

Attitudes To Epilepsy In Malawi

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Abstract

In this questionnaire study we evaluated views about epilepsy in an urban population in Blantyre, Malawi, and we contrasted these with the opinions of groups of nurses and medical students. The findings indicate that lay people now have a more sophisticated view of epilepsy, its causes and treatments than was evident in previous studies in rural or urban African settings, but there is still substantial prejudice that influences how epilepsy is regarded and inhibits access to effective therapies. The association of epilepsy with insanity and mental impairment is still commonplace, even among nurses, and treatment is too often considered to be the premise of the traditional healer rather than the trained nurse or doctor. Modern and effective control of epilepsy will only be possible when these views are changed. This can be achieved with minimal resources but requires local initiative and enthusiasm.

Introduction

To a greater or lesser extent we each hold the attitudes of the society from which we derive. Our approach to chronic disease is no exception, where atavistic concepts or prejudice guide our response to a particular disease, sometimes irrationally. Both leprosy and epilepsy are examples of this form of human behaviour where entrenched views may lead to inadequate care of conditions which otherwise are eminently treatable^{1,2}.

Previous studies in rural^{3,4} and urban^{5,6} African settings have indicated the extent of stigmatisation of epilepsy. This undoubtedly plays a significant role in maintaining the *treatment gap*, whereby only a small proportion of those who would benefit receive treatment, even where it is available. These earlier studies have shown the persistence of views that seizures are attributed to supernatural factors⁷, epilepsy is thought to be contagious⁸, and those with the condition are invariably mentally subnormal, if not frankly insane.

We re-evaluated these issues after an interval in a modern urban African population in order to gauge the progress which has been made in the maturation of knowledge and attitudes of ordinary people. A community which regards epilepsy as a physical disease of the brain that can be controlled with allopathic medicines will have thrown off the traditionally held prejudices. This is an essential pre-requisite to developing comprehensive epilepsy care.

Subjects and methods

In order to facilitate comparison, a knowledge, attitude and practice questionnaire used in a previous study⁴ was slightly modified and first applied to a group of 16 fourth year medical students at the College of Medicine, Blantyre, Malawi. The students then assessed the responses of a sample of 28 nurses

from the Queen Elizabeth Central Hospital, Blantyre. Finally 100 randomly chosen people identified in the street were questioned in the same way.

The medical students were requested to interview equal numbers of males and females, to ensure a range of ages and to select people who appeared to have a variety of occupations and educational backgrounds. Of the 100 interviewees there were 60 males and the mean age of the group was 28.4 years (range 16-81). The employment of the sample varied from a bank manager to watchmen and labourers. The area chosen has a high proportion of students and this was reflected in the survey.

Results

The results are presented to allow a comparison between the views of the lay people, the nurses and the medical students.

Witnessed Seizures

Seventy eight per cent of the lay people had witnessed an epileptic attack. Their feelings were said to be sorrow, pity or "bad" in 54%, frightened or scared in 24%, puzzled or surprised in 2% and no feelings in 5%. Of the nurses, 93% had seen a seizure, 54% felt pity, sorrow or "bad", 25% were frightened and 15% were concerned, in two cases for fear that the person would die in the attack. The medical students expressed pity or sorrow in 38% and fear in a similar number.

On witnessing the fit, 37 of the lay people took no action, 16 held the person down, 12 helped in various ways, 4 placed an object between the teeth, 3 poured water, 2 took the person to a cool place under a tree and 2 ran away. Ten of the nurses helped in various ways, in 5 cases a soft pad or hard object was placed between the teeth, a clear airway was ensured in 6 and tight clothing was loosened in 2. Three of the medical students placed an object between the teeth, 4 ensured the airway, 2 held the patient down and others helped in various ways. Similar actions were proposed within all the groups should another fit be witnessed.

Causes of Epilepsy

Forty four percent of lay respondents did not know a cause for epilepsy, 18% considered it to be inherited, 14% regarded the condition as stemming from witchcraft or spirits, in 9% it was due to brain problems, in 8% to worry, stress or thinking too hard, in 7% to malaria, fever or brain infection and in 17% to other factors. The nurses listed inheritance in 54%, brain problems in 21%, brain trauma in 21% and brain tumours in 11%. In 31% of the medical students epilepsy was said to be due to abnormal electrical discharges within the brain.

