SOCIAL AND EDUCATIONAL ASPECTS OF EPILEPSY

W. H. Barnard, *Jan Kriel School for Epileptics, Kuilsrivier, CP*

As the principal of a special residential school for epileptics for more than 20 years, I am well acquainted with the social and educational problems of epileptics, and with the handicaps faced by them in their rehabilitation.

To be sure medical science and medical practice has a major contribution to make towards the solution of the entire problem of epilepsy. I am reminded of the wise words of Mrs. Davidson, wife of Dr. Romanes Davidson of the Bridge-of-Weir Colony for epileptics in Scotland; 'No matter what beautiful schemes you may plan for epileptics, the best you can do for them is still to rid them of their seizures.' Much has been gained, also from a social point of view, once the seizures have been brought under control.

At the same time the educational and social problems of epileptics are matters of grave importance, and they may be more resistant to treatment than the seizures themselves. This point was recently stressed by no less an authority than Dr. Samuel Livingston of the Johns Hopkins Hospital Epilepsy Clinic; 'We now believe (in contrast to the practice of 30 years ago) that the consideration of such problems as how to cope with epilepsy, how to get schooling, and what the future holds, is just as important as the administration of anti-epileptic medication'. It is precisely out of this conviction that the multidisciplinary approach has come to be widely adopted in epilepsy clinics the world over.

INCIDENCE

To gauge the magnitude of the problem some orientating facts may be in order, especially regarding the incidence of epilepsy. Reliable statistics are hard to come by, but it is generally agreed that, in a Western type of community, the incidence is 4 - 5/1,000.[1]

It may be on the increase as a result of improved survival rates of infants who have suffered childhood diseases, or anoxia and brain damage at birth. Surveys of various school populations have shown an incidence of 1·2, 1·43 and 1·8 per 1,000 schoolchildren, but figures ranging from 0·3 to 2·5 have also been found. This lower incidence among children of school age is hard to reconcile with the over-all incidence, as epilepsy is predominantly a disease of childhood. The Interdepartmental Committee on Deviate Children[2] estimated the White epileptic population of South Africa, between the ages of 7 and 18+ years, as being 1,200 in 1945, of whom 400 were considered candidates for special education.

We may conclude that, viewed only in respect of numbers, the problem of epilepsy does not seem to be one of major proportions. Then also, a significant percentage, unfortunately not readily possible to determine, are candidates for custodial care and life-long institutionalization.[3] They do not constitute a social problem, except to the taxpayer. Likewise those of the highest category, intellectually of normal or above-normal endowment, with well-controlled epilepsy, need not concern us greatly. Most of them are able to take care of themselves. Their precise numbers cannot be determined. They are not known to be epileptic in the majority of cases, except to their doctors.

The Group Concerned

When we consider the educational and social problems of epileptics, we therefore find ourselves dealing mainly with the middle group. They are the patients whose epilepsy has not been entirely controlled, although they may be seizure-free for long periods of time. They are of average, low-average or slightly subnormal intelligence, and some may have multiple handicaps of a not too serious degree. Some cases of superior intelligence, but with resistant seizures, may also be classed with this middle group. These epileptics are all more or less educable, can be taught, trained and gainfully employed under favourable circumstances. In the present state of things, many of them fail to become rehabilitated, may become recipients of disability grants, and are mostly cared for by relations. Although little may be known about them, they are perhaps the greatest burden of epilepsy on the community, as well as a constant source of prejudice against other, more competent epileptics.

ANALYSIS OF EDUCATIONAL AND SOCIAL PROBLEMS

Let us first try to give an analysis of the nature of the educational and social problems of epileptics in general. In the limited time at my disposal it will be impossible to present a comprehensive review or to go into details. I shall have to content myself with rather general remarks.

