



PSYCHOSOCIAL STUDY OF EPILEPSY IN AFRICA

LOUISE JILEK-AALL,^{1*} MARTICA JILEK,¹ JOHN KAAYA,²
LILIAN MKOMBACHEPA³ and KALISTER HILLARY²

¹Dept. of Psychiatry, University of British Columbia, Vancouver, BC, Canada, V6T 2A1, ²Mahenge Hospital, Mahenge, Tanzania and ³Ruaha Dispensary, Ruaha, Tanzania

Abstract—As documented by many authors, the social position of epileptics in many small scale societies of Africa is marginal at best, and is often characterized by rejection, discrimination, even ostracism. Such negative and noxious attitudes toward persons suffering from epilepsy are rooted in traditional beliefs about causes and nature of convulsive disorders and these have parallels in European history. This article focuses on the psychosociocultural aspects and indigenous concepts of epilepsy, on popular attitudes towards, and social status of, sufferers from epilepsy in a Tanzanian tribal population. The authors present a comparative analysis of focus group discussions conducted with epileptics and with matched controls in two isolated communities. In one community (Mahenge) a clinic for epilepsy has been operating for over 36 years, with a public education component during the last four years, whereas in the other community (Ruaha) epileptics have only been sporadically treated in a small mission dispensary and people have had little opportunity to learn about the nature and modern treatment of convulsive disorders. The responses obtained in focus group discussions reflect the significant change in notions about the illness, in the attitude toward and in the social status of epileptics in Mahenge, while the people of Ruaha still regard epilepsy as a typical “African” affliction fraught with supernatural danger and not effectively treatable by modern medicine. © 1997 Elsevier Science Ltd

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INTRODUCTION

In the Western world with its modern medicine and emphasis on public health education, the attitude toward epilepsy is still coloured by residual beliefs from the Middle Ages. The reaction to epilepsy in Africa is not only coloured by the influence of ancient European misconceptions (Jilek, 1979) but is also shaped by traditional indigenous beliefs which are surprisingly similar throughout the African continent and result in severe psychological hardship. Since the African epilepsy sufferers share these beliefs, they have a hard time to achieve positive feelings about themselves and frequently suffer deprivations without protest (Jilek and Jilek-Aall, 1970, 1980; Jilek-Aall, 1976; Giel, 1968; Johnson, 1979; Awaritefe, 1985, 1989; Whyte, 1986; Beneduce and Koumare, 1989; Hutten, 1994). In 1970 Osuntokun and Odeku (1970) reviewed 522 Nigerian epilepsy sufferers and observed that the patients suffered psychosocial handicaps including a suicidal tendency because they themselves considered epilepsy a social disgrace. Modern treatment for epilepsy is often unavailable in Africa. The reason might be lack of treatment facilities, but also the general belief that epilepsy is of supernatural causation and therefore not treatable by Western medicine (Aall, 1962; Aall-Jilek, 1964; Danesi, 1984; Jilek-Aall and Jilek, 1989). Few indigenous medi-

cine men know how to treat convulsive disorders effectively and except for some herbal remedies, their treatment mostly consists of ritual procedures performed for the patient and for the protection of other family members against the dreaded affliction. Epilepsy therefore takes its natural course and the patients may suffer uncontrolled seizures daily, weekly, or monthly for years on end (Jilek-Aall and Jilek, 1989).

Research on epilepsy has shown that persons with a long history of uncontrolled tonic-clonic seizures may develop serious psychopathology. Frequent seizures can lead to post-ictal confusion states, sometimes with violent outbursts and inappropriate behaviour. Acute psychotic episodes with vivid hallucinations may occur or chronic psychotic conditions may develop with paranoid delusions and periods of aggressive behaviour (Asuni and Pillutla, 1967). Gerrits (Gerrits, 1983, 1994) wrote that psychological and intellectual disturbances were observed in 25% of all patients with epilepsy seen in a region of Liberia, and Odejide and Bademosi (1976) found in a 1976 study that 29.1% of epilepsy patients over a period of six months were suffering from psychiatric illnesses while attending the University Hospital in Ibadan, Nigeria.

