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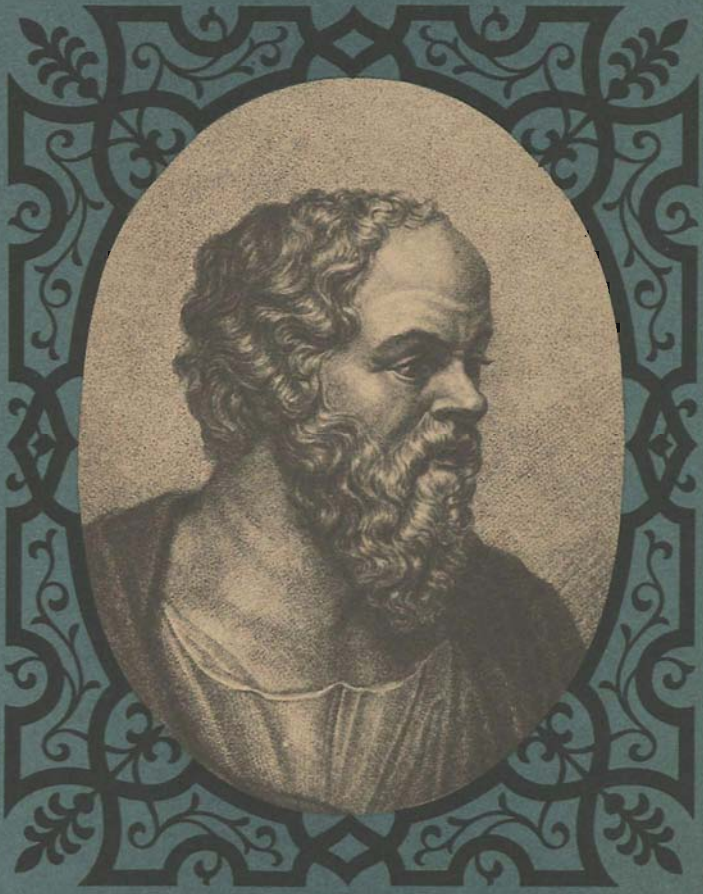
EPILEPSY IN SOCIETY



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EPILEPSY IN SOCIETY

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Office of Health Economics

The Office of Health Economics was founded in 1962 by the Association of the British Pharmaceutical Industry. Its terms of reference are:

To undertake research on the economic aspects of medical care.
To investigate other health and social problems.
To collect data from other countries.
To publish results, data and conclusions relevant to the above.

The Office of Health Economics welcomes financial support and discussions on research problems with any persons or bodies interested in its work.

Introduction

As early as 2080 BC reference can be found to epilepsy in the code of Hammurabi, King of Babylon. Special laws affecting the marriage of people with epilepsy and the validity of their testimony at court probably reflected unfounded fears and prejudices that have by no means been dispelled by twentieth century enlightenment.[1] The dramatic and sometimes bizarre manifestations of epilepsy have given it a special place in medical history. From antiquity to the relatively recent past, diseases were seen as phenomena more or less dependent on the supernatural, as divine retribution for wickedness or as products of possession by spirits. Epilepsy more than any other condition was susceptible to explanation in these terms. For this reason the history of epilepsy provides a paradigm for the history of medicine as a whole. Tempkin (1945) wrote, 'In the struggle between the magic and the scientific conception, the latter has gradually emerged victorious in the western world. But the fight has been long and eventful, and in it epilepsy held one of the key positions'.

The different approaches of the scientific and the non-scientific schools of thought were first made explicit in the discourse 'On the Sacred Disease' around 400 BC. In this, Hippocrates attacked the supernatural explanation of epilepsy as a cover for malpractices among pseudo physicians. He correctly attributed epilepsy to abnormal cerebral function but the value of the advance was somewhat limited by its association with an equally unverifiable theory of causation, that the cerebral abnormality was due to an excess of phlegm, one of the four humours. Galen, whose synthesis of Greek and Roman theories of medicine lasted into the seventeenth century, confirmed the view that attacks of epilepsy began in the brain, but so long as limited attempts at rationality could offer no practical advantages to patients the magical explanations and treatments of epilepsy remained in vogue. By Galen's time the supposed link between epilepsy and lunacy had become a part of the mythology surrounding epilepsy. A later elaboration of this notion, that epilepsy could be caused by the influence of the moon was not discredited till the end of the seventeenth century. Although the eccentricities of treatment at the time of Hippocrates, including the use of hippopotamus

1 A few American states still have laws prohibiting the marriage of all epileptics despite evidence that the likelihood of transmission of epilepsy from parent to offspring is normally small and varies widely according to the type of epilepsy.

testicles and tortoise blood, were no longer acceptable in the seventeenth century, demonical possession was accepted as fact and equally ineffective treatments such as enemas, purges and fomentations were commonly prescribed.

The enlightenment of the eighteenth century brought an end to the notion of demonical possession in the western world.[2] Advances in neurology during the eighteenth and particularly the nineteenth centuries improved knowledge and perception of the condition. Perhaps the most important contributor was Dr. Hughlings Jackson during the latter part of the nineteenth century. He gave his name to a particular type of focal, motor epilepsy, now known as Jacksonian epilepsy, which he observed in his wife. More important, he developed the concept of epilepsy as a sudden discharge of cerebral neurones, a concept later supported by electroencephalographic studies. However, the enlightenment of the eighteenth and nineteenth centuries did not bring an end to myths which were believed to have been empirically established as facts. Thus, in keeping with the morality of the time, sexual excess and masturbation were regarded as the commonest cause of fits, a view which reached its apogee in the latter part of the nineteenth century when castration was reported as a therapeutic procedure for men with epilepsy.