When asked whether epilepsy could be contagious, 23% of the lay subjects answered affirmatively, with 6 considering that seizures could be transmitted by inhaling the flatus passed by a person with epilepsy. None of the nurses or medical students regarded epilepsy as infectious. Furthermore,

40% of the street interviewees associated epilepsy with madness, as did 46% of the nurses and 19% of the medical students. Only 28% of the lay group considered that the intelligence of those with epilepsy was usually normal, 8% did not know and in 1% the condition was linked with supranormal intelligence. The nurses had a similar view with 75% of the opinion that most people with epilepsy were also afflicted with low intelligence, as was also the view held by 19% of the medical students.

Risks and Handicaps of Epilepsy

The street interviewees considered that there was a risk of burns (57%), drowning (41%), accidents or other injuries (38%), road accidents (10%), death (9%) and other risks (7%). The corresponding figures for the nurses were burns (75%), drowning (39%), road accidents (32%), other accidents (21%), death due to choking or suffocation (25%), rape (7%) and robbery (4%). The medical students cited burns (56%), accidents (50%), road accidents (31%), drowning (31%). In 25% the risk of driving with epilepsy was recognised.

The lay people stated that employment would be limited by epilepsy (12%), that there would be social isolation (5%) and that various other physical restrictions would apply (14%). The nurses and medical students also recognised the restrictions on driving and swimming and the reduced educational opportunities. The nurses were also concerned about their patients suffering burns leading to limb contractures. Some of the lay people specifically suggested that epilepsy correlates with being quarrelsome, laughed at, lacking control, being short-tempered, unreliable or unhappy, and that such people should not be provoked and could bring bad omens to the community.

With regard to the inconvenience or risk to those living with someone with epilepsy, the perceived need for regular or constant attention was mentioned by 51% of the lay group, 32% of the nurses and 62% of the medical students. Violence directed to the carers by the person with epilepsy concerned 22% of the lay people.

Control, Cure and Treatment

Epilepsy can be controlled or cured in the opinion of 67% and 54% respectively of the lay group but some suggested that this would not be the case if the person had been burned in a fire. The nurses also suggested that epilepsy can be controlled (79%) or cured (25%). All of the medical students were aware of the potential to control epilepsy and 69% thought that it can be cured. However, 60% of lay people thought that epilepsy was primarily treated by traditional healers, that doctors had a role in 40%, other health workers in 4%, and that the condition should be left in the hands of God in the view of 3% of respondents. The nurses and medical students were aware that a majority of treated patients sought help from the traditional healer rather than from modern medicine, but mostly perceived this as inappropriate.

Many of the lay people had no idea of the mode of

treatment for epilepsy, but 37% knew that herbal agents were used, 23% were aware of allopathic drugs, 2% prayers, 1% steam from the herb pot and 1% traditional spirit rituals. It was known that therapeutic cuts may be part of the traditional healing process.

School or Play Restrictions

The lay people were generally enlightened with regard to epilepsy and schooling but 11% felt that school attendance should not be permitted a child with epilepsy for reasons of dullness, high risk of injury or spreading the disease to other children. None of the nurses or medical students had reservations about children attending school. The street group would allow their child to play with another with epilepsy (84%) or to sit in the same class (90%).

Placement

Eighteen percent of lay people considered that those with epilepsy should remain at home, and 27% would like to see them cared for in a special hospital. The nurses thought that people with epilepsy should lead a normal life (89%) as did the medical students (94%).

Discussion

This survey in an urban population in Blantyre, Malawi, indicates a significantly more enlightened attitude to epilepsy than has been recorded in earlier years from rural populations in Malawi³, Tanzania⁴ or Ethiopia², and urban studies from Nigeria⁵ and Ghana⁶. Nevertheless, misconception, superstition, ignorance and prejudice are still evident and contribute to the low levels of conventional epilepsy care, the treatment gap and hence the high morbidity and mortality amongst epilepsy sufferers⁹. It would be wrong to attribute these factors entirely to economic disadvantage, although this is of course a major factor in Malawi as in most other African countries¹⁰. Similar superstitions have been reported from the United Arab Emirates where the population enjoy a high level of health expenditure and yet 40% believe in faith healing for epilepsy¹¹.

