizure frequency from the onset of the group to completion. Whilst keeping a diary of their seizures participants also recorded information about their epilepsy that was pertinent to them and this subsequently evolved into an information folder for their own use. In addition another measure known as the Epilepsy Rating Scale (Espie et al, 1998) was used to compare concerns about epilepsy before the group and on completion. Espie’s outcome scale is a set of questions outlining concerns that people may have about their epilepsy. Each question is rated using a three point likert scale. The questions cover areas such as management of epilepsy, injury resulting from epilepsy and effects on daily living. Espie’s outcome scale was selected because it was designed from studies with people with learning disabilities and is a well validated measure (Espie et al, 2003b).

**Demonstrable outcomes**

The ME project demonstrated that the groups had an impact on the ability of people with learning disabilities to manage their epilepsy. Based on the pre and post intervention measures, the outcome showed there was an increased awareness amongst people with learning disabilities about risk and this was demonstrated by their account of the strategies they devised to minimise risk. For instance people with learning disabilities were able to recognise when they were about to have a seizure and inform others or find a safe place to sit. This correlates with the comparison of findings from the Epilepsy Rating Scale (Espie et al, 1998) that showed people with learning disabilities had sustained less falls and injuries on completion of the group, providing further evidence that people had put their learning into practice.

Another outcome was the development of a ME folder designed by group participants for their own use to monitor their epilepsy. The use of this folder during the group sessions enabled people with learning disabilities to keep their own seizure diary which showed improved seizure frequency. Group participants reflected on the usefulness of recording information gained from the group such as
Epilepsy Care

Awareness of medication, compliance and concordance that also contributed to improved seizure frequency. Following requests from group participants, the ME document has now been published into a hard back folder that can be utilised by all people with learning disabilities and epilepsy for their use in consultations with medical staff.

A key discovery during the group sessions was people with learning disabilities interpretation of key messages and information given by health staff. For instance one member was informed that people can die from epilepsy and so they became frightened to go to sleep. The consequences from lack of sleep resulted in frequent seizures which no one was aware of. This finding further demonstrates the usefulness of the group sessions that enabled people with learning disabilities to discuss their fears and anxieties and to understand information that was delivered in a simpler format and in context with their lives.

Finally, we found that environment played a big part in the delivery of information and this was instrumental in engaging people with learning disabilities. The use of a non-health venue enabled people with learning disabilities to attend the group without fear of repercussions. As the group progressed the increased self-confidence of people with learning disabilities became more visible and a number of participants made assertive changes to their daily lifestyles. An example of some of the changes reported by participants were speaking for themselves at GP consultations and asking questions about their medication. All group participants reported that this was the first time they had been to a hotel and eagerly returned each week to a venue that made them feel both good and valued.

Conclusion

The success of this project has opened up the prospect of taking this model of working with people with learning disabilities further so as to embed meaningful participation for this population group. The support and funding from the Queens Nursing Institute provided an opportunity to test out alternative ways of delivering healthcare to people with learning disabilities and epilepsy.

The project established a means for understanding the needs and preferences of people with learning disabilities and epilepsy that enabled their visibility as active participants to transform the way their epilepsy is managed. The benefits of learning, sharing knowledge and concerns include increased confidence and self-esteem resulting in a much more empowered group on completion.

This project has demonstrated that a group approach proved to be a lever for engaging people with learning disabilities and epilepsy, and further supports the need for change in how we deliver health care to people with learning disabilities. To do this we need to shift the balance of power by providing more opportunities for people with learning disabilities to engage in projects that promote self-awareness of health that can lead to better self-reporting and participation. People with learning disabilities have the same rights as every other member of society to participate in their care and as professionals we have an obligation to ensure that their voices are heard.

References


Department of Health (2006b) Our Health, Our Care, Our Say: A new direction for community services. London: HMSO.