These misconceptions led by chance to the first real therapeutic breakthrough. Potassium bromide was known to cause temporary impotence in men, and for this reason it was tried as a treatment for epilepsy in the 1850's. It turned out to be the first effective anticonvulsant drug though its importance was only gradually realised. The most important advance in medical treatment of epilepsy came in 1912 when Dr. Alfred Hauptman in Germany published a paper on the use of phenobarbitone in epilepsy. This was the first anticonvulsant drug which was both effective and relatively safe and had few side effects. The next major advance in anticonvulsant therapy came with the development of the hydantoinates in America just before the second war. Then in 1945 the first of the succinimides brought a major advance in the treatment of petit mal epilepsy. Since then there have been no further fundamental pharmacological advances but the range of drugs of value in epilepsy has expanded considerably by providing second line drugs in cases where the first choice is ineffective or has unacceptable side effects. Some drugs like the tranquiliser diazepam have been found to be of great value in status epilepticus when given intravenously. The result has been a steady, if not dramatic, increase in the proportion of epileptics deriving benefit from medical treatment. Drug treatment has been the most valuable contribution of medical science to the welfare of the epileptic

2 The notion of demonical possession is still prevalent in parts of Africa. So too is the notion that epilepsy is contagious.

population and the majority of Britain's 300,000 people with epilepsy can live potentially normal lives, free or virtually free from fits. Approximately three-quarters of people who are susceptible to epileptic attacks can now have three-quarters or more of their fits prevented if the treatment regime is properly maintained. However, there is still a lot of scope for developments in treatment among the minority of the epileptic population who do not respond to any of the existing drugs or who do not tolerate them well.

During the nineteen thirties the development of the electro-encephalograph led to great strides forward in the understanding of epilepsy and the diagnosis of its particular forms. As a tool it has been as basic to epilepsy as X-ray equipment has been to chest disease and the electrocardiogram has been to heart disease. The EEG is invaluable in the differential diagnosis of epilepsy and in locating the site of lesion in the brain, if it is focal. Together with the use of the EEG, surgical techniques have been developed which offer the possibility of successful treatment in some of the cases which do not respond to drug therapy.

Types and causes of epilepsy

Epilepsy is no longer considered as a disease in itself, but as a term used to describe a set of symptoms with a wide range of underlying causes.[3] The common factor is sudden abnormal electrical discharge in the brain, though the neurochemistry of the condition is not yet understood. It is possible to precipitate a fit in any person by electrical stimulation.[4] A comprehensive clinical classification of epileptic phenomena therefore presents major problems.

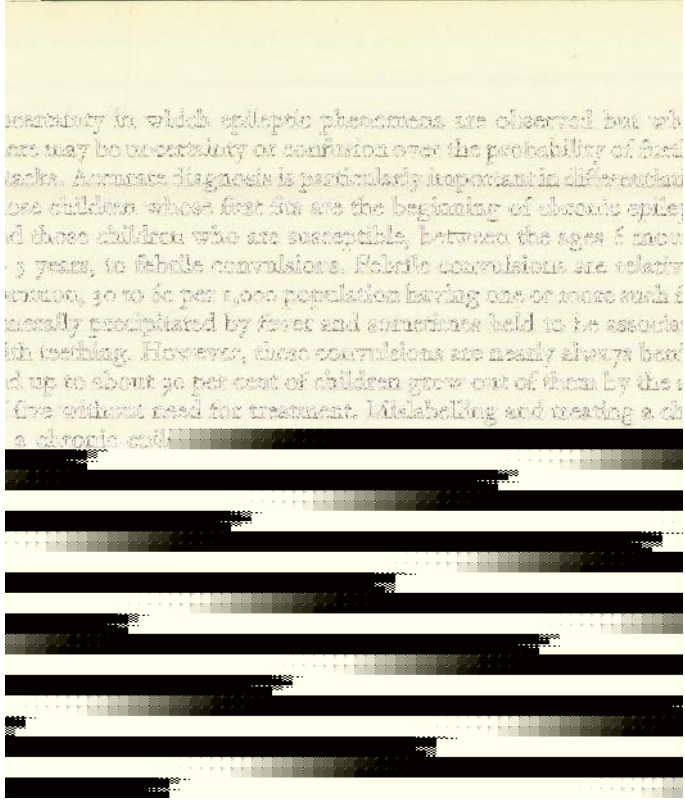
Two main groups can be distinguished, focal and generalised. In focal epilepsy the abnormal electrical discharge begins at one area, or possibly a number of areas, in the brain. It may spread slowly without loss of consciousness and without causing a convulsion and it can be associated with any combination of sensory, motor, or psychic experience depending on which parts of the brain are affected. The most common form is temporal lobe epilepsy where the site of the focus is in the temporal lobe of the brain and it is in these cases that bizarre psychic phenomena are often associated with fits. Focal epilepsy can also spread to affect the whole brain and cause the unconsciousness and convulsions of a grand mal fit.

On the other hand, generalised epilepsy, although it can result from a lesion at one site of the brain, is characterised by electrical discharges throughout the cerebral cortex of both cerebral hemispheres and a sudden disturbance of consciousness. There are two manifestations, grand mal and petit mal. In grand mal, which is the commonest type of fit among adolescents and adults, the fit is convulsive and is associated with complete loss of consciousness. Very rarely, status epilepticus may ensue, a dangerous phenomenon where one convulsion may follow another without consciousness being regained. In petit mal which is commonest among children there is only a brief interruption of consciousness without convulsion and the only discernible signs may be a pause and a fluttering of eyelids. Such attacks may take place many times a day without being noticed by bystanders.