General Factors

It cannot be denied that uncontrolled seizures impose severe limitations and may cause grievous embarrassment. When they occur in a public place they generally result in consternation, a concourse of people and an obstruction of traffic. The embarrassment of the patient upon regaining consciousness may be well imagined, especially if there has been incontinence. He is fortunate if he escapes the kindly attentions of a well-meaning individual who has him rushed off in an ambulance to the emergency ward of the nearest hospital. On the other hand his life may be actually endangered and lamentable accidents do occur. Psychomotor attacks, with their bizarre manifestations, and post-epileptic confusional states may land the epileptic into serious trouble, often involving the police. His seizures, therefore, keep the epileptic at home, and severely restrict his life experience. This may be aggravated by unnecessary restrictions, imposed by overanxious parents, and even by physicians, who may be unwilling to accept calculated risks.

The necessity of continuous treatment, incessant examinations and investigations, frequent admissions to a hospital or clinic, the daily routine of pills, the inevitable side-effects of some forms of anti-epileptic medication, etc., may foster unwholesome and morbid attitudes of mind, a preoccupation with symptoms, and a degree of autistic and egocentric isolation and self-indulgence, as well as a tendency to hypochondria and invalidism. If unchecked this will seriously hamper the social adaptation of the epileptic child or adult. These are tendencies to watch out for in your patients. They may be iatrogenic!

The impairment of native ability, and coexistent physical disabilities or psychological deficits, associated perhaps with brain-damage, of which epilepsy is but one symptom, are among the further real or factual handicaps which may unavoidably impede the social and educational development of the epileptic person. It is no use trying to gloss over these real problems or to minimize their impact. We must concede that many epileptics are unfortunately suffering from such real handicaps. There are, e.g. among epileptic children, some who present the now more or less well-recognized syndrome of hyperactive behaviour, with characteristic impairment of concept-formation, memory and learning ability, distractibility, emotional disturbances, explosive behaviour, etc., ascribed by Strauss *et al.*[4,5] to brain-damage, which may render such children incapable of profiting from normal methods of tuition and training, and make it difficult for them to establish acceptable modes of behaviour. Associated with these neurological handicaps may be impairment of the means of communication, e.g. aphasia, or specific scholastic disabilities, for instance, in arithmetic.

The gravest problems are, however, those imposed on the epileptic by society itself, by lack of social acceptance of the epileptic, ignorance of his real condition and of the possibilities for his rehabilitation, superstition and prejudice, and the indiscriminate relegation of all epileptics to the human refuse-bin.

Family Problems

Even in his immediate family circle, the young epileptic child soon finds that he is considered 'different'. He may be treated as sick or delicate, pampered and spoiled, given preference over his healthy siblings, to the detriment of his relationship with them. Often in this setting he develops his own particular brand of tyranny and parasitism, exploiting the concern lavished on him. Or he may be considered a burden and a tribulation, an undeserved misfortune, the cause of bickering between parents who feel guilty or blame each other for the child's condition, a 'spoil-sport' who, by the constant care he demands, imposes restrictions on home and family life, an object of shame to one's self-esteem or social advancement, an unproductive and often excessive expenditure, frequently as a result of futile shopping around from doctor to doctor or specialist to specialist with the mistaken idea that there must be a cure for epilepsy as for everything else. It is, indeed, hard to find, among the parents of epileptics, a happy compromise between these extreme attitudes.

Social Relationship Problems

As he grows up the epileptic child finds it very difficult to gain access to what the Americans call 'peer groups'. Neighbours do not want their children to play with the epileptic, for fear that they may be harmed by the contact. Children themselves are proverbially cruel, passing on remarks overheard from their elders, or teasing and taunting the victim of these inexplicable and bizarre seizures, branding him as 'loony' or mad. His seizures may actually upset their games, or render him incapable of partaking and competing in them, so that he gets ousted, neglected and forgotten.

When he grows up he will find this same reluctance to accept and associate with him among adult groups, either in employment or in recreation. This reluctance cannot entirely be blamed upon prejudice and ignorance, or on an uncharitable disposition towards the epileptic as a fellow human being. Even epileptics themselves have sounded a warning to fellow epileptics to refrain from forcing themselves upon people 'who do not want to have the embarrassment of an epileptic thrust on them in their leisure hours'.[6] The epileptic is consequently advised to be more self-reliant and less dependent upon social intercourse with normal people. It cannot be denied that the presence of a known epileptic, liable to have an unpredictable seizure at awkward points of time, does occasion some restraint, uneasiness and tension, even in the company of well-informed and well-disposed people.