Dangerous behaviour, often of sudden unpredictable onset, and the release of violent energy during convulsive seizures make the victim appear as if in the grip of a strange power. This provokes intense

*Author for correspondence.

fear in those present and has probably done much to perpetuate the belief that epilepsy is caused by evil spirits or other supernatural forces (Aall-Jilek, 1964). Therefore when the first grand mal seizure throws epileptic sufferers to the ground, a catastrophic psychological shock awaits them when returning to consciousness, surrounded as they will be by people displaying intense emotional upheaval and frantic activity. The smitten person believes, as do the other people, that somebody is to blame for the calamity. Maybe someone in the family has broken a taboo or in other ways offended an ancestral spirit who thus shows its wrath. Shame, guilt and fear grip the sick person and every family member, and while trying to hide the illness from outsiders, they will together consult a diviner or medicine man in order to find the culprit and to pacify the ancestral spirit. When this does not help, demoniac influence, witchcraft or sorcery is suspected; rituals and counter magic will be performed. An atmosphere of suspicion and fear will destabilize the family unit. As the seizures continue, hostile feelings towards the "troublemaker" will develop and place the epilepsy sufferer on the road to rejection and social isolation (Giel, 1968; Beneduce and Koumare, 1989). Fortunately not always, but in the majority of tribal societies, persons with convulsive disorders are therefore feared and rejected, not least because of the pervasive belief that epilepsy is contagious. This belief, which was also held in Europe before modern medicine proved it to be false, appears to be ubiquitous throughout Africa (Jilek, 1979; Awaritefe, 1989; Jilek and Jilek-Aall, 1980; Edo and Haddock, 1970; Giel, 1970). People believe that the saliva or other excretions are contagious, especially during an attack, and that touching the convulsing person may cause the epilepsy spirit to leap over onto one. In many societies this fear leads to further isolation of the epilepsy sufferers; they have to eat out of separate bowls, draw water from a separate water hole and sleep in a separate hut. The most devastating effect of this belief, however, is that the people will retreat in horror as soon as they see a major convulsion starting, lest they contract epilepsy themselves. The person who suffers tonic-clonic seizures is therefore unprotected during an attack. Crippling or death by burns or other accidents are often the consequence, as are falls into the water and drowning. The deep unconsciousness of the ictal phase makes the onlookers assume that the epileptic is dying. This is reflected in local names for the affliction, like *kifafa*, Swahili, in East Africa meaning "the little death" (Aall-Jilek, 1965) or *abiku* in Nigeria meaning "born to die" (Dada, 1968). The complete recovery which mostly follows a grand mal seizure appears to the people just as mysterious as the attack itself and is therefore often attributed to the healing power of medicine men or religious healers, or to procedures undertaken by the relatives themselves on the

advice of such practitioners. These procedures, made to awaken the unconscious person to life, are often extremely painful and damaging: burning the foot soles, dripping acid liquid into the eyes which may lead to blindness, or forcing a mixture of cow urine with pepper down the throat of the unconscious person which is done among some West African populations and may be life threatening (Osuntokun, 1972, 1978).

Chronic epileptics may notice that seizures tend to occur at regular intervals, or in two to three month intervals. Anxious to avoid confrontation and "treatment" by their kin people, they will observe the phases of the moon as periodic time measure and will try to withdraw or go into hiding until the period of risk has passed. A connection between the phases of the moon and convulsive attacks has been made since ancient times. It was, and still, is believed that either the new moon or the full moon is directly influencing and provoking seizure activity (Jilek-Aall *et al.*, 1979).

To suffer from epilepsy in Africa thus often means to also suffer from a very specific psychological and social trauma (Billington, 1968; Dada and Odeku, 1966; Jilek-Aall and Jilek, 1989; Orley, 1970). It will drastically change the way a person perceives life and his or her position within the family unit. Epileptic children are refused school attendance, and people with epilepsