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Epilepsy and learning disabilities—a challenge for the next millennium?

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People with learning disabilities often have seizures in addition to other disorders. Precise diagnosis may be difficult, but accuracy can be improved using electroencephalographic and video investigations. Following the establishment of a diagnosis of epilepsy, individually tailored care is necessary taking into account other health, behavioural and therapeutic issues. Neuroimaging may indicate a need for surgery which should not be automatically excluded as a treatment option. Rational antiepileptic drug use is advised, with emphasis upon the newer agents due to their better tolerance and ease of use. A programme of regular review will prevent over-medicating. Drug therapy may be withdrawn in a seizure-free patient. Realistic goals should be established for each individual coupled with an optimistic approach to care. However, future developments require a solid evidence base combined with rationality in all aspects of management. The community learning disability epilepsy nurse specialist is the key health-care professional who can ensure that a learning disabled individual with epilepsy is able to take full advantage of all available services. Education, closer collaboration and the mutual recognition of skills will ensure more cohesive and comprehensive care for this disadvantaged patient population.

Key words: learning disabilities; epilepsy; investigation; antiepileptic drugs; management; specialist nurse.

INTRODUCTION

The recent sad deaths of Diana, Princess of Wales and Mother Theresa of Calcutta have drawn hearts and minds to the needs of people and causes that are frequently shunned. In the world of epilepsy, it is often the patient with learning disabilities who falls into this category despite the work of the dedicated individuals involved in their care. This multiply disadvantaged group are often regarded with a sense of despair as diagnosis can be difficult and treatment ineffective. However, the redefinition of aims and objectives and the realization that 'seizure-free' should not be the only goal will allow the adoption of a more liberated and positive attitude to this patient population.

In the past, people with learning disabilities have been regarded financially as 'major burden[s] on the National Health Service[1]. However the use of a rational approach to care allows clearer justification of expenditure and may gradually prise away this unfortunate title. The aims of high-quality care for people with epilepsy and learning disabilities are the same as those for epilepsy alone: increased quality of life adjusted years and more effective, efficient use of resources[2]. Those involved in the therapeutic pathway are not just health professionals but also families, carers, social service, employment and educational agencies, and people in the voluntary sector[3]. Developing close links between all of these contributors provides the best opportunity for optimal management.

EPIDEMIOLOGY

An average general practitioner with a list of 2000 has 36–38 patients with learning disabilities, of whom about six will have severe learning disabilities[4,5]. Epilepsy has a lifetime prevalence of 2–5% of the population. Thus, the same general practitioner will have approximately 10–15 epileptic patients on active treatment and another 15–25 with a history of seizures but not currently receiving treatment[3]. An average general practitioner will see only one or two new cases of epilepsy each year[6]. In general terms, the prevalence of epilepsy is high is childhood and adolescence, is stable in the adult years, and increases again in the elderly[7]. In contrast, the prevalence of epilepsy in patients with learning disabilities decreases from the age of 50 years[8].

The common coexistence of epilepsy and learning disabilities has been the subject of studies that have

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used a variety of epidemiological methods and definitions. Goulden *et al.*[9] and Sillanpää[10] have raised concerns regarding the interpretation of results as they can be significantly different depending on the study design. Following his review of existing studies, Sillanpää[10] gave an overall prevalence of epilepsy of 15% in people with mild learning disabilities (IQ > 50) and 30% in those with severe learning disabilities (IQ < 50). He recommended the use of the unselected prospective cohort study as the best method of examining life-time prevalence or preferably cumulative incidence of epilepsy in this clinical setting. People with mild learning disabilities (IQ 50–70) and no other concomitant conditions are at the lowest risk (5–7%) of developing epilepsy[9,11]. In contrast up to 75% of those with additional disabilities such as cerebral palsy or a postnatal brain injury have epilepsy. In addition, severe learning disability is more likely in patients with early seizure onset and less likely if there are only partial seizures[12].

Learning disabilities and epilepsy commonly coexist in certain chromosomal or dysplastic conditions such as Down syndrome. Approximately 8–10% of this population have a history of seizures[13–15], the distribution of which occurs in a bimodal pattern. Infantile spasms contribute to the first peak although this has a relatively benign outcome in Down syndrome[13,16,17]. The second peak occurs in the oldest age groups[13] and is believed to be associated with the dementing process[14,15]. Interestingly, seizure control is generally straightforward[13,16,17] particularly if linked to early onset and the presence of one seizure type[18]. This promotes the hypothesis that mechanisms exist in Down syndrome which limit seizure generation or spread, the clarification of which could be of more general significance[19].