But the epileptic will meet with much more than this understandable reluctance when he tries to join in the social activities of the community. There is still a great deal of sheer prejudice against the acceptability of the epileptic in the public mind, and there is even a certain amount of baseless fear and dread of his seizures. In many ill-informed circles, epilepsy is held in more or less mediaeval awe, and the epileptic is considered repulsive or evil, reminiscent of the belief that they were possessed by devils.

Scholastic Problems

When the epileptic child goes to school he is faced with many problems. His difficulties in establishing satisfactory personal relationships and in gaining access to peer groups, may be aggravated by the competitive atmosphere of the school situation, in which he may be incapable of achieving success. He may have special learning problems, associated with neurological defects, of which his teacher may be quite unaware, because her training has been on entirely different lines. He soon experiences a frustrating sense of inadequacy and inferiority, with consequent aberrations of personality and behaviour. If his seizures persist and occur during school hours and on the playground he may soon find himself *persona non grata*, the butt of ridicule, avoided by his classmates, ignored by his teachers or picked upon for his misdemeanours, while the parents of the other children protest against his attendance and the school authorities deliberate about his speedy removal from the roll. It is at this point that in South Africa the special school comes into the picture.

Employment Problems

Ultimately, after having attended either the normal or the special school, or some other training centre, maybe even university, the epileptic faces the necessity of finding employment and earning a living. It is here that he will face the greatest handicaps of all, what Lennox[7] has called the 'roadblock of employment'.

In this connection Livingston[5] is careful to distinguish between the epileptic's capacity for work and his acceptability for work. About the former, there can be little doubt if the epileptic person in question has had the requisite training and education, and thereby is able to provide evidence of his ability to perform certain appropriate skills. This does not, however, as with almost anyone else, make him acceptable for work. 'Acceptability is affected not only by capacity for work, but by factors inherent in the job under consideration and by the attitude of prospective employers and fellow employees'.[5]

Factors inherent in the job are naturally important. An epileptic may well be able to carry out the operations required in a particular job, but the conditions under which these operations have to be carried out, may make it inadvisable for him to undertake the job. He might have to move among power-driven machinery or to scale heights where he could come to grief. Having a seizure while serving the public may be damaging to the interests of his employer. These are considerations of commonsense and, however they may limit the scope of employment for the epileptic, he cannot in all fairness rebel against them. It is in his own interest that he should be safely, suitably and permanently placed.

The prejudice of employers and fellow employees, based upon ignorance, mistaken views, erroneous beliefs and superstition, etc., is quite another matter. Of this we have had plenty of experience in our own efforts to find employment for our ex-pupils. The great majority of employers will not knowingly employ an epileptic in any capacity whatsoever, and many non-epileptics will not tolerate the presence of an epileptic in their office or workshop on any account. They will have all epileptics committed to an institution, professing sympathy for their misfortune, or advocate their admission into sheltered employment, but they will not consider their engagement in the open labour market. They could never be expected to make minor adjustments in job situations to make them safe or suitable for epileptics. Their refusal to the epileptic of normal work opportunities is categorical and absolute.

Yet most employable epileptics of adult age must be employed somewhere. They are not generally the recipients of disability grants. Those who do receive these grants are mostly quite unemployable, although this is not always so. Some are, of course, in sheltered employment. But the numbers of these are small, almost negligible. A great number of epileptics must therefore be in regular employment, in a variety of suitable and unsuitable jobs. Some are engaged in the most unlikely occupations. The key to this enigma is that they are not employed as known epileptics. Even ex-pupils of my school, realizing that a stigma attaches to having been to such a special school, seek and find employment without ever divulging the fact that they are, or have been, epileptics. The danger attached to this policy is, of course, that they may be placed in entirely unsuitable, and indeed very dangerous situations.

Many carry it off for a long time, perhaps indefinitely. They may be lucky in never having an attack on the job and in not being discovered. Others drift from one job to another, getting fired every time they have a seizure on a job, or even after years of successful employment, as soon as it is discovered that they are, or have been, epileptics, although they may never have shown any symptoms in their present occupations. Many who are successful in maintaining secrecy, do so at a cost to themselves, relying on deception, living in fear of discovery, and paying for it in tension, insecurity and nervous symptoms, even, perhaps, by having a recurrence of the dreaded seizures.

