

Social-Psychiatric Aspects of Epilepsy

SPECIAL REFERENCE TO THE SOUTH AFRICAN NATIONAL EPILEPSY LEAGUE (SANEL)

H. MOROSS

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As the South African National Epilepsy League (SANEL) has not been in existence for very long, I should, by way of introduction, like to say something about its beginnings. It is an offshoot of the South African National Council for Mental Health. In the 1950s the Council appointed a committee to prepare a blueprint for an integrated mental health service for South Africa, and epilepsy was one of the aspects considered. Dr Allan Bird presented a comprehensive report on the need for a co-ordinated service to cater solely for all aspects of this condition. Based on the recommendations of this report, a Division for Epilepsy of the National Council for Mental Health was set up in 1964.

At a National Conference on Epilepsy held in 1967 it was resolved that the Division for Epilepsy become an autonomous body and be constituted the South African National Epilepsy League. As epilepsy does not demand a great deal of public attention like other manifest handicaps, progress of the league has been slow. People subject to epilepsy do not generally show outward signs of the condition, many of them either suffer privately or successfully conceal their epilepsy. The actual number of persons suffering from it is not very large, a substantial proportion are successfully employed and are otherwise self-sufficient. Those who do have problems, however, while their number is small, may be severely handicapped by their epilepsy, especially in the social sphere, and it is to these, in the main, that SANEL must cater.

The need in South Africa for an organisation whose sole purpose would be the promotion of the interests and welfare of this latter category of persons had been felt for a long time, because most other agencies who provided social welfare services were at a loss when dealing with epileptics and their problems, because of a lack of specialised knowledge of this condition and its implications.

To date SANEL has set up four branches—in Pretoria, Natal, Cape Town, and one in Johannesburg, known as the Witwatersrand Branch, established in June 1969. Being associated with this branch, I am more familiar with its progress and work than with the activities of the other branches. It was not until October 1970 that the branch

became sufficiently viable to appoint a full-time secretary; and it was only in January 1972 that a part-time social worker could be appointed. Despite many hampering factors, not the least being lack of public interest, the branch has made reasonable progress.

The branch office caters for all races and provides an information service free of charge. It is available to people subject to epilepsy, their families and friends, as well as to professional colleagues and groups who may be directly concerned with the many problems associated with epilepsy. Advice and guidance may be obtained over the telephone, by letter or by personal appointment.

Medical assessment of the epileptic is often necessary before advice can be given or social action taken. The office is linked with the Neurology Department of the Johannesburg Hospital and the University of the Witwatersrand, as well as with the Department of Psychiatry, where such assessment is done and treatment prescribed. It may be mentioned here that Professor L. A. Hurst, Head of the Department of Psychiatry and Mental Hygiene at the Johannesburg Hospital and the University of the Witwatersrand, has a special interest in the genetics of epilepsy.

Good treatment facilities existed in Johannesburg long before SANEL came into being. There was, however, no organised body to deal specifically with such referrals, and to implement medical recommendations and social action, including follow-up and aftercare by social workers. Thus far, the number of cases dealt with is not large, but is slowly building up; the Head of the Neurology Department, Dr H. E. Reef, believes there has been manifest improvement in the lot of the epileptic since the advent of SANEL.

One of the important objectives is public education about epilepsy. At present this is being done through the medium of the excellent New Zealand film 'Just a Ripple on the Surface'. At the moment the principal focus is the Rotary movement in the Witwatersrand area. The Rotary District Governor in whose area the Witwatersrand is included, is encouraging Rotary members to support the League—not necessarily financially but more from the standpoint of offering employment to epileptics, and as far as possible retaining their services. Rotary members are also asked to encourage a tolerant attitude towards epileptic employees on the part of work supervisors and foremen. This is a very slow but hopefully worth-while effort. There are many other sections of the community to be approached in due course, including other service clubs.

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H. MOROSS, M.B. B.S., D.P.H.

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Reference has been made to the role of the work supervisor and foreman in dealing with epileptic employees. Education and persuasion must be directed at these people in the work situation, as they are personally involved in their own achievements and future, and want the greatest productivity from the employee in their charge.