The neurocutaneous syndromes, such as the Sturge–Weber syndrome and tuberous sclerosis, can also be associated with learning disabilities and epilepsy, although this is not always the case[20–22]. Everyone with learning disabilities and tuberous sclerosis in the study by Webb and colleagues[22] had epilepsy. The authors stressed that tuberous sclerosis does not cause learning disabilities in the absence of seizures, and learning disability is rare if seizures do not occur in the first few years of life. Other syndromes most recently highlighted due to their association with epilepsy include the congenital bilateral perisylvian syndrome[23–25], the Aicardi syndrome[26], and the northern epilepsy syndrome[27–29].

MORTALITY

The life expectancy of people with learning disabilities is lower than that in the general population[30] with the probability of survival decreasing as the severity of learning disability increases[31]. The death rate for patients with mild to moderate learning disabilities is around twice that of the general population, while those with severe and profound levels have rates 7 and 31 times respectively those of the general population[31]. Individuals with a higher functioning ability have a longer life expectancy[32], and those who survive beyond the age of 50 have fewer health problems than do younger age groups[33]. Eyman and co-workers[34] found the poorest outlook in patients with severe disabilities who were non-mobile and required to be tube-fed by other people. Approximately 50% died within a 5-year follow-up period.

People with epilepsy are reported to have a higher mortality rate than the general population, especially in the first 10 years following diagnosis[35,36]. Particular attention has been drawn to sudden unexpected death in association with epilepsy[37–39] including in patients with learning disabilities[40]. The coexistence of learning disabilities and epilepsy results in a further rise in mortality rate[30–32,41–43]. Forsgren *et al.*[43] followed a complete cohort known to have learning disabilities in a Swedish province over a 7-year period. During this time 8.4% of the 1478 patients died. The standardized mortality ratio was significantly greater than that of the general population of 1.6, but was further raised at 5.0 for patients with learning disabilities and epilepsy, and 5.8 for those who, in addition, had cerebral palsy. Mortality rose with increasing seizure frequency in the preceding year, and was highest in patients with primary generalized seizures.

The leading cause of death in people with learning disabilities is pneumonia[30,31], and this is also true for those who have epilepsy[41–43]. In some instances death was directly attributable to the epilepsy[42]. For example, Forsgren *et al.*[43] reported that a seizure was the probable cause of death in 6.7% in their study group. Nashef *et al.*[40] found that most sudden deaths in their study population were unwitnessed and all occurred when the pupils under study were not under close supervision at their special school.

DIAGNOSIS

The diagnosis of epilepsy relies heavily upon an accurate description of events and the presence of a witness. Due to limitations in communication[44] and the wide differential diagnosis[10], diagnosing epilepsy and classifying syndromes in patients with learning disabilities can be very difficult[45,46]. The individual is often unable to describe the symptoms and sensations, which are experienced during an aura or postictally[10]. Professional carers attending a clinic with such a patient often vary, and there may be a lack of continu-

ity in information sharing. All this adds to the unease about the accuracy of diagnosis compared to other patient groups.

The most common seizure type in people with learning disabilities is the generalized tonic–clonic seizure. These were found in 87.3% of an institutionalized group[47] and in 68.2% of a population-based group of learning disabled people with epilepsy[8]. Steffenburg *et al.*[12] carried out a population-based study of learning disabled children. Of those studied 20.4% had partial seizures only, 60.2% generalized seizures only, and 19.4% had mixed partial and generalized seizures. Accuracy of classification is limited by communication abilities. In particular, the prevalence of partial seizures may be underestimated[10].