Epilepsy in Africa: an update from rural Tanzania

Ewan Hunter¹, Katie Burton², Jane Rogathe³, Richard Walker¹, ¹Northumbria Healthcare NHS Foundation Trust, UK, ²Kilimanjaro Christian Medical Centre, Tanzania

Introduction

In last year’s December issue of Epilepsy Care we reported on the early progress of a study of the epidemiology of epilepsy in a rural district of northern Tanzania.¹ The project is being conducted by researchers based at Northumbria Healthcare NHS Foundation Trust (NHCFT) in the UK, in collaboration with staff based at Kilimanjaro Christian Medical Centre (KCMC) in Tanzania and field workers from Hai, the district where the study is based. This article recaps on the background to the study, gives an update on project activities over the past year and briefly outlines further planned research.

Epilepsy in sub-Saharan Africa

Of the estimated 50 million people living with epilepsy worldwide around 80% live in low-income countries such as those in sub-Saharan Africa (SSA), including Tanzania.² Health systems in these countries are characterized by relatively sparse clinical infrastructures, particularly at community level. Given such difficulties, it is understandable that reliable data on the epidemiology of epilepsy from developing countries are scarce. It is generally agreed, however, that the prevalence of epilepsy is higher in developing countries than in developed countries, with door-to-door surveys from SSA showing a median prevalence of 15/1000³, compared with figures of 3.5 – 6.8/1000 reported by studies from European nations and the US.⁴ Furthermore, for people with epilepsy (PWE) living in SSA there is often little or no access to regular treatment or follow-up, and estimates for the treatment gap in these countries are consistently over 90%.⁵ Treatment gap (TG) is defined as the proportion of people living with a condition who do not have access to effective treatment. In this context, epilepsy remains a poorly understood condition which is often highly stigmatised. In the case of uncontrolled seizures there is also a very significant risk of injury or death, particularly in communities where many people still rely on open fires for cooking and on fetching water from open sources such as rivers or lakes.

Tanzania

The United Republic of Tanzania in central East Africa is one of the world’s poorest countries. Up to 39% of the population are considered to be living in poverty, and many rural areas have limited access to safe drinking water, education and health care.⁶ Life expectancy at birth in 2006 was 50 years, with the leading causes of death being malaria in children who survive the neonatal period, and HIV/AIDS in adults.⁷ The economy of Tanzania is mostly based on agriculture, which provides up to 85% of exports and employs approximately 80% of the workforce.⁸ We are aware of only two resident neurologists working in Tanzania, serving an estimated population for 2009 of over 43 million people, and to our knowledge there are only three functioning CT scanners, one MRI scanner and three EEG units in the country at present.⁹

Project background

Hai is a rural district situated on the slopes of Mount Kilimanjaro in the northern part of Tanzania. It is one of the three demographic surveillance sites (DSS) established in Tanzania between 1992 and 2003 as part of the Adult Morbidity and Mortality Project (AMMP). This large scale epidemiological programme was funded by the Department for International Development (DfID) in the UK, and conducted in partnership between Newcastle University and the Tanzanian Ministry for Health.⁴ Since 2003 the network of village-based workers established in Hai has remained active with the support of Professor Richard Walker at NHCFT, who has conducted community-based studies of stroke and Parkinson’s disease in the district.¹⁰-¹² In mid-2008 NHCFT agreed to sponsor a study of epilepsy in the district as part of their Teaching and Research Fellowship scheme.

The aims of the study are to provide an accurate estimate of the prevalence of epilepsy in the Hai population (c. 161,000 people) and to describe the patterns of disease in terms of seizure types and risk factors. In pursuing these research questions we also aim to gain an understanding of the
particular experience of PWE in this population, including TG, and to find ways of using this information to help improve services for PWE using resources available locally.

The first line anti-epileptic drugs (AEDs) generally available at community level in Tanzania are phenytoin and phenobarbitone. These appear on the WHO essential drugs list, and are made available to patients either free or at cost price. The cost of one 30mg tablet of phenobarbitone is 5 Tanzanian Shillings. A typical daily maintenance dose of 90mg therefore costs around 450 Shillings a month, equivalent to about £0.21. Although the local economy is a largely subsistence one, this modest cost is still affordable to most families.