MEASURES FOR IMPROVEMENT

Having gained some insight into the problems facing epileptics in their educational and social adjustment, one might briefly consider appropriate measures for improving the outlook for them.

Treatment Facilities

First of all, and obviously, there should be adequate facilities for the treatment of the epilepsy itself, and for the neurological, physical, psychological and psychiatric symptoms which might accompany it in particular cases. Ideally such treatment should be available in special epilepsy clinics run on a multidisciplinary basis, including medical, neurological, surgical, psychiatric, paramedical, psychological, educational and social services. Such clinics should place their services at the disposal of general practitioners, for reference of patients for full investigation and assessment, referring the patient back with a full report and detailed instructions. It seems to be the consensus of opinion overseas that epilepsy should not be treated merely as one of a variety of neurological disorders by the department of neurology or psychiatry of a big hospital, nor, in the case of small children, as a purely paediatric case. It is of supreme importance that optimum facilities for treatment should be provided ; without this there can be little hope for improving the rehabilitation of the epileptic, and, as the cost of such a comprehensive service affects the taxpayer, he will have to be educated to accept the financial responsibility.

Educational Facilities

The provision of adequate and appropriate educational facilities ranks next in importance. I cannot here argue the pros and cons of attendance at normal schools, special classes or special schools. Different kinds of provision may be desirable for different individual children, or may be feasible in a particular community, subject to geographical or demographic conditions. The study of various programmes advocated in various countries is an intriguing subject. The best possible and the most appropriate education, academic as well as vocational training, must obviously be provided, whatever the measures employed to ensure this ideal. Whatever the intrinsic merits of our own system in South Africa, I do not think that we fall too far short of this ideal, at least not as far as White children are concerned, and a propitious start has been made in the education of Coloured epileptic children.

Employment Opportunities

With regard to the employment of epileptics, as I have pointed out, we, in common with most other countries this side of the 'Iron Curtain', have a long way to go. Proper vocational guidance and placement for epileptics is still virtually non-existent. The Department of Labour, with the most determined efforts, does not seem to progress beyond rather futile attempts at persuading reluctant employers to accept such an employee. To get an epileptic any job at all, is difficult almost beyond belief, unless he prefers to sneak in under the cloak of secrecy. Utopian conceptions, mentioned in the literature, like 'on-the-job' training, special measures to safeguard or adapt the job to the requirements of the epileptic employee, job re-engineering, etc., seem doomed to remain Utopian. (The epileptic rehabilitation service in the USA seems to be proving that only minor adjustments are really necessary to accommodate epileptics in industry.) As long as the civil service, however, keeps its doors virtually shut to the epileptic, one can hardly expect private enterprise to take the lead in their employment, which is still, erroneously to be sure, considered a philanthropic undertaking.

The education of public opinion is probably our only and final hope of achieving any worth-while and lasting improvement in the social care of epileptics. This is a slow and laborious process. It takes a tremendous amount of effort to get new ideas across to the public, especially when people have strong convictions about the matter. An indication that some progress is being made was shown in surveys of public attitudes toward epilepsy in the USA (Gallup polls), conducted at 5-yearly intervals during the past 2 decades.[9] In most countries there are special organizations, devoted to the cause of epileptics. Nowhere have they achieved spectacular success, although much has been accomplished. We may hope to hear a great deal from the S.A. National Epilepsy League in years to come. My own organization, as well as the Rand Epileptic Employment Association, have done a great deal during the past quarter of a century to present the case of the epileptic to the public, but we have not been actively engaged in establishing the epileptic as an employee on the open labour market. We have been mainly concerned with education and sheltered employment.