Sheltered employment is provided by the State Department of Labour, and by EEA. A major problem exists for the severely handicapped epileptic, especially in the social sphere. Many of them are suitable only for sheltered employment, which they reject, wanting to work in the open labour market, for which they seldom have training; others who might be suitable for the open labour market are, for various reasons, not equipped with a trade, owing to the scanty facilities for vocational training.

Having digressed somewhat, I return to the need for public education. There are, of course, the usual pamphlets available, issued by the International Bureau for Epilepsy, and others published in the USA; in the course of case work the social worker is in a good position to do a vast amount of public enlightenment.

RESEARCH

The Witwatersrand branch of SANEL has assumed research as one of its important functions. Not long after its inception in 1969 it was fortunate in interesting a research organisation in the private sector to conduct a survey on attitudes towards epilepsy (at no cost to SANEL).

In 1970 three research projects were sponsored by a private individual. The branch is indebted to Dr H. E. Reef for motivating these projects, one of which, and perhaps the most interesting from the standpoint of this meeting, is related to the fact that we have a unique situation in South Africa which has never been fully explored, namely our mixed population groups, their diverse cultural heritage and social circumstances, and perhaps even different genetic and physical constitutions. Combined with the excellent medical services in certain areas, this provides us with unparalleled scope for research.

During the past 10-15 years, those working in this field have been puzzled by the following facts:

1. Head injuries and post-traumatic epilepsy among the urban Blacks.

2. The incidence of epilepsy in Western Europe and the USA has been assessed at 0,5-0,75% of the general population. It has always been our impression that the incidence of epilepsy in the Black population of South Africa was lower. It is therefore surprising to learn that in Nigeria it is 1,4%—an incredibly high figure.

3. There are Black communities in South Africa who do not fight—with a subsequent low incidence of head injuries. The Transkei and Sekukuneland are two such areas. What is the incidence of epilepsy there?

4. It is of great importance to find out the incidence of epilepsy in our three basic communities, i.e. Whites, and urban and rural Blacks. Apart from the purely scientific value of such knowledge—if there is a difference—the analysis of the data may lead to knowledge about causation.

5. Is the response to therapy different in the three groups?

6. The Blacks have a completely different attitude toward epilepsy. To them it is not a 'sinister' disease and it has no adverse social effects. Why is this? Does it have any effect on therapy or prognosis? Their ideas about causation are also odd but in keeping with their cultural background—they are concerned with evil spirits and phases of the moon. The Black epileptic in rural areas does not regard the affliction as something to be ashamed of, and makes no attempt to hide it. The disorder is not regarded as a bar to employment because as a rule the work is not done under circumstances where, during an attack, there might be danger to the patient or others. The urban Black occupies an intermediary position between his rural counterpart and the White population. Whites try to hide epilepsy.

These are some of the questions which intrigue us. Answers would not only increase the general body of our knowledge, but might conceivably have socio-economic application by preventing waste of manpower in a country which can ill afford it. This project is under way.

I referred earlier to an attitude survey. As the results may have sociopsychiatric implications, I shall expand on them. In 1969 a report was published on a Brand Barometer study conducted by Market Research Africa on attitudes of South African housewives towards epilepsy. Two similar studies had been carried out in 1964 and 1969, respectively, by Gallup and Ruby among men and women in the USA. Similar questionnaires were used in the South African and the USA studies, and showed a parallel level of knowledge and experience regarding epilepsy in both countries.

The similarity of results recorded in the USA from men and women, and women only in South Africa, suggests that women express the view held by the total population of both male and female. Market Research Africa, from their survey, lend themselves to further thinking, and I am indebted to Mr W. H. Barnard for his collaboration in this regard.

PERSONAL KNOWLEDGE AND EXPERIENCE OF EPILEPSY

An analysis of the findings of the survey shows a marked disparity in the two language groups—63% of Afrikaans- and 49% of English-speaking people knew someone with epilepsy, and 62% of Afrikaans- and 51% of English-speaking people had seen someone have a seizure.

We also noted that 52% of city dwellers, as against 64% and 68% of town and village dwellers, knew someone with epilepsy, and that 54% of city dwellers, as against 62% and 65% of smaller town and village dwellers, had seen an epileptic having a seizure. City dwellers are in the main English-speaking and the others speak Afrikaans.