Preparations and Progress

In October 2008 two Tanzanian nurses with prior experience of managing epilepsy travelled to the UK to gain experience of epilepsy services in this country. During their visit they completed the Certificate in the Care of People with Epilepsy at the National Centre for Epilepsy in Chalfont, Buckinghamshire. This was complemented by clinical experience in the North East of England, where the two nurses observed clinics, investigations and home visits, attended regional scientific meetings and also a meeting of a patient support group based in Sunderland.

Between January and May 2009 a complete door-to-door census of the Hai district was conducted. Prior to the census a week of workshops around the subject of epilepsy was conducted for the 65 census enumerators. Different seizure types were illustrated using video demonstrations, and the nature of epilepsy as a treatable brain disorder was discussed. During the census each of the 47,000 households in the district was visited by an enumerator to collect demographic data and to ask a set of screening questions for possible cases of epilepsy. Anyone who responded positively to any of the screening questions was invited to be interviewed and examined by the research team in order to confirm or refute a diagnosis of epilepsy, with histories also being taken from eye witnesses or family members where possible. As well as clinical details, information was also collected on patients’ experience of living with epilepsy, including access to treatment, injuries, perceived stigma, barriers to education, work or marriage. As the team travelled around the villages of the district they also liaised closely with local health workers in an effort to gain an understanding of the networks in place for provision of care, offering specific advice and training where appropriate. Anyone identified as having epilepsy was also offered further investigation by way of EEG and CT scan, both of which are available locally at KCMC. All clinical work was conducted by Dr Ewan Hunter and Dr Katie Burton from the UK, assisted by Sister Jane Rogathe, one of the two Tanzanian nurses who had been trained in the UK. CTs and EEGs will ultimately be read in the UK, with the results fed back to patients in Tanzania.

Early findings

Field work for the initial prevalence phase of the study is now complete and data analysis in progress. At the end of the clinical assessment phase, over 400 cases of active epilepsy had been identified, many of whom had previously had either little or no treatment. Around 25% of all cases had sustained seizure-related burns, which were often disfiguring or disabling due to soft-tissue contractures or amputation of limbs or digits. There were also numerous instances of dental and long bone fractures sustained during seizures. The perceived level of stigma amongst PWE was high, with patients describing being excluded from school, having difficulty finding work, and being limited in their social function, both at home and in the community. Where patients had accessed treatment, many had sought care late and relied heavily on traditional medicine rather than AEDs. An in-depth qualitative study of these latter aspects has recently been accepted for publication.

Figure 1: Self-scarification to treat epilepsy
Further research

Once a final estimate of prevalence is established, the cohort will be studied further to better understand various aspects of epilepsy in this population.

Tape worms and epilepsy

In seeking to clarify the risk factors for acquired epilepsy, there will be a particular focus on neurocysticercosis, a disease caused by the larval stages of the human tape worm taenia solium. The usual intermediate host for this parasite is the domestic pig, with the tape worm being passed to humans through consumption of undercooked pork containing larval cysts. Human cysticercosis occurs following the accidental ingestion of t.solium eggs which have been excreted in the faeces of an individual carrying the parasite. Following ingestion the eggs hatch to liberate embryos which are carried in the bloodstream to host tissues, where they develop into larval cysts. The presence of cysts in the nervous system is known as neurocysticercosis (NCC), and it is the calcified remnants of dead cysts in brain tissue which have the potential to act as foci for seizure activity. NCC is endemic in many developing countries including Latin America, India and China where its impact has been studied extensively. While evidence from SSA is less robust, it is suggestive that NCC may also be a significant contributor to the burden of acquired epilepsy in this region.

In Hai we know that all the factors needed to make NCC a potential problem are present; many households keep pigs, eating pork is increasingly popular, and there are relatively poor levels of sanitation in the district. PWE identified in Hai during the prevalence study have been recruited into a case-control study that will use blood serology to establish levels of previous exposure to t.solium amongst cases and controls. These findings will be correlated with radiological findings from the case series.