Legal Protection

Legislation is one of the aspects of the social care of the epileptic. Certain provisions have been made for epileptics by way of legislation in South Africa. We have legal machinery for the establishment of special schools, for institutional care, disability grants, commitment of children in need of care, etc. Our penal codes do give due consideration to the position of the epileptic who might have committed a crime in an epileptic twilight state or even in an ictal epileptic condition which may have rendered him temporarily inculpable. Proving this to a judge or a jury is of course another matter, and unfortunately ill-advised attempts to blame epilepsy for crimes of violence, etc., is a sad practice from the point of view of the epileptic person.

Fortunately we do not have harsh restrictive laws applying to epileptics, curtailing their rights and privileges, such as are still found unrepealed on the statute books of some Western countries and states, like those prohibiting marriage, barring the epileptic from certain occupations, making epilepsy a notifiable disease, etc. At the same time we have no laws providing for the employment of epileptics in industry, such as the UK and the USA have passed, even though they are reported to be ineffective in many cases.

General Problems

There are a number of points of practical interest and vital importance to epileptics, which I would have liked to discuss, but I shall have to confine myself to a mere enumeration of these. I refer to the following matters: marriage and family life for the epileptic; holding a driving licence; life and other types of insurance; participation in sports, especially the question of contact sports, bathing, etc.; life expectancy of the epileptic; the acceptance of calculated risks; the advisability of certification; environmental factors in the course of epilepsy; civil service regulations; military service; the pros and cons of secrecy, and many other matters besides, which look very different from the point of view of an epileptic than they do to us in our everyday lives.

OPSOMMING

Die opvoedkundige en maatskaplike probleme van epileptici is belangrik en hou verband met hulle mediese behandeling. Dit is veral die gemiddelde epileptikus wat probleme oplewer, weens tekortkomings in vermoë en onbeheerde aanvalle. Bloot in terme van getalle, is dit skynbaar nie so 'n groot probleem nie. Die swaarste las op die samelewing is waarskynlik dié wat 'n ongeskiktheidstoelaag ontvang en deur familielede versorg moet word.

Epileptiese aanvalle, en ander omstandighede wat die aanvalle mag vergesel, kan belangrike beperkings op die epileptiese persoon plaas en sy opvoedkundige en maatskaplike aanpassing strem. Die gedurige behandeling wat hy ontvang, is ook nie bevorderlik vir gesonde geestelike ontwikkeling nie. Neurologiese gebreke mag die skoolontwikkeling belemmer. Die grootste probleme spruit egter nog steeds uit die verkeerde opvattings en gesindhede van die publiek teenoor epilepsie en die persoon wat daaraan ly. Hy ondervind dit in die huislike kring, op die speelgrond, in die skool, in die algemene omgang met sy medemense, maar veral later in sy lewe wanneer hy 'n beroep wil aanvaar. Hoewel baie epileptici heeltemal beroepsbekwaam is, is nie almal aanneemlik vir werkgewers en mede-werknemers nie, as gevolg van werklike moeilikhede in verband met werksomstandighede en die vooroordeel wat nog teenoor epileptici bestaan. Nogtans word baie epileptici wel in die arbeidsmark opgeneem, meestal onder die dekmantel van geheimhouding. Dit lei dikwels tot beroepswanaanpassing en onoordeelkundige plasing van epileptici.

Vir die volle rehabilitasie van epileptici is in die eerste plek doeltreffende mediese behandeling noodsaaklik, wat liefs voorsien moet word deur spesiale epilepsie-klinieke. Voldoende en toepaslike opvoedkundige fasiliteite en opleidingsgeriewe is ook van baie groot belang. Op die gebied van indiensneming van epileptici heers daar nog 'n groot agterstand, wat aandag moet geniet, veral deur die opvoeding van die publieke opinie en desnoods deur wetgewing.

'n Aantal praktiese probleme van epileptici word, weens gebrek aan tyd, net genoem, bv. die huwelik en ouerskap; motorbestuurderslisensies; lewens- en ander vorms van versekering; deelname in sport, veral wat betref spele waarin fisieke kontak voorkom, swem, ens.; die lewensverwagting van epileptici; die aanvaarding van berekende risiko's; die raadsaamheid van sertifisering; omgewingsfaktore in die verloop van epilepsie; die staatsdiensregulasies; militêre diens; die voor- en nadele van geheimhouding, ens.

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