Accuracy of diagnosis can also be affected by the presence of behavioural problems in approximately 55% of people with learning disabilities[48]. Deb and Hunter[48] found that patients with mild degrees of learning disabilities, multiple seizure types, frequent seizures and generalized epileptiform activity on the electroencephalograph (EEG), had more problem behaviour than similarly affected people who did not have epilepsy. Severe learning disabilities and slow-wave EEG activity, paradoxically, was associated with less problem behaviour than in non-epileptics. Maladaptive behaviour was one specific area of study but much of this could be due to or related to epileptiform activity. Gedye has proposed that extreme self-injury[49] episodic rage, aggression[50] and stereotypic movements[51] in patients with learning disabilities could be due to seizure phenomena. Involuntary movements, such as orofacial dyskinaesia, may be a consequence of treatment with neuroleptic drugs[52] but could also be due to seizure activity.

In approaching this potentially diagnostic minefield in any learning disabled individual with suspected epilepsy, the standard method of history taking should be used to gain a full description of possible seizure events. This includes any precipitating factors, a description of what occurred during the prodromal period, the 'seizure' itself and the aftermath. Codes can be used by carers and individuals to simplify subsequent event recording. The past medical history should include details about any aetiological factors for the learning disability and for the epilepsy, including genetic or metabolic disorders, birth trauma, febrile convulsions, and family history of epilepsy or learning disability. A social and psychological evaluation including a measurement of IQ (unless already known) should be carried out. Physical examination should incorporate an assessment of the disabilities and the effects of injury, nutritional status and drug side-effects[53]. It may be possible to classify seizure type(s) and epileptic syndrome at this early stage using the International League Against Epilepsy criteria[45], but often further time and investigation are required.

INVESTIGATION

Routine and ambulatory electroencephalography, sometimes with synchronous video recording, are used to help differentiate between seizure activity and behavioural disorders[46,54]. EEG–video techniques, however, may not be widely available and, if long-term monitoring is used, the cost is high and the procedure can be frustrating for patients and carers alike. Antiepileptic drug dose reduction methods have been examined as a way of increasing the likelihood of capturing a seizure or event occurrence during a monitored period[55]. Concern has been raised about how well people with learning disabilities tolerate EEGs and, in particular, long-term monitoring. Reassurance about the level of technical success and benefit to patients has been offered by both Lannon[44] and Holmes *et al.*[56]. Carers too value EEG and video recording as it can help them respond appropriately to particular patterns of behaviour[54]. However, Brodtkorb[47] was only able to obtain EEGs from 53 out of 63 institutionalized learning disabled individuals due to 'cooperation problems'.

A learning disabled individual with a presumed psychiatric problem may be found using EEG techniques to have a seizure disorder such as non-convulsive status epilepticus. This may present with insidious or paroxysmal change in neurovegetative, behavioural, cognitive or affective symptoms[57]. Non-convulsive status may be under-diagnosed in people with learning disabilities and the symptoms can result in inappropriate treatment if they are of a predominantly psychiatric nature. It has also been reported that benzodiazepines can be ineffective in treating non-convulsive status and, if used excessively, can even precipitate recurrent episodes[58].

A variety of guidelines are available to help differentiate nonepileptiform or psychogenic episodes from epileptic seizures[10,54,59]. Although this process can be made easier using EEG–video recording, such techniques may not pick up all of the seizures[10]. Binnie and Prior[60], therefore, recommended that interpretation of an apparently negative ictal EEG depended 'on the nature of the seizure and co-registration of the EEG and behaviour to facilitate detection of minimal EEG changes'.

Neuroimaging is used when seizures appear to have a focal onset to identify any causative abnormality. Difficulties in obtaining accurate seizure histories for people with learning disabilities may result in a high proportion being referred for neuroimaging. Sedation may be necessary due to the nature and duration

of the investigation. Computer-assisted tomography (CT) scans are best able to identify gross structural pathology, while magnetic resonance imaging (MRI) is now regarded as the neuroimaging technique of choice due to its high sensitivity[61]. Magnetic resonance imagery allows a more accurate correlation of epileptogenic foci and brain lesions and, thus, aids decisions about possible surgical treatment[20,62,63]. Unfortunately, there is limited access to MRI in some areas due to availability and financial restrictions. A variety of other scanning techniques are possible in some centres such as functional MRI, single photon emission computed tomography (SPECT), magnetic resonance spectroscopy, and positron emission tomography (PET).