Behavioural problems and epilepsy in children

Rates of behavioural problems are known to be higher in children with epilepsy compared to children without epilepsy, and also compared to children with other chronic conditions such as diabetes and asthma. There is only limited information on the prevalence and nature of behaviour problems in children with epilepsy in low-income countries, and no published data from Africa.

Dr Katie Burton is a UK-trained paediatrician with an interest in epilepsy and neuro-developmental problems in children. She has been responsible for the paediatric component of the prevalence study, and will now conduct a case-control study based on the Hai cohort to determine the burden, nature and associations of behavioural problems in children with epilepsy in this population. This work will represent a unique contribution to knowledge of this field in Africa.

Liaising with local services

Beyond any contribution to the academic literature, a project like this also seeks to generate knowledge and insights that will be of use to local service providers, and which will ultimately benefit patients and their families. Last year we reported on a training workshop that was delivered to representatives from each of the 23 government health facilities in the district. A simple algorithm was introduced for the initiation and titration of anti-epileptic treatment, and guidance given on when and how to refer cases in whom the diagnosis is uncertain or in whom treatment is proving problematic. Now that the initial data gathering phase of the project is complete, we have been able to provide a complete list of the cases identified to local health
administrators, including details on their current treatment. In the absence of extensive record-keeping systems, this kind of information is very difficult to generate out with a formal epidemiological study, and we hope that this can now be used to facilitate ongoing follow-up of patients already identified.

An initial challenge will be to match the supply of AEDs in the district to the numbers of patients served by the various local facilities, known as dispensaries. Health workers at the dispensaries have been involved in all clinical follow-up of patients under the study to date, with very encouraging results. Early indications are that either seizure-freedom or a dramatic reduction in seizure frequency have been achieved in at least 50% of those patients who were previously undiagnosed, or who were not using any kind of regular drug treatment. Any wider impacts of the study in terms of changing attitudes towards epilepsy are harder to quantify, but we feel that there is now an increased awareness of the treatable nature of epilepsy among both patients and health workers in the district. By continuing to develop the relationship that has been established between the project team and the local health infrastructure we intend to offer further training, and to continue following the patient cohort with regards to treatment outcomes and prognosis.

Figure 4: A typical dispensary in Hai

Acknowledgements

Training in the UK for the Tanzanian nurses was made possible with the generous help of Penny Burt, Epilepsy Nurse Practitioner at Newcastle Hospitals NHS Foundation Trust, Pam Mantri and Leslie McGowan at County Durham PCT, and Carol Jordan and Jan Duerdoth at the National Centre for Epilepsy, Chalfont, Buckinghamshire. Clinical support for Dr Hunter has been provided by Dr Margaret Jackson and Dr Roger Whittaker in Newcastle, and for Dr Katie Burton by Prof Charles Newton and Prof Brian Neville, Institute of Child Health, University College, London. The project is sponsored by Northumbria Healthcare NHS Foundation Trust and supported by the Helen H Lawson Grant, administered by BMA Charities, and by the Wellcome Trust UK. Sister Jane Rogathe was available to work on the project by arrangement with the administration at Kilimanjaro Christian Medical Centre, Tanzania. We would also like to thank the editors of Epilepsy Care for their continued interest and support.

Anybody wishing to know more about the project can contact Dr Ewan Hunter directly by e-mail at ewan.hunter@nhct.nhs.uk
References


8. Personal communication.


Recently Published Papers

As per normal, this section highlights recently published papers. Hopefully this is very useful to all, helping to keep everyone up to date with the latest developments. It will certainly save you research and reading time, not having to search so many journals.

Due to the number of excellent REVIEW papers published in the last six months we are again using the present system for accessing abstracts. You can instantly access them for all the papers by using the on-line pdf version of “Epilepsy Care”. These are available at http://www.vnccprofessional.org/index.asp. The access code is esna2009. From the home page click on “E-library”, then “Free journals” and finally scroll down to “Epilepsy Care”. The final link takes you to the present issue and all the back copies.