The occurrence of a convulsion does not necessarily mean the person is likely to have recurring attacks. There is an area of

3 Epilepsy: derived from the Greek word meaning 'to take hold of'.

4 This is the basis of electro-convulsive therapy sometimes used in the treatment of depressive illness.



Out of 39 applicants for jobs at the steelworks, 33 were employed and satisfactorily settled but over half of them had to change their jobs within the steelworks for safety reasons or in order to prevent possible disruption of production. These were therefore classified as having employment difficulties. Similarly in Aston's (1964) motor works study, one-third of 51 epileptic employees were recommended at some time by the works' doctor to change their jobs within the factory, mostly on the grounds of safety, while another third of the 51 had job changes within the factory at the request of the management or of the individuals themselves. Safety was not the sole reason for the changes. The possible effects of grand mal attacks on productivity were highlighted by Aston who pointed out that a major attack of epilepsy in a crowded work environment can cause 'considerable disturbance and interference with production, the effects of which can be felt for far longer than the attack'. Fear, suspicion and ignorance on the part of the employee's work mates may not only reinforce similar feelings among management but also provide a pressing economic reason why epileptics subject to fits should be employed separately from these persons. This has the effect, as Jones pointed out, of placing them in jobs which are menial, uninteresting and poorly paid. Among non-staff employees at the motor works, only 9 per cent of epileptics were employed in skilled work as compared with 21 per cent of non-epileptic employees.

If the two studies noted above are typical then most of the 140,000 epileptics on the employment market have job problems. The most seriously affected will be the 21,000 on the Disabled Persons Register, a voluntary register set up for the purpose of giving employment help to persons who are 'substantially handicapped in getting or keeping work on their own account'. 3,500 or 16 per cent of these were unemployed in April 1970, compared with 11 per cent unemployed among all disabled classes and under 3 per cent for the working population as a whole. For the most severely disabled epileptics, whose fits are frequent and very difficult to control, and who have particularly severe behavioural and intelligence problems, there is the possibility of sheltered employment. However, there are only about 800 people whose primary disability is epilepsy working in sheltered employment, mostly in the government supported Remploy factories and a few in local authority schemes. The vast majority of epileptic employees and prospective employees must depend on the open labour market.

There are some opportunities for epileptics and other disabled persons to be retrained for future employment but here again this only applies to a small minority. The 45 government training centres cater mainly for people whose skills have become redundant with the decline of various industries, but they can be used where appropriate

for people with epilepsy and other disabilities. Most particularly for the long-term sick and disabled there are the Industrial Rehabilitation Units but they only deal with a small number of epileptics. About 600 trainees with epilepsy enter IRU's every year. There are also residential training centres for the disabled, run by voluntary organisations and supported by the Department of Employment. These offer training for office jobs as well as for manual trades and could thus be very useful to the poorly controlled epileptic. However, only four of these residential training centres are in existence in the United Kingdom at present.

The cost of epilepsy

The costs of illness are commonly divided into three categories. First there is the direct cost to the health services of prevention, diagnosis and treatment. This represents a measurable consumption of resources which could have been put to other uses and which can be valued in monetary terms even though the NHS and social service accounting systems were not designed with this purpose in mind. Second, there are the more indirect costs of illness associated with lost productivity through absence from work. These tend to be diffuse and difficult to measure in their real impact though conceptually the magnitude of the loss to society as a whole should be capable of expression in monetary terms. Third, there are the costs of personal hardship and disability to the sick person himself. These costs are quite specific although no monetary value can be validly placed on them and therefore they cannot be quantified in the same terms as the other costs.

In a comprehensive analysis of the costs of diseases to the NHS (OHE 1969), using various official and unofficial records of resource usage by disease category, diseases of the nervous system were found to absorb 2.6 per cent of expenditure which could be allocated. Table 5 gives estimates of the cost of epilepsy, a subset of diseases of the nervous system, in those sectors of the NHS where available data allowed more refined calculation. Epilepsy is found in 1969 to account for £9.2 million or 0.7 per cent of the overall cost of those sectors.

The hospital sector absorbed the major share of the costs with £7.6 million spent on in-patients with epilepsy in 1969. In addition an unknown amount was spent through out-patient departments which play a large part in the diagnosis and treatment of epilepsy. Half of the hospital in-patient cost was attributable to cases treated in non-psychiatric hospitals, which rose from 10,800 in 1955 to

Table 5 *The cost of epilepsy to the National Health Service, U.K. 1969*

Health service sector	*Cost attributed to epilepsy £ million*	*Total cost of the sector £ million*	*Per cent attributed to epilepsy*
Hospital service in-patient costs (current)	7.6	842	0.9
General Practice	0.7	147	0.5
Pharmaceutical Service	0.9	189	0.5
Dental & Ophthalmic Services	0	115	0
Sub-total	9.2	1,293	0.7
Other services, including local authority health services. Hospital out-patient costs.			
Hospital capital expenditure. Miscellaneous (no basis for allocation of costs to epilepsy).	Not available	587	Not available

Source See Appendix

16,340 in 1967 in England and Wales. The average length of stay for epilepsy has not shown the steady rate of decline experienced in in-patient treatment as a whole. It remains around 25 days which now represents a cost of about £200 per case.

The other half of the expenditure on in-patient treatment covers cases admitted to psychiatric hospitals, primarily mental illness hospitals, with a primary diagnosis of epilepsy. In England and Wales in 1963, the latest year for which detailed figures are available, there were 3,900 persons in mental illness hospitals and units with a primary diagnosis of epilepsy or epileptic psychosis and 1,800 with this as a secondary diagnosis. Only 180 persons in mental subnormality hospitals had epilepsy or epileptic psychosis as the primary diagnosis, but 5,200, or nearly 10 per cent of the total population of mental subnormality hospitals had one of these as a secondary diagnosis.

