THE CLINICAL PSYCHOLOGIST'S HANDBOOK OF Epilepsy

Assessment and Management

Edited by
Christine Cull and
Laura H. Goldstein

ROUTLEDGE

The Clinical Psychologist's Handbook of Epilepsy

It is becoming increasingly recognised that epilepsy is no longer the sole domain of the medical profession. In particular, over recent years the contribution made by psychologists to the understanding and treatment of this disorder has developed enormously. *The Clinical Psychologist's Handbook of Epilepsy* addresses those psychological aspects of epilepsy that are important for both assessment and management.

Following a brief introduction to epilepsy, its causes, classification and investigation, the topics addressed in detail by the book include: neuropsychological assessment; memory deficits in epilepsy, their assessment and rehabilitation; the impact of anti-epileptic medication on cognition and behaviour; psychological disturbance associated with epilepsy; behaviour problems in children with epilepsy and the impact of epilepsy in people with learning disabilities.

The book contains contributions from experts in the field and provides a review of the latest research findings. It will be a valuable handbook and a practical guide for all clinical psychologists, and other clinicians, working in, or new to, the field of epilepsy.

Christine Cull is a Clinical Psychologist with the Learning Disabilities Service, Mid Anglia Community Health NHS Trust.
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and Laura H.Goldstein

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Preface

Epilepsy is a relatively common neurological disorder, which traditionally has been the domain of the medical profession (general practitioners, neurologists, neurosurgeons and psychiatrists). However, it is becoming increasingly clear that other professional groups have a valuable role to play in the assessment and treatment of epilepsy and its psychosocial sequelae. In this particular text we are concerned with one of those professions, namely, clinical psychology.

Clinical psychologists have been working in this field for many years, and from the work carried out to date, it is clear that, as a profession, we can make a major contribution to the understanding of epilepsy, its assessment and treatment. Our aim, therefore, in editing this volume is to bring together current expertise and knowledge in order to provide a readily accessible source of information for psychologists coming to the field for the first time, for those with some experience, and for other interested professionals.

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Introduction

Clinical psychologists work in a variety of settings where they may encounter individuals with epilepsy (e.g. child guidance clinics, child development clinics, general practice, services for older people and learning disabilities) as well as in child or adult neurology and neurosurgery services. Traditionally, in a clinical setting, psychologists have been asked to carry out assessments of neuropsychological functioning and to repeat assessments over time to evaluate cognitive decline. However, clinical psychologists are increasingly being asked to become involved in the treatment of individuals with epilepsy, in particular those who are thought to display seizures for which there are identifiable psychological factors. They are also becoming involved in the treatment of people with non-epileptic seizures. In addition, in the last twenty years, psychologists have been undertaking epilepsy-related research from an increasingly wide range of perspectives. These have involved the assessment of anti-epileptic drug effects on behaviour and cognition, investigations into the psychosocial sequelae of epilepsy, examinations of the relationship between environment and seizure occurrence, non-medical (i.e. psychological) approaches to seizure management, the assessment of cognitive and psychosocial functioning pre- and post-surgery for epilepsy, and the factors that affect the quality of life of those with epilepsy.

Our aim here is to present a collation of this work, reviewing the available literature to date and highlighting its broad-ranging implications. In this way it is hoped that this text will be of value to researchers and practising clinicians alike.

We start off with those areas which have traditionally been the domain of the clinical psychologist, and about which relatively more is known, notably neuropsychological assessment (Chapter 2); epilepsy and memory (Chapter 3) and assessment related to surgery (Chapter 4).

Chapter 4 considers not only what is known about pre- and post-operative cognitive/neuropsychological procedures, but also what is known about changes in psychosocial functioning and assessment of this. In any assessment, part of the clinician's skill is to evaluate the reliability of their findings, and the extent to which factors other than the critical variable of interest may have a contributing role to play. In this respect, in Chapter 5 we consider one of those factors, the impact of anti-epileptic drugs on cognitive functioning and behaviour. This is also of importance, as claims that AEDs do not have adverse effects on behaviour and cognition are an important marketing strategy for drug developers.