J Neurol Neurosurg Psychiatry. 2010 Jul;81(7):719-25. Does the primary literature provide support for clinical signs used to distinguish psychogenic nonepileptic seizures from epilepsy seizures? Avbersek A, Sisodiya S.


Epilepsy Care


Due to lack of space we have had to exclude two pages of references. These all appear with full abstracts in Epilepsy Care on-line.

ESNA News

Conference 2010

This years conference held at the Belfry Hotel in Nottingham was well attended and featured a faculty that would not have been out of place at any leading epilepsy meeting. Indeed, many of the speakers delivered similar lectures at the ILAE’s European Chapter Convention in Rhodes the following month. Feedback from the conference has now been evaluated. Overall comments rate this as the best ever ESNA conference. The only negative comments regarded the IT facilities where there was particular criticism of the lack of a roving microphone. Delegates would also have liked the ESNA Executive to have introduced themselves and said a little bit about their role in the organisation. This oversight will be rectified at future conferences.

The next ESNA Conference will be held in the Spring of 2012. The Executive are already considering venues. The Belfry came in for almost universal praise and there are compelling reasons for keeping it for the 2012 event. However, if anyone has other suggestions then please contact a member of the Executive so that it may be considered.

New ESNA Website

The site has been up and running for about four months at the time of writing. Although there are still a few teething troubles, it is certainly much clearer & easier to navigate than the previous site. Updating is also a relatively simple task which means that new content can be added promptly and equally importantly old material can be deleted.

We hope to add new content to the website in the near future. This will include a training library with fairly generic presentations that members can use & adapt as well as medication protocols, patient information leaflets and other epilepsy related resources. Esther Whitten is co-ordinating this initiative. If anyone has any guidelines, protocols, teaching aids or other epilepsy related material that they would be prepared to share, please email Esther at estherwhitten@nhs.net. All submissions would be subject to peer review by members of the ESNA Executive.

ESNA now plans to communicate with members exclusively by electronic means & the website is an integral part of that strategy. If you haven’t already done so, try out the site at www.esna-online.org.uk and let us know what you think.

Due to lack of space we have had to exclude two pages of references. These all appear with full abstracts in Epilepsy Care on-line.
ESNA News (continued)

Learning Disabilities Competencies

Catherine Doherty and Esther Whitten are involved in a project to look at the practices of all Epilepsy Specialist Nurses (ESNs) who work with people with learning disabilities. From this they aim to build on previous work to develop competencies for ESN’s working in the field of learning disabilities. The competencies will be in line with the existing paediatric competencies as well as the generic Knowledge and Skills Frameworks (KSFs). The team hope to have a draft ready within six months.

ESNA News Online

Many people may have noticed that there hasn’t been a new edition of this publication for over six months. The Editor, Phil Tittensor is very keen to keep it going but desperately needs members to contribute articles for inclusion. These can be as short as 100 words right up to 1000 (any more than that and authors should consider submitting their work for inclusion in this journal instead). If anyone is interested in writing a piece on any epilepsy related topic then please email Phil at phil.tittensor@midstaffs.nhs.uk.

ESNA Executive Committee Members

Mel Goodwin...................................................................................................Chair
melesina.goodwin@ngh.nhs.uk
Sue Higgins.............................................................Membership Co-Ordinator
Sue.Higgins@glos.nhs.uk
Christine Morley....................................................Treasurer/Conference Organiser
christine.morley@hercs.nhs.uk
Sarah Goodman.................................................................
sarah.goodman@rsh.nhs.uk
Walter Louden.................................................................walter.louden@bsuh.nhs.uk
Phil Tittensor........................................................................
phil.tittensor@midstaffs.nhs.uk
Esther Whitten........................................................................
estherwhitten@nhs.net
Siobhan Hannan................................................................
hannass@gosh.nhs.uk
Catherine Doherty................................................................
Catherine.Doherty@sbpct.nhs.uk
Danielle Wilkins........................................................................
danielle.wilkins@ngh.nhs.uk

“Epilepsy Care” is funded by an unrestricted educational grant from UCB Pharma.