In general practice in 1969, 0.5 per cent of consultations by patients were specifically for epilepsy (Medical Data Index 1969) and this proportion was used as the basis for estimating the cost of epilepsy to general practice at £0.7 million. The proportion of consultations for epilepsy has changed little in recent years. Similarly, there has been little change in recent years in the proportion of drug costs attributable to epilepsy. In 1969, the figure of £0.9 million represented 0.5 per cent of the total cost of the Pharmaceutical Service in the United Kingdom.

In addition to the £9.2 million of resources absorbed by diagnosis

and treatment in various parts of the NHS in 1969, there is also the cost of welfare services provided by local authorities. Most of the cost directly attributable to epilepsy in this sector is for long stay accommodation in homes for the aged and infirm and in epileptic colonies. There are 10 long stay institutions specially for people with epilepsy, seven of which are termed 'colonies'. They accommodate about 2,100 persons, 87 per cent of whom are under the age of 65, as compared with 11 per cent of all residents in all local authority accommodation. These people tend to suffer from multiple handicaps and to be in colonies for social rather than medical reasons (Jones and Tillotson 1965). More by accident than design the financial responsibility for the colonies was placed in the hands of the local authorities under the National Assistance Act of 1948, instead of the hospital service under the NHS Act. In addition to the persons accommodated in colonies there are about 1,000 accommodated in other voluntary and local authority homes, making a total of 3,100 persons with epilepsy altogether in 'Part III' accommodation financed by local authorities. With the comparatively low cost of Part III accommodation, this adds about another £1.6 million to the cost of epilepsy to the health and welfare services in 1969. There are also other welfare services provided for the disabled by the local authorities but the resources absorbed by people with epilepsy cannot be identified separately.

Thus the direct, quantifiable costs of epilepsy to the health and welfare services amounted to a minimum of £10.8 million in 1969, not counting hospital out-patient costs and the costs of some local authority health and welfare services. The estimate of costs would also be higher if the wider effects and consequences of epilepsy were taken into account, for instance, the mental disorders which are more prevalent among the epileptic population will generate further demand for medical care and welfare services which are not recorded as being originally attributable to epilepsy or the lesions which give rise to epilepsy.

But further analysis is necessary to present a comprehensive picture of the magnitude of all the direct and indirect costs, economic and personal, associated with epilepsy.

Consideration of the indirect cost of lost productivity leads into a general discussion of the nature of the losses involved and the problems associated with their measurement. A first indicator of the cost of epilepsy in terms of lost productivity can be derived from certified sickness absence statistics. In Great Britain in 1967/8 1.7 million man days and 1.0 million women days were recorded as having been lost to industry and services through employees staying off work due to epilepsy. This understates the total in at least two ways. First, because it ignores short-term uncertified absence and the absence

of such groups as the majority of married women, who are not covered by the national insurance scheme. Second, because it ignores absence originally generated by epilepsy but not recorded as such on medical certificates, for instance, some absence attributed to mental illness. Bearing these reservations in mind, the 2.7 million lost days attributed to epilepsy represented nearly one per cent of all recorded days of absence.

The problem is to place a value on these lost days. On the one hand, from the point of view of the exchequer, there is an immediate commitment to pay sickness benefit to an insured person off work. The cost of 2.7 million days recorded against epilepsy would have been £3 million at 1969 levels, or just over £1 per day of absence. However, this is merely a transfer payment from public funds to the individual and does not in any way measure real loss of economic resources due to absence. The same could be said of sickness benefit payments made by employers. What a measure of loss should really identify is the value of goods and services which are not produced because of reductions in the input of labour due to absence. In view of this it is necessary to see how sickness absence really affects total working time, and here two opposite illustrative situations can be described. On the one hand, absence may be due to a trivial complaint, lasting only a short time. In this case, the sick employee does not alter his long-term financial position. He can make up for his absence through overtime. In their turn, employers can and do use overtime as a means of regulating the total number of hours worked, or the same effect could be obtained by a longer standard working week or conceivably by a generally higher age of retirement.

At the opposite end of the spectrum there is long-term absence due to chronic disease. In this case the individual is probably no longer on a payroll so there is no disruption of production schedules and plans. However, the individual does not make up for his absence by working longer at other times. He is involuntarily idle over a long period and real increases in labour resources could be achieved by making him employable. The true value of lost productivity will approximate to the value of the individual's gross income when employed, and the benefits will fall on the individual himself to the extent that income from employment is higher than income when idle. Also, since the degree of incapacity associated with these absences is likely to be high, prevention of absence from the particular cause is likely to lead to a real reduction in the overall level of sickness absence.[6]

6 In contrast, prevention of absence from a particular trivial complaint is unlikely to reduce the overall level of sickness absence because the underlying cause of absence, such as dissatisfaction at work is likely to remain and manifest itself as absence due to some other minor complaint.

To the extent that epilepsy tends towards the long-term chronic end of the spectrum it would not be unrealistic to put a value of £12 million in 1969 on lost productivity caused by certified sickness absence attributed to epilepsy. In addition, epilepsy is associated with a failure to achieve maximum potential among people actually in employment. Thus Aston's motor works survey indicated that epileptics were kept out of employment where fits could disrupt production, that is, the jobs which were on the whole better paid. In so far as this means an underuse of competent labour this represents an additional though unquantifiable loss to both industry and the individual. To industry as a whole the loss of productive potential in the under-employment of a proportion of epileptics is probably negligible. The burden of the cost falls most severely on the individual whose long term income prospects are likely to be very poor.