Chapter 6 addresses the relationship between epilepsy and psychological disorders in adults, reviewing the literature and exploring the psychologist's contribution to the assessment/treatment of such disorders.

It is becoming increasingly clear in the literature that seizure occurrences, be they spontaneous epileptic seizures or pseudoseizures (non-epileptic seizures) may be affected by factors in both the person's external and internal environments, and that psychological approaches can be used beneficially in both the assessment and management of such seizures, as can be seen in Chapter 7.

A diagnosis of epilepsy can have a major impact on the individuals themselves—their self-image, their expectations for the future, not to mention their family and friends and, in the broadest sense, on their quality of life. It is only in recent years that this issue has been addressed in relation to epilepsy, and this is the topic of Chapter 8.

Thus far we have concerned ourselves mainly with epilepsy as it affects adults. The next two chapters deal with children. The first is on neuropsychology and cognitive assessment (Chapter 9), as the assessment of children presents a different set of challenges and the need to use different measures to that of adult neuropsychology. Behaviour problems are commonly associated with a diagnosis of epilepsy in childhood, and can be of such severity that residential schooling may seem the only solution to an apparently insurmountable problem. Chapter 10 deals with this issue, focusing on assessment and management, having considered the prevalence and aetiology of such problems.

Epilepsy occurs more commonly in people with learning disabilities than in the normal population, and most frequently in those with severe/profound learning disabilities. Surprisingly, this group has been the focus of very little research interest. In an attempt to redress the balance, research is reviewed in Chapter 11 with respect to the psychological implications of epilepsy for people with learning disabilities, and its contribution to

our understanding of epilepsy in people with learning disabilities is highlighted. The practical implications for psychologists working with individuals with both learning disabilities and epilepsy are explored. In Chapter 12 we summarise issues raised in the book and consider future developments. Finally, as several chapters discuss the use of neuropsychological tests, we provide the reader with an Appendix containing names and sources of materials referred to, especially those in Chapters 2, 3, 4 and 9. However, before all of this, we felt that it would be of value to present in Chapter 1 a brief overview of the disorder of epilepsy itself.

We have endeavoured throughout the text to use terminology that is not pejorative or demeaning. For example, we refer to 'people with epilepsy' rather than 'epileptics', since, while the term may be an appropriate description of seizures, it only serves to perpetuate inappropriate stereotypes when applied to people.

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Chapter 1

An introduction to epilepsy

Christine Cull and Laura H.Goldstein

WHAT IS EPILEPSY?

Epilepsy is . . .

> a chronic disorder characterised by recurrent seizures
> (Gastaut 1973)

and a seizure is . . .

> an occasional, an excessive and a disorderly discharge of nerve tissue
> (Hughlings Jackson in Taylor 1958)

that is, an episode of altered behaviour and/or consciousness, which can take many forms, but which results from an abnormal electrical paroxysmal discharge in cerebral neurones. Types of epileptic seizures will be described later in this chapter but, a clinical diagnosis of epilepsy is made if two epileptic seizures occur within a two-year period.

EPIDEMIOLOGY

Epilepsy is a common neurological disorder, occurring in 5:1000 children (Cowan *et al.* 1989) and in 4–7:1000 adults (Hauser and Annegers 1993), such that in the UK it has been estimated that there are approximately 350,000 people with a diagnosis of epilepsy (Brown and Betts 1994). The prevalence of epilepsy is reported to be ten times that of multiple sclerosis and a hundred times that of motor neurone disease (Brown *et al.* 1993).

New cases reported each year are in the region of 20–70 per 100,000 (Hauser and Annegers 1993), the highest rates occurring in infants and

young children and in the elderly (Brown *et al.* 1993). The incidence is consistently found to be higher in males than females, although in most studies the difference fails to reach statistical significance (Hauser and Annegers 1993).