ANTIEPILEPTIC DRUG THERAPY

For many years now the previously pessimistic views on prognosis for people with learning disabilities and epilepsy, including a reluctance for trials off treatment even if seizure free, have been discouraged. This is not to say that these individuals do not have refractory seizures, concomitant conditions, and require polypharmacy. They are, as Mattson[46] states, 'unique management challenges'. However, management plans should be in keeping with the findings of many studies supporting the beneficial effects of simplification of antiepileptic drug regimens, reducing polypharmacy, and, where possible, discontinuing treatment in a seizure-free patient[64–72].

The current pharmacological treatment of epilepsy raises particular concerns regarding side-effects, a limit to increasing efficacy with polypharmacy, and pharmacokinetic and pharmocodynamic drug interactions. Monotherapy is advocated whenever possible at a dose which results in plasma drug levels within a target range but without unacceptable side-effects[73]. In practical terms, however, regular plasma drug-level monitoring is not always desirable. Where drugs are used in combination, a 'rational' approach has been suggested using the fewest possible antiepileptic drugs at the lowest effective doses[74,75]. Pharmacological intervention in patients with learning disabilities and epilepsy should be used in parallel with nonpharmocoligical measures such as environmental and personal support.

A balance must often be struck in treating epilepsy in patients with learning disabilities due to the presence of concomitant conditions and drug side-effects. The use of multiple antiepileptic drugs can have detrimental effects on psychosocial functioning independent of seizure frequency[76] and result in sedation, cognitive deficits and psychomotor impairment[69,77]. Families or carers may recommend the compromise of an increased number of seizures rather than looking after an individual who is heavily sedated due to anticonvulsant toxicity. Such views should be highly respected.

Few therapeutic assessments have been carried out in learning disabled patients, and there is a conspicuous dearth of placebo-controlled double-blind trials in this population. In clinical practice, there should be a high index of suspicion regarding potential side effects of AEDs. The individual may be unable to express what he or she feels is wrong, and so a change in mood or behaviour may be all that is apparent when drug toxicity exists. Concern about the side-effects of phenobarbital is so strong that it is now being increasingly replaced by less sedating drugs[71]. Valproate may be the drug of choice in many instances due to is wide range of efficacy, but it is teratogenic and often causes weight gain, the latter a problem already present in many learning disabled individuals. There appears to be a move towards the newer generation of anticonvulsants although solid evidence in support of their superiority over established drugs is lacking. The argument is that they appear as effective as the older drugs, but are better tolerated and less sedating. In addition, they do not require plasma level monitoring, cause fewer drug interactions and, for some at least, there is no evidence so far of teratogenicity[78,79]. The issues of contraception and pregnancy should not be overlooked in the learning disabled population as they may be sexually active.

Lamotrigine should be regarded as a particularly useful antiepileptic drug in patients with learning disabilities as it may not only improve seizure control but also mental state[80,81]. Buchanan[82] found that 74% of his study group showed a greater than 50% improvement in seizure control with 35% becoming seizure-free. Sixty-five per cent had an enhanced quality of life, as assessed by improved alertness, mobility, speech and independence. Lamotrigine has also proved efficacious in the treatment of Rett syndrome[83] and Lennox–Gastaut syndrome[84,85]. Uvebrant and Bauziene[81] reported improved seizure control in 63% and 38% of individuals with infantile spasms and Lennox–Gastaut syndrome respectively. Starting lamotrigine at low doses with an initial slow titration minimizes the risk of the potentially serious side-effect of a rash[86].

Vigabatrin has also been studied in patients with learning disabilities and epilepsy[87–91]. It reduced seizures by at least 50% in 42% of 36 patients with learning disabilities, with a gradual reduction to 22% of patients after 5 years follow-up[89,90]. Topiramate is being used cautiously but optimistically in people with learning disabilities. It is also effective in treating seizures in patients with Lennox–Gastaut

syndrome[92], with the best response being noted for tonic–clonic seizures, followed by tonic, atonic, absence and myoclonic seizures[93]. However, like the majority of the newest anticonvulsant drugs, topiramate has been linked with behavioural and psychiatric problems. Similarly, gabapentin has been associated with hypomania and behavioural changes in people with learning disabilities[94–96].