Finally, there are the personal costs of disability to the individual. The monetary aspect of the cost to the individual has already been described, but in addition there is the cost of disability which is not eradicated by treatment or compensated by sickness benefits. This, in the case of epilepsy and other chronic conditions, includes the inability to fulfil a work role adequately, with all the adverse psychiatric responses that this may entail. Though unquantifiable in monetary terms these 'intangible' costs must clearly be an important determinant of priorities. An indication of the extent of severe personal disability and the magnitude of some of the social consequences of epilepsy can be derived from the sickness absence statistics. In June 1967 there were 4,180 insured men and 2,980 insured women who had been absent from work due to epilepsy for 6 successive months or more. It is unlikely that any of these would have retained their jobs for that length of time. They can be added to the 3,500 people with epilepsy as their primary disability who were on the disabled persons employment register and who were unemployed in 1970, making a minimum total of over 10,000 persons, or about 8 per cent of all epileptics in the working population whose disability, physical, mental or social, is so severe as to cause them to be unemployed or unemployable. Two other specific costs which are borne by most epileptics can be described, both of which confirm epileptics in their status as an under-privileged group. They concern life insurance and driving licences.

Life insurance companies have no British mortality data upon which to calculate risks associated with epilepsy and determine premium rates to be offered to epileptic applicants. A study of American Life Insurance companies (Society of Actuaries 1954) found that 1,000 insured epileptics followed between 1935 and 1949 had mortality rates 2½ times as high as standard risks, with excess mortality in

heart disease, strokes, accidents, homicide and suicide as well as epilepsy. This was the basis for refusing life insurance to epileptics or requiring loaded premiums. The study was criticised as being out of date, based on too small a sample and probably biased towards the more serious cases who would find it more difficult to hide their epilepsy. However, the magnitude of excess mortality was confirmed by a later Danish study of 3,671 patients discharged from neurological clinics with a diagnosis of epilepsy between 1950 and 1964. (Henriksen *et al* 1970). Observed deaths among the 75 per cent of epileptics who were not thought to be sub-standard risks for other reasons were compared with expected deaths among standard risks. It was found that mortality among male epileptics was $3\frac{1}{2}$ times as high as expected and twice as high as expected among female epileptics.[7] The immediate causes of excess mortality among Danish epileptics were similar to those found in the American study. The causes most frequently recorded on death certificates were epilepsy itself and suicide. An important point which arose from the study was that improvement in the frequency of fits during treatment was associated with a reduction in mortality rates. Following this study, British insurance company practice is now such that the quarter of epileptics whose fits are not well controlled, many of whom have multiple handicaps, will probably not be accepted even as sub-standard risks. Those who claim to have a moderate number of fits, about 4-6 per annum, will have to pay three times more than the standard premium though the loading is reduced with every fit-free year until five years have elapsed since the last fit, when an applicant will be accepted as a standard risk. Thus some groups of epileptics are placed at a severe disadvantage in securing their own and their families' futures. This may cause some to hide their condition in the same way as they hide it from employers. However, it is fortunate that in the insurance field at least the criteria of evaluation are now sufficiently refined to be able to dis-aggregate the various groups of epileptics with their varying mortality risks so that the epileptic population *en bloc* is not wholly deprived of life insurance cover because of the excessive risks attached to a proportion of epileptics, and so that epileptics can benefit in this field from control of fits through medical treatment.

7 Factors associated with high mortality were found to be high frequency of fits, more than one type of fit, moderately and severely abnormal EEG readings and severe mental disorder. Factors associated with relatively low mortality included older age of onset, one type of fit only, normal EEG and epilepsy caused by a brain lesion together with mental normality. These are in general the characteristics of the patient with 'symptomatic' epilepsy where there is a relatively clear-cut and demonstrable cause of the condition. All figures relate to discharged patients who did not suffer from other conditions, e.g. brain tumours, which were known to reduce life expectancy.

Some similar points can be made about driving licences. The Vehicle and Driving Licences Act of 1969 which came into operation in 1970 allows those epileptics who have not had an epileptic attack while awake for 3 years, but who may have had one while asleep, to obtain a driving licence. While the vast majority of epileptics are still debarred from driving, thus maintaining an incentive to conceal the condition, the law does at least indicate a willingness to distinguish groups of epileptics, as in life insurance, and thus prevent the characteristics of one group from determining the treatment of another.

Epilepsy and the health and welfare services

Bearing in mind the medical, economic and social profile of epilepsy, what are the roles of the health and welfare services and where should they spend money and concentrate effort and expertise in order to provide the greatest benefits at the lowest costs?

There is scope for primary prevention of epilepsy to the extent that the causative factors are known and are susceptible to control, but the causes of epilepsy are so diverse that the function of prevention must be a function which is carried out by the health services as a whole, irrespective of the existence of epileptics. For instance, antenatal and post-natal care, the minimisation of birth trauma, the prevention of damage from accidents and the eradication of certain infections are all likely to reduce the incidence of epilepsy. But clearly efforts in all of these fields could be justified with or without any pay-off from reduced incidence of epilepsy. Where primary prevention of epilepsy by whatever means fails, the next stage is the diagnosis and treatment of epilepsy at its onset. In the vast majority of cases, treatment means an attempt to control fits medically, rather than cure or eradication of the cause. This can also be considered the stage at which secondary preventive measures are applied in order to control resultant psychiatric morbidity and social maladjustment. To the extent that treatment and prevention at this stage are unsuccessful there is a need for rehabilitation and supportive services of many kinds and finally for protective institutional care for the most intractable cases.

Three official reports since the war have looked at the organisation of medical and welfare resources which are available to epileptics (HMSO 1953, 1956, 1969). The first dealt with the special welfare needs of epileptics. The latter two, the Cohen report in 1956 and the

recent Reid report of 1969 also looked at medical services for epileptics. They came to much the same conclusion that the services were insufficient, and made similar recommendations as to the priority areas where resources should be spent and effort and expertise should be concentrated. The Cohen Committee in 1956 recommended the expansion and integration of diagnostic and treatment services for epileptics, including the establishment of hospital epilepsy clinics and long-stay treatment and rehabilitation centres. The Minister of Health asked hospital authorities to implement these recommendations within the limit of their resources. However, with that financial qualification, the recommendations were not in fact implemented. The Reid report on 'People with Epilepsy', noted in 1969 the lack of action since Cohen and generally confirmed and extended the Cohen recommendations.