Secondly, the lowest income bracket showed greater personal experience of epilepsy; 65% and 64% knew an epileptic or had seen a seizure, as against 58% and 56% of the higher income groups who had had similar experience. From this it would seem that Afrikaans-speaking people have greater experience of epilepsy, and this suggests a probable higher incidence among Afrikaans-speak-

ing people. If the supposition is correct it is important for us to know if the work of SANEL is to be guided by such a finding.

ATTITUDES REGARDING EMPLOYMENT AND EMPLOYABILITY OF EPILEPTICS

It seems that persons in the lower income group have a relatively more discouraging attitude. Have they had first-hand experience of the difficulties epileptic persons have in finding work? Do they reflect the unfortunate experience of epileptics known to them? It is doubtful if they are less enlightened regarding the capacity of most epileptics.

Should epileptics be employed like other people? Among women in the younger age group there is an encouraging attitude in this regard, but this decreases with age. Is it possible that with increasing age, there is also an increased awareness of the difficulties encountered by epileptics in finding work? Afrikaans-speaking people are relatively more pessimistic about employing epileptics: 58% and 25% were against, as against 69% of the English-speaking people in favour and 16% against.

What does this mean? Does it signify a greater experience of Afrikaans women of the difficulties of epileptics? Does it reflect a more enlightened attitude among English-speaking people? Does it indicate a more protective attitude on the part of the Afrikaans people, viz. that persons with epilepsy should be cared for and should not be left on their own and have to earn their keep?

Considerable differences in the four provinces in attitude toward the employability of epileptics were found. In Natal 77% were in favour, and in the Orange Free State 55%, with the Cape and Transvaal 60% and 62% in between. Do these figures corroborate the other figures, because Natal is predominantly English and the Orange Free State predominantly Afrikaans? These figures emphasise the vast problems people have as regards employment. This is obviously the task of SANEL—to educate the public on the question of the employability of epileptics.

OPINIONS REGARDING THE CAUSE OF EPILEPSY

Persons in the lower income group attach much importance to the vague category 'nervous system disease' and little importance to birth injury (42% and 7%, respectively). The latter might reflect lack of insight into the importance of good obstetrics. This may indicate the need for

education in prenatal, natal and postnatal care as a prophylactic measure—especially at the level of the less privileged.

Higher income groups attach more importance to brain pathology—30% as opposed to 14% for the lower income group. The higher income group also recognises the importance of birth injury—2% to 7% of the lower income group.

Clearly then, SANEL should advance the study of the causes of epilepsy and of measures for its prevention; and promote training of personnel of relevant disciplines in the adequate care of epileptic disorders. In the words of Drs Taylor and Bower: 'Knowledge of epilepsy has reached a stage where some degree of prevention is possible. We consider here the possibility of preventing the birth of persons particularly liable to suffer serious epilepsy; prophylaxis against seizures; the prevention of cerebral damage due to seizures; and the forestalling of secondary handicaps in affected persons—usually such handicap is not due to the disruption caused by epilepsy itself but to psychosocial difficulties that attend it. The efforts which have been made to improve public attitudes to epilepsy have achieved a great deal in lessening its stigma. Yet epilepsy is still surrounded by much mystery and fear. Public enlightenment may not become complete until technical advances prove that man is master of this condition; and this is more likely to be brought about by prevention than by cure.'

Further, certain social psychiatric aspects of epilepsy are the direct concern of SANEL, and call for its attention, such as community care; epilepsy and insurance; epilepsy and air travel; epilepsy and driving of motor vehicles; and epilepsy and immigration in South Africa; and of great importance is the need to provide residential accommodation, occupation and supervision and care for those epileptics who are severely handicapped by their epilepsy in the occupational and the social spheres and for whom SANEL in the main exists.

In conclusion, the Witwatersrand Branch of SANEL is at present engaged in taking steps towards the development of a centre to provide accommodation for 40 such persons aged 18 years and over, but excluding persons qualifying for admission to homes for the aged, and the certifiable. It will cater for epileptics who cannot be placed in the open labour market or in sheltered employment because of their low productivity, and who on account of their personal and social circumstances cannot maintain themselves in normal community life but require supervision and care. It is envisaged that simple contract employment will be undertaken by these persons, as well as poultry-keeping and cultivation of vegetables. It is hoped that this scheme will come to fruition in the not too distant future.