CAUSES OF EPILEPSY

Everybody has the potential to have an epileptic seizure. When considering the aetiology of seizures, Lishman (1987) emphasises however that epilepsy must be thought of as a symptom rather than a disease. He also indicates that for many people the cause of the disorder may never be identified. The proportion of cases of unknown aetiology may account for as many as two-thirds of cases (see Lishman 1987). He indicates that the majority of such seizures are generalised (either absence or tonic-clonic) in nature, and that in most cases the presence of a focal component to the seizures will indicate the existence of a discrete structural brain lesion. In addition, an hereditary component is found more commonly for seizures of unknown origin than for seizures that occur in the presence of readily identifiable brain lesions.

Where causes can be identified, they may be varied in nature. Lishman (1987) reviews these causes, and categorises them as seizures due to birth injury or congenital malformations, due to brain damage, infections, cerebrovascular disease, tumours, neurodegenerative disorders, drugs or toxins, or metabolic disorders. Chadwick (1994) distinguishes between acute symptomatic seizures that are the result of some metabolic disorder or cerebral insult, and remote symptomatic seizures that reflect some form of persisting brain damage. Hopkins (1987), on the other hand, considered two main classes of aetiology—predisposing and precipitating factors—and this subdivision will be used here.

Predisposing factors

When considering predisposing factors, it is important to remember that these may not be independent of each other. Thus, a genetic predisposition towards epilepsy may involve either the inheritance of a convulsive threshold, or of a condition associated with epilepsy (see Anderson and Hauser 1993). Lishman (1987) indicates that family loadings seem to be more marked with certain types of seizures, but he cautions that the potential to have an epileptic seizure is present throughout the population, given the right precipitating circumstances.

Developmental brain abnormalities that predispose to seizures may or may not be inherited. Porencephaly, microgyria (and other abnormalities of the cortex), tuberous sclerosis and arteriovenous malformations are other congenital malformations that may be associated with the development of epilepsy. In addition, the person may have acquired structural brain abnormalities that then predispose to epilepsy. With respect to epilepsy arising from birth injury, Lishman (1987) indicates that pregnancy and delivery complications may produce brain damage and lead to epilepsy. Particularly relevant here is damage that produces anoxia or cerebral haemorrhage. Illnesses early in infancy (e.g. cardiorespiratory disorders, infections or metabolic disorders) may also produce seizures. The occurrence of febrile convulsions, possibly with status epilepticus, may give rise to anoxic damage and the formation of scar tissue. This so-called 'mesial temporal sclerosis', which consists of gliosis of mesial temporal lobe structures, is commonly found in patients with temporal lobe epilepsy. Whilst this was initially thought to occur unilaterally in most cases, data revealing the more frequent bilateral presence of abnormality is now appearing (Incisa della Rochetta *et al.* 1995).

In terms of post-traumatic epilepsy, head injury carries a high risk for the subsequent development of seizures. In cases of closed head injury, the underlying neuropathology may include the formation of scar tissue (gliosis) with focal cerebral atrophy. The incidence of epilepsy will be about 5 per cent once the immediately post-traumatic seizures have been excluded (Jennett 1975). Post-traumatic seizures may not appear for several years after injury even though more than half of those going on to develop epilepsy after head injury will do so in the first year post-injury. Where there has been an open head injury, with skull penetration or fracture, there is a much higher incidence of post-traumatic epilepsy (e.g. Russell and Whitty 1952). Post-traumatic seizures may prove difficult to treat, and have important implications for rehabilitation following head injury. Their development must be considered when estimating compensation following head injury.

Certain infections of the central nervous system are likely to be associated with the development of epilepsy. Thus encephalitis or cerebral abscesses are more likely to lead to the development of epilepsy than is meningitis (Lishman 1987). In certain parts of the world, parasitic cysts play an important role. Epilepsy may also develop as a consequence of subtle brain involvement during childhood mumps or whooping cough, although this may be hard to determine in individual cases. In older patients, neurosyphilis should be ruled out as a cause of seizures.