The Reid report concentrated attention on the stages from diagnosis and treatment at the onset of symptoms to the treatment and rehabilitation of specially difficult cases. The central theme was that the application of modern treatment methods from the early stages could enable nearly all epileptics to lead normal, well adjusted lives. The core of the recommendations was the setting up of diagnostic and assessment services at most general hospitals (and at all District General Hospitals and hospitals which have neurological or neurosurgical units). Normally the services would be given in epilepsy outpatient clinics which would operate as parts of relevant departments and be staffed by what were termed multi-disciplinary teams. These teams would include a consultant, a social worker, a clinical psychologist and sometimes local authority staff, a disablement resettlement officer and the family doctor. The hospital personnel in the team would frequently be involved in after care of the patient as well as the initial investigation and assessment.

In addition, the Reid Committee recommended setting up special centres (initially five or six in England and Wales) for epileptics whose management problems were particularly difficult. The centres would have two components, the first a neurological or neurosurgical unit and the second a residential unit so that assessments could be carried out under everyday living conditions. The special centres would form focal points for research and for professional and general teaching about epilepsy. Initially they would be provided by the grouping of appropriate existing facilities such as a neurological unit and an epileptic colony. These two sets of recommendations, the first dealing with the routine initial assessment stage and the second with the handling of problem cases can be dealt with separately.

The report recognises that modern methods of treatment are not always available to epileptics at the initial assessment stage. For

instance, the College of General Practitioners (1960) survey found that 26 per cent of chronic epileptics had never been referred to a consultant and the survey of Pond and Bidwell, where referrals of epileptics to hospital out-patient clinics ranged from 100 per cent in one practice to 27 per cent in another, suggested that the main factor determining the chances of obtaining specialist advice was the easy availability of consultants close at hand. As a solution, the report concentrated on the expansion of services at the hospital level. On both medical and logistic grounds there are good reasons for doing so. A patient who has had a fit for the first time needs access to specialist advice and specialist diagnostic equipment if maximum benefit is to be derived from modern medical science. Precise diagnosis and assessment is necessary to determine the best out of a range of possible treatment regimes.

It is vitally important that a person who has had a fit, particularly a child, should not be treated as a chronic epileptic on that evidence alone. To mislabel a child an epileptic on scanty evidence as to the probabilty of further attacks can have disastrous consequences on his future development. Such specialist advice and equipment could only be economically provided in the hospital sector. In an average health centre serving 10,000 people there would only be six new cases of epilepsy a year. This would not justify holding out-patient clinics at the centre with visiting consultants. Nor would the work load be sufficiently large to hold out the possibility of many individual general practitioners developing sufficient expertise in diagnosis and assessment to be able to perform the specialist service themselves. In addition, diagnostic equipment such as the EEG where the patient must be on the spot, could not be provided for such a small case load. The district hospital serving 150,000 or more people, providing a caseload of about 90 new cases a year, is in most areas clearly the most appropriate level of the health services hierarchy at which to centre initial diagnosis and assessment.

However, the Reid recommendations go further than this and the rationale behind them becomes more susceptible to criticism. Not only is it suggested that the hospital centred team should diagnose and assess the patient but also that hospital personnel should continue to be involved frequently in the after care of patients. This could, of course, be interpreted in a number of ways, but if it is taken to mean that hospital-based personnel should maintain a good deal of the responsibility for continuing and routine care, and if resources are to be reorganised accordingly, then this may be altogether the wrong approach.

The Reid report does welcome the recent advances in general practice organisation, including group practice, attachment of ancillary personnel and free access to hospital diagnostic departments. It

suggests that as these developments become more widespread most of the routine supervision of patients with epilepsy at present undertaken by hospital follow-up clinics could eventually be carried out by family doctors. However, the reorganisation of resources around the hospital clinic as recommended by Reid could in itself militate against the transfer of responsibility from the hospital service to modern general practice. It is the primary medical care level that will normally be the most appropriate place for development of resources for routine follow-up and continuing care but the Reid report makes no positive recommendations to develop the potential within general practice for the treatment of epileptics. Although general practitioners may at present lack the necessary training and up-to-date knowledge on epilepsy,[8] continuing care for stabilised epileptics is precisely the sort of service which the general practitioner and his community team ought to be able to provide, needing only occasional support from specialist hospital facilities. A number of general arguments in favour of developing primary medical care as an alternative to concentrating new investment in the hospital sector (OHE 1970) apply particularly to the routine continuing care of epileptics. It is likely to be more economical in health service resources, and more convenient for the patient if continuing care takes place at the primary level. The general practitioner has the great advantage in chronic conditions like epilepsy of being able to deal with the patient over a long period of time because he probably knows about the patient's home background and its relationship to the condition.

Thus while more resources should be devoted to the hospital sector for initial diagnosis and assessment, equal priority should be given to the positive encouragement of these trends within general practice which the Reid report recognises could enable most of the burden of after care to be taken away from hospitals. Although there would be only about six new cases a year in a population of 10,000 served by four general practitioners there are likely to be almost 60 chronic epileptics in need of continuing care in such a population.