Learning disabled individuals often require both antiepileptic and antipsychotic medication. Clarke *et al.*[97] found that up to 40.2%, 19.3% and 10.1% of people with learning disabilities in hospital, community and family homes respectively were taking major tranquillizers. Similarly, 26.2%, 9.3% and 18.5% took anticonvulsants. Reassuringly, despite the fact that high doses of antipsychotics may provoke seizures, small to moderate amounts do not carry the same level of concern[70]. The Royal College of Psychiatrists' Consensus Panel[98] produced guidelines on the use of high doses of antipsychotic drugs, identifying in particular the difficulties in prescribing these drugs for patients with learning disabilities due to the frequent coexistence of epilepsy. Deb and Fraser[99] advise a 'common-sense rational approach' to their use.

In the Epilepsy Unit at the Western Infirmary in Glasgow, the broad-spectrum antiepileptic drugs sodium valproate, lamotrigine and topiramate are used singly and in combination, particularly frequently in patients with learning disabilities who often have multiple-seizure types and difficult-to-control epilepsy[100]. Withdrawing enzyme-inducers, such as carbamazepine and phenytoin, makes antiepileptic (and other) drug therapy easier to manage. The cautious removal of barbiturates and benzodiazepines may improve problem behaviour. The end-point may not necessarily be a seizure-free state, but substantial improvement in seizure control, altertness and behaviour.

SURGICAL TREATMENT

There may be reluctance at some epilepsy surgery centres to assess people with learning disabilities and refractory epilepsy. This is due to the view that those most at risk of cognitive deterioration after surgery are over 55 years of age or with an IQ below 70[101]. Another viewpoint has been taken by Silfvenius[102] who has argued that learning disabilities (IQ < 70) in a child should not be considered a contradiction for paediatric epilepsy surgery as 'it may ameliorate socially disturbing seizures or distressing behaviour'. Potential surgical intervention should include corpus callosum section in patients with learning disabilities and generalized seizures or frequent daily drop attacks. Although not necessarily curative, surgery can result in a higher quality of life[20,102,103]. Kotagal and Rothner[20] believe that, until evidence to the contrary is available, patients with tuberous sclerosis should not be denied epilepsy surgery. In their experience, those with a stable seizure focus could benefit from resective surgery, even if tubers were present in other locations; this was confirmed by Bebin *et al.*[104]. Surgical approaches are also possible in the Sturge–Weber syndrome[20], the Lennox–Gastaut syndrome, and infantile spasms (West syndrome)[102]. With appropriate surgery, children with conditions such as hemimegaloencephaly and other diffuse corticodysplasias, Sturge–Weber syndrome, large porencephalic cysts, and Rasmussen's encephalitis, which are associated with inevitable developmental delay, have a 60–80% chance of leading a nearly normal life and avoiding institutional care[103]. It makes sense, therefore, to identify early those patients with learning disabilities and epilepsy who might benefit from resective surgery.

PROGNOSIS

The outlook for many people with learning disabilities and epilepsy is not as bad as has been believed previously, but it does vary according to underlying and concomitant conditions. After a 12-year follow-up period in one study, 39% of children with learning disabilities and/or abnormal neurology were seizure free, compared with 79% of those with epilepsy alone[41]. Alvarez[64] discontinued antiepileptic drug treatment in 50 patients with learning disabilities, who had been seizure free for at least 2 years. After 8 years, the recurrence rate was 52%. Predictors for seizure freedom without treatment were few documented seizures in a lifetime, no gross neurological abnormalities, drug concentrations below target levels at time of discontinuance, and persistently normal EEG s before and after discontinuation of therapy. This study should encourage others to modify their approach to care in seizure-free patient.

Concomitant conditions strongly influence the risk of seizure recurrence. Brodtkorb[47] found that people with learning disabilities who developed epilepsy in adult life usually were well controlled, particularly if there was no history of cerebral palsy. Conversely, poorly controlled epilepsy and cerebral palsy were associated with early-onset seizures. Another study examined the risk of seizure recurrence in children with cerebral palsy who had been seizure free for 2 years. Patients with spastic hemiparesis had the highest relapse rate (61.5%) and those with spastic diplegia the lowest (14.3%)[105].