We evaluated responses in an urban population and it is therefore likely to reflect a more enlightened view of epilepsy than would be evident in a rural area where more resistant traditional opinions may still apply. It would be interesting to make a direct comparison in a parallel study and this would be important in a country where a large proportion of the population are rural dwellers.

Even among the town people there is still a strong feeling for traditional medicine in the treatment of epilepsy, as has been confirmed elsewhere¹². This need not necessarily be entirely disadvantageous to epilepsy care. While there is no convincing evidence that herbal potions are of any value as antiepileptic remedies, the spiritual aspects of traditional healing may be of help to those with epilepsy who have faith in such methods. It must be remembered also that access to a local traditional healer is much more readily available than to a modern health care facility. Nevertheless, there is a belief that the persistence

of ignorant myths about epilepsy may be propagated by traditional healers⁸ and this cannot be endorsed.

Education of the healers to properly understand epilepsy and to provide phenobarbitone as well as spiritual counselling has been shown to work in some communities, and it has been suggested that modern and traditional methods can be complementary¹³. This approach may represent a pragmatic compromise until more appropriate means of delivering treatment can be made readily available. There is evidence that once those with epilepsy have experienced the benefits of orthodox treatment they are unlikely to return to the methods of superstition^{12,14}.

The first aid treatment of witnessed seizures in this study was often inappropriate. Forcibly restraining the patient in the fit was often attempted, with the risk of injury or even of suffocation. Using a soft or firm gag to prevent tongue biting is also inadvisable, although this was as much the practice of the nurses as of the lay people. These well-meaning but ill-advised interventions are probably as commonplace in Western societies.

The consequences of a general lack of epilepsy care are tragically emphasised in the results from an audit in the Burns Unit at Blantyre where 14% of admissions were in people with epilepsy and the mortality in these patients was double that in the unit as a whole (J. James-personal communication). This contrasts with 1.6% of burns (scalds) admissions in epileptic patients in a unit in Wales¹⁵. Many of these burns may have been prevented if antiepileptic treatment had been available, since only 10 of 44 patients were on therapy. The point is also made in a prognosis study from Tanzania⁹ where a high mortality rate associated with epilepsy revealed that the cause of death was related (status epilepticus, drowning, burns, dying in a seizure) in greater than 50% of cases. Thus the importance of changing the attitudes of people to epilepsy cannot be underestimated, in anticipation that this will lead inevitably to wider uptake of treatment and a reduction in associated morbidity and mortality.

It is disappointing to note that there is still a belief that epilepsy is linked with violent behaviour, mental illness and in particular with low intelligence. There is little published work on the intelligence of an African epileptic population but there is no reason to consider that the levels of mental subnormality would be significantly greater than in series from the West, accepting that a small increase may arise from higher numbers of obstetric mishaps and undertreated infections in early childhood.

A figure of 7.9% of cases of mental retardation was given in a study from Ethiopia¹⁶ which is likely to be more accurate than the substantial overestimation by the lay people and the nurses in the present study. This attitude must contribute adversely to the prejudice directed against epilepsy in the cases of schooling, marriage and employment. On the other hand it is encouraging to note that most of the persons questioned are not concerned at the thought of their children playing with an

epileptic child, nor did the majority feel that such children should be excluded from school.

In a list of the requirements to establish a viable epilepsy care service in Malawi¹⁴, the first points were that there should be good publicity and education of staff and patients. To this must be added the continuing need to educate the population as a whole. The development of local epilepsy associations, the involvement of high profile people and cooperation from the media are some ways of achieving this aim. Simple and inexpensive interventions such as the training of health care workers are of proven value¹⁷. Improved services for epilepsy represent a cost effective and worthwhile expenditure of scarce health resources.

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APPENDIX

In addition to the named authors, the following medical students also contributed to this study:- K Chiwaya, L Dullie, M Kagoli, K Kawaza, V Luhanga, M Maliwichi, L Mankhambo, T Mdezo, A Msusa, S Mzumara, H Ndindi, M Nyirenda, J Phuka, P Tembo, and C Valera.