More material resources in the form of both buildings and equipment need to be devoted to modern general practice. It is necessary to make general practice more attractive professionally in order that the quantity and quality of manpower and other resources can be maintained and improved. The education of prospective general

8 There is evidence in the Reid report of patients who collected prescriptions for anti-convulsants over long periods of time without seeing the general practitioner for assessment or regulation of therapy. There is also illustrative evidence from Jones' (1965) steelworks that in 15 epileptic employees out of 33 the works' medical officer had to intervene to obtain better control of fits.

practitioners, undergraduate and postgraduate, needs to take account of their changing role and to provide them with an understanding of conditions like epilepsy, and its relationship to other aspects of the patient's life.

Another strategy for the general deployment of resources which gains support from the needs of epileptics is the development and expansion of occupational health services in medium and large scale industrial establishments. There should be close informal links with general practice, especially with health centres and group practices. Ideally a health centre doctor should work part time in a local occupational health service. It has been suggested (OHE 1971) that a large number of medical functions could be conveniently and economically performed at places of employment with additional benefits of improving the quality of the work force and possibly reducing sickness absence. It is in the field of employment that the costs of epilepsy are greatest in both economic and personal terms. Epilepsy is an excellent example of a condition whose sufferers could benefit greatly if doctors were fully aware of their patient's working conditions. Evidence from Jones' (1965) steelworks illustrated the potential of occupational health services. Medical intervention by the works' doctor was found to be necessary in this case for epileptic employees to derive the maximum benefit from modern drug therapy.

It is apparent from the discussion that the central problem in organising services for epilepsy is communication. So many aspects of the patient's life are affected, including education and employment and so many different administrative authorities are involved, that the people providing advice and services are often unaware of the activities of each other. Equally important since epileptics are hesitant about disclosing their condition, authorities responsible for providing services can be unaware of the existence and the needs of many epileptics. For instance it is estimated that only about half of all epileptics of school age are known to the school health service and even fewer are known to the teachers themselves. The solution proposed by the Reid Committee, and earlier by the Cohen Committee too, was to bring the relevant authorities into physical proximity to each other at the assessment stage in hospital epilepsy out-patient clinics. These clinics would provide a formal setting for communication and mutual education between the interested parties and would help to bring an end to the present fragmentation of responsibility.

In so far as the Reid recommendations encourage communication, they are to be commended. However, communication does not necessarily involve a formalised structure revolving around a hospital epilepsy clinic suggested by Reid.

The main dangers of setting up special out-patient clinics are first, the likelihood of expensive proliferation of space, equipment and staff, second, the probability that functions would spill over into routine after care, and third the expense and impracticality of gathering together the multidisciplinary team in one place at one time. The Reid report did say that the whole multidisciplinary team would not need to meet in every case but when they did the gathering of a hospital consultant, local authority staff, the disablement resettlement officer and the general practitioner or his representative would not only create considerable practical difficulties but would also be extremely expensive in professional time.

For these reasons a less formalised means of communication between the parties which did not necessarily involve bringing many professional people together regularly at one time and place, and did not involve investment in a special supporting infrastructure, would be more appropriate to the magnitude of the problem of epilepsy. All responsible personnel should be aware of each other's views and activities and there should therefore be an accepted routine for consultation between them to ensure that patients receive the best available services. It is arguable, however, that the focal point of responsibility and communication should normally be at the health centre or the group practice level rather than the district hospital, certainly as far as continuing care of patients is concerned. The general practitioner working as part of a community health team which includes health vistors is well placed to act as the receiver and a disseminator of information. The performance of this function for epileptics would fit in well with the growing recognition of the importance of the general practitioner's managerial role as a selector of the various health and welfare services for those patients whose needs he cannot meet alone.

If it were to become increasingly common for health centre based general practitioners, after some form of training in industrial medicine, to take part-time appointments in occupational health services, there would be an added reason for giving the general practitioner the central role of co-ordinator and communicator. It is likely to take some time before the sort of general practice described could become the norm. However, as much priority should be given to the development of general practice as to the development of facilities for diagnosis and assessment at the hospital level.

Some of these points are also relevant to the other main Reid Committee recommendation on the organisation and deployment of health resources, that is, the creation of special centres to deal with the needs of the relatively small number of more intractable cases. Epileptics whose primary disability was mental disorder or severe physical handicap would be excluded.

The committee was at pains to recommend that units should be created from existing resources and should not initially involve an increase in financial allocations. Existing neurological units could be tied in with existing residential epileptic colonies. The Department of Health, in studying the feasibility of such units, has also been very conscious of the cost aspects. It emphasises the experimental nature of the units, as did the Reid report. However, there is little doubt that if these recommendations finally become official policy then purpose built special centres, recommended by the Reid report as the ideal solution for the difficult cases, would ultimately emerge. Here lies the danger of proliferation of ward blocks, equipment and staff, especially if, as Reid recommended, teaching and research were concentrated at the special centres.

Judgement on the merits of this set of recommendations depends largely on the number of centres to be set up and their precise function in relation to the remainder of the health services. About numbers, the Reid Committee rightly declines to say how many would be ultimately required or how large they would be, but suggests that five or six could be established in England and Wales as a first step. The report does not describe their functions fully, but suggests they would be for poorly controlled epileptics and those who require medical supervision under everyday conditions, with the emphasis on intensive rehabilitation efforts.

The special centres could be considered as having two different roles. The first is the role of a 'centre of excellence', an institution whose primary functions are the development of a high degree of expertise and research into the treatment of epilepsy, rather than the treatment of as many epileptics who could benefit as possible. Such an institution should not be regarded as the apex of a hierarchy of health services, but would be a special institution apart from the main hierarchy, experimenting, researching, teaching and feeding back information into the operational bulk of the health services. The second role, which could run in harness with the first, is that of a centre for treatment, whose primary objective is to receive, treat and rehabilitate those more difficult cases which cannot be dealt with elsewhere in the health services hierarchy. As well as being judged by the quality of its experimental work, it would be judged by its ability to cater for demand or for arbitrarily defined 'need' for its services. It is the first role, that of a centre of excellence, that is probably more suitable for the special centre in the present state of knowledge. It is not suggested that the more intractable cases should be left without facilities for treatment and rehabilitation, but that the scarce health service resources which would be absorbed by a number of special centres might be more productively employed elsewhere. As far as rehabilitation is concerned, money might be

better spent in improving and expanding facilities outside the formal structure of the National Health Service, for instance in Industrial Rehabilitation Units or Government Training Centres, or residential training centres for the disabled.