CURRENT APPROACHES TO CARE

People with learning disabilities in the U.K. currently under-use health services[106] despite the common occurrence of conditions such as epilepsy, cerebral palsy, congenital heart disease, musculoskeletal problems and obesity in this population[107]. In addition, 50% of those affected have a single sensory loss and 18% have two[108]. Understandably, the Department of Health has called for improved access to health promotion, education and surveillance, and to primary and secondary care for people with learning disabilities[105]. Following the publication of the Command Document *Better Services for the Mentally Handicapped* in 1971[109] more learning disabled individuals have been integrated into or remained in community settings rather than being cared for in institutional environments. In the U.K. health provision for the majority of people with learning disabilities comes through community teams and primary care. In Wales for example, between 1987 and 1996, the number of people with learning disabilities resident in hospital fell by 58%. Community learning-disability nurses dealt with 55% more people in 1995–1996 than in 1991–1992[110].

Primary Care for People with a Mental Handicap offers recommendations on care to general practitioners, as they may have little knowledge of, or experience in, treating people with learning disabilities despite an increasing requirement to do so[4]. Concern has been raised about this[111] and postgraduate training has been suggested[5]. Particular management difficulties arise in individuals with dual disability[112], an example of this, of course, being epilepsy. Although some general practitioners and other health professionals are involved in health surveillance and promotion for the learning disabled, most oppose this kind of activity due to current lack of evidence of resulting benefit[113]. However such activities can provide the ideal opportunity to carry out an epilepsy review. This would overcome the criticism that only a minority of individuals with learning disabilities and epilepsy had any regular assessment of their anticonvulsant drugs.

The majority of people with epilepsy prefer to receive their care in general practice[114]. In 90% of cases in one study, there was no hospital specialist input[115]. In response to this, general practitioners are showing greater interest in epilepsy, its treatment and the implications of the diagnosis[114,116,121]. It is hoped that a 'knock-on' effect in the care of people with learning disabilities and epilepsy will follow as this population has been largely excluded from primary-care studies.

Unfortunately problems in epilepsy care at primary and secondary levels[122] continue to exist as do calls for comprehensive epilepsy services, with adequate specialist input[6,123]. Secondary-care provision including inpatient assessment and long-term care for patients with learning disabilities and epilepsy varies widely. Such individuals may be referred to centres of excellence or to centres with no expertise in the fields of learning disability and/or epilepsy. Knowledge of and experience with the mushrooming number of antiepileptic drugs now available are essential. 'Mixed' clinics and wards offering services to people with or without learning disabilities can pose problems. Busy clinics and a reliance on ambulances can result in long waiting times, which can be particularly distressing for patients with learning disabilities. Due to the stigmas attached to both learning disabilities and epilepsy, other patients may feel threatened by the presence of the learning disabled.

An increasing asset to all is the Registered Nurse in Mental Handicap (RNMH) as an epilepsy specialist nurse, both within hospital settings and in the community due to their dual qualification and training[124]. Such nurses liaise with individuals with learning disabilities and epilepsy, their carers, health professionals and other agencies. They provide information and education, and can offer training in the use of rectal diazepam. In general, nurse specialists are regarded as an effective means of tackling shortcomings in epilepsy management[122,125,126]. Indeed, they have 'outscored' general practitioners and hospital specialists across all aspects of treatment and care[127]. Sadly, there is a great lack of community learning disability nurses who can also be regarded as epilepsy specialists.

Psychologists are increasingly becoming involved clinically and on a research basis with patients with learning disabilities and epilepsy[128]. They are particularly well qualified to distinguish between behavioural activity and seizures, especially with the advent of video telemetry[54]. In addition they are at the forefront in developing measures to assess the impact of epilepsy and its treatment on individuals with learning disabilities and their carers[128]. Currently available measures relate to seizures, drugs, cognitive function, behaviour, social functioning, attitudes, motivation and 'quality of life'.

FUTURE APPROACHES TO CARE

Care provision for people with learning disabilities and epilepsy should be based on the general model described in the document *Specification for Epilepsy Services*[2]. The aims for patients with learning disabilities are the same as those for people with epilepsy alone, i.e. achieving maximum health gain, reducing morbidity and preventing avoidable mortality. Morbidity can be decreased by controlling seizures, by re-

ducing seizure-related injury, and by providing effective support. Due to the variety of concomitant conditions and specific problems presenting in an individual with learning disabilities, adaptations to traditional approaches to care may be necessary with close collaboration among different health disciplines[129].