Again, in older patients, cerebral arteriosclerosis and episodes of hypertensive encephalopathy may be important aetiological factors. Lishman (1987) indicates that a cerebral embolus is more likely to lead to epilepsy than are either a thrombosis or a cerebral haemorrhage; however, any cerebral infarct may provide a focus for the subsequent development of seizures. With ageing, the increased incidence of dementia may also be accompanied by the development of epilepsy, and seizures may occur in 25–33 per cent of cases of Alzheimer's disease and in Huntington's and Creutzfeldt-Jakob disease (see Shorvon 1988). Demyelinating neurodegenerative disorders such as multiple sclerosis may accompany seizure onset in adults, whereas in children degenerative disorders such as tuberous sclerosis may be causative. The development of seizures in a previously healthy adult may reveal the existence of a brain tumour. Sumner (1969) indicated that in 20 per cent of cases of cerebral tumour, the first symptom may be the onset of seizures.

Precipitating factors

A number of factors can be shown to precipitate seizures. Many of these are due to toxic conditions or metabolic disturbances, with an interaction between these. Thus, in addition to alcohol and rapid withdrawal from other drugs, Lishman (1987) notes the wide range of substances that may be associated with seizures. These include barbiturates, amphetamines, ergot alkaloids and steroids, as well as exposure to lead and the chlorinated hydrocarbons found in some pesticides. In addition, certain antipsychotic and antidepressant agents may lower seizure thresholds, thus making them more likely to occur.

A wide range of metabolic causes have been found for seizures. These may include porphyria, and occasionally hypoglycaemia, as well as uraemia, hypernatremia and hypercalcaemia. Electrolyte disturbances, such as those occurring in eclampsia may also be associated with seizure occurrence.

Certain external stimuli may precipitate seizures. Thus, there are accounts of reading, music, flashing lights, TV screens, loud sounds and other such events precipitating seizures (see Chapter 7 for further discussion of so-called reflex epilepsies).

Changes in the sleep–wake cycle have also been shown to precipitate seizures, as has sleep deprivation, and some seizures occur on waking. For seizures which occur in sleep and arise from the frontal lobes, the precipitating factor is the transition between different stages of sleep.

Rapid alterations in arousal level in the waking state may also be associated with seizure occurrence (see Chapter 7).

In some women with epilepsy, seizure occurrence is related to the menstrual cycle. So-called catamenial epilepsy, where there is an increase in seizure frequency pre- or perimenstrually in the majority of menstrual cycles, has been shown to occur in anything from 9–72 per cent of women with drug resistant epilepsy (Crawford 1991).

Other precipitating factors may take the form of illnesses and intercurrent infections. The possibility that psychological factors may influence seizure occurrence will be considered in Chapter 7.

Overall in terms of the epidemiology related to aetiology, Sander *et al.* (1990) found that in newly diagnosed patients with seizures, tumours were a rare cause of seizures in people younger than 30 years of age, accounting for only 1 per cent of the sample studied; however in adults between the ages of 50 to 59 years, 19 per cent of cases were attributed to the presence of a tumour. Vascular disease accounted for 49 per cent of cases of epilepsy in elderly individuals. In general, cerebral infection was the cause in 2 per cent of cases and traumatic brain injury was found in 3 per cent of the sample. Alcohol was the most likely single cause of what Chadwick (1994) termed acute symptomatic seizures, accounting for 6 per cent of these, with the highest incidence occurring in adults aged between 30 and 39 years old.

PROGNOSIS

Chadwick (1994) reviewed a number of studies that have considered prognostic indices for seizure remission. Prognostic factors may include age at onset of epilepsy, duration of epilepsy before the onset of treatment, seizure type and aetiology and although Chadwick indicated that none of the studies to date permit adequate quantification of the relative weights that each of these factors may play in overall prognosis, age at onset of seizures seems to be the most important factor, with seizures beginning in the first year of life carrying a poor prognosis. In addition, the absence of early brain damage and the absence of evidence of generalised seizure activity are positive indications of good outcome. The interested reader is referred to his useful paper for more details.

It is important to note that a diagnosis of epilepsy carries with it increased risk of mortality, perhaps some two or three times higher than expected for the general population (Chadwick 1994). The risk is highest in the first year of life, and in individuals with tonic-clonic and frequently occurring seizures. Sudden unexpected death in people with epilepsy is