Any changes in the deployment of resources must take account of the vital importance of communication and the education of those concerned to make the best possible use of existing resources, including the effective use of anti-convulsants which properly used can control most fits. The importance of educating providers of services is illustrated by the needs of schoolchildren. The maximum incidence of new cases of epilepsy occurs during school age. The reaction of the child's teachers and playmates to his epilepsy will play a very important part in his adjustment to epilepsy, and, as the Reid report emphasised, improved communication between the health services, parents and teachers is essential. Teachers themselves probably only know the minority of cases and this can be a great disadvantage when dealing for instance with a child with petit mal epilepsy whose attention appears to wander. Epileptics should not only be known to all concerned and each party be made aware of the responsibility to communicate with other parties, but all parties should be giving the same advice. Often conflicting advice is given when those responsible for the care of epileptics are insufficiently educated. Teachers, for instance, should be better equipped through their training to recognise and deal with handicaps such as epilepsy. At present little attention is given in teacher training to the problems of this minority group of children. For their part, if general practitioners were always fully aware of the interaction between the child's milieu and his condition, they could help to ensure that there was useful interchange of information between themselves and the schools.

The critical importance of educating doctors and teachers about epilepsy also applies to the education of the community as a whole. Medical intervention from the earliest stages can go a long way towards ensuring good control of fits and the prevention of psychiatric morbidity and social maladjustment. However, the value of the work of professional health and welfare personnel in dealing with psychiatric and social complications is likely to be limited. Services provided must often be supportive rather than curative or preventive, making little impact on the primary cause of the social difficulties of epileptics which lie in the suspicion and ignorance of the general population and the consequent stigma which is attached to epilepsy. If adverse attitudes to epilepsy in the population as a whole could be eradicated through public education this would amount to the primary prevention of many of the psychiatric and social consequences of epilepsy just as the reduction of birth trauma, brain infections and accidents would prevent many cases of epilepsy

from developing at all.

In view of this, the medium to long-term approach of education and propaganda should receive high priority. Polls conducted by the American Institute of Public Opinion over the past 20 years indicate a steady reduction in the proportion of American citizens objecting to the employment of epileptics and to their children playing with an epileptic child. The more liberal state of public opinion in America (Table 4) is believed to reflect the stress placed by the Epilepsy Association in America on public education, and the amount of money put into influencing opinion through advertising in the mass media–something which is not yet happening in Britain.

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Appendix

The costs of treating epilepsy in the various sectors of the health services were estimated as follows:

a) Hospital Service

The figure of £7.6 million in 1969 covers only current in-patient costs. Both in-patient costs and capital expenditure are excluded because there is no valid basis upon which the cost of epilepsy could be extracted from the total.

Current in-patient costs are divided into two parts, those which are incurred in mental hospitals and those which are incurred in non-mental hospitals. For the latter, the number of cases of epilepsy treated in England and Wales derived from the Hospital In-Patient Enquiry for 1967, was multiplied by the average length of stay per case. This in its turn was multiplied by the average current cost per in-patient per week in non-teaching acute hospitals of over 100 beds in England and Wales derived from the 'Hospital Costing Returns'. The resultant figures were adjusted to 1969 levels for the United Kingdom. The cost of treating epilepsy in mental hospitals was based on 1963 figures from 'A Census of Psychiatric Beds in England and Wales' (HMSO 1966). The number of bed days consumed by in-patients with a *primary* diagnosis of epilepsy or epileptic psychosis was multiplied by the average current cost per week of mental illness and sub-normality hospitals (Hospital Costing Returns). The figures were then adjusted to 1969 levels for the United Kingdom on the assumption that the reduction in the total number of mental illness beds throughout the country was matched by an equivalent proportionate decline in the number of mental illness beds occupied by people with a primary diagnosis of epilepsy or epileptic psychosis.

b) General Practice

The proportion of consultations specifically for epilepsy in general practice was extracted from the 'Medical Data Index' (Intercontinental Medical Statistics). This proportion was applied without adjustment to the total expenditure on the General Medical Services in the United Kingdom in 1969 (Annual Abstract of Statistics 1970).

c) Pharmaceutical Services

The 1969 United Kingdom consumption of ethical products for epilepsy by epileptics, at wholesale prices, was estimated from the Medical Data Index and the British Pharmaceutical Index (Intercontinental Medical Statistics). The resulting figure was adjusted to

the retail price level in order to include the cost of distribution through pharmacies.

The Office of Health Economics wishes to acknowledge the assistance of Intercontinental Medical Statistics Limited in making some of their data available for estimating the costs of epilepsy to the health services.

British Epilepsy Association

The Office of Health Economics wishes to acknowledge the assistance and advice of the British Epilepsy Association during the preparation of this paper.

The British Epilepsy Association was set up in 1950 to advise and assist people suffering from epilepsy and to help their families and friends to a better understanding of this condition.

A programme of information for professional groups and the general public has played a major part in the activities of the Association and the Epilepsy Information Unit was set up under the auspices of the Association to expand and develop this activity.

An Advice Service is operated from the offices of the British Epilepsy Association, which are at 3/6 Alfred Place, London, WC1E 7ED.

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