A specialist opinion should be sought for any learning disabled person with suspected or proven epilepsy. Particular attention should be paid to those with uncontrollable epilepsy, those who have been seizure free for at least 2 years and who may benefit from a reduction or withdrawal of antiepileptic medication, and those in whom there is concern about drug toxicity or unnecessary polypharmacy. Prior to an initial hospital appointment, much information can be gleaned from a home assessment carried out by a learning disability epilepsy specialist nurse following an agreed protocol. This protocol should cover not only the description of events or behavioural patterns suspected to be seizures, but an indication of the individual's IQ, concomitant condition, all medication, difficulties in administration and side-effects of drugs, antiepileptic drug assay, information about support networks, and the individual's and carer's particular concerns. A vital area is establishing the existence of sensory loss and the best method of communication. The learning disability nurse, if suitably trained, can show carers how best to record behavioural patterns thought to be seizures, and begin the initial information provision and educational process. General support of family members is important due to the impact of chronic epilepsy on levels of stress, feelings of dissatisfaction with social situations, perceived low levels of support, poor emotional adjustment and depression[130].

Prior to the first hospital appointment, all the information obtained should be discussed with the hospital specialist and, if appropriate, electroencephalography, video recordings and brain imaging arranged. The aim is to obtain the maximum amount of information in the simplest and most efficient way with the least possible disruption and inconvenience to the patient and carers. This will allow the hospital specialist to make appropriate management decisions when the patient first attends the clinic, and may even negate the need for subsequent clinic attendances.

At the outset, following a review of the diagnosis and drug therapy, it is important to formulate a management plan and set realistic objectives. Numbers and doses of antiepileptic drugs should be rationalized. The projected outcome should be planned involving assessment of seizure severity and numbers and, in addition, the likely effects of the seizures and their treatment on behaviour and mood. Particular emphasis should be placed on sleep pattern, appetite, communication, cooperation, and alertness. Specific questions on positive or negative changes in the patient's quality of life will often yield important information. In keeping with 'An epilepsy needs document'[3], the majority of secondary care referrals should be discharged back to the general practitioners within 12 months.

General practitioners are known to value the input of community teams in the care of their patients with learning disabilities[113]. Together they can develop epilepsy review procedures that would reduce the need for hospital attendance, be more convenient to patients and result in more effective use of health-service resources[131]. Evaluation of such procedures[2] would address potential concerns about their value in terms of benefit to the individual or in terms of cost[113]. General practitioners would be more likely to participate in the development and running of epilepsy treatment programmes if new or reallocated resources were made available to fund them[121,126]. It is not clear why epilepsy care is not targeted in the same way as diabetes within primary care with general practitioners receiving specific incentives to participate. Chronic disease clinics are generally run by the practice nurse, who could undergo specific training led by the learning disability specialist nurse. Particular clinical problems would then be passed onto the general practitioner and/or the community learning disability epilepsy specialist nurse.

Education and training for all staff involved in caring for people with learning disabilities and epilepsy is essential with encouragement to 'network' with others working in the same areas. Those in contact with people with learning disabilities and epilepsy should be fully aware of the facilities and specialists available within their own locality. Cooperation among such groups optimizes the chance of effective care provision, adequate staff training and improving local facilities to meet the many needs of the learning disabled population.

CONCLUSION

The time is right to look afresh at the management of people with learning disabilities and epilepsy. The cohesive link between the affected individual and everyone providing care is the community learning disability epilepsy nurse. Such specialist nurses can liaise with a wide range of individuals, and their education and training puts them in a good position to coordinate care in this clinical setting. The use of standardized assessment and investigation techniques will improve the accuracy of diagnosis. A greater awareness of the benefits of restricting polypharmacy has led to a more positive approach toward reducing treatment. This in turn has resulted in less drug

toxicity. There is now a wider choice of antiepileptic drugs, with easier dosage regimens and fewer side-effects. Surgery is an increasingly useful option for people with learning disabilities. Outcome measures currently available and in development will allow a clearer understanding of the effects of epilepsy and its treatment on patients and their carers. Increasing interest in this field is bubbling up world-wide, but there is a great need for better communication and cooperation to avoid the repetition of mistakes and to allow the wider adoption of successful methods of assessment and pharmacological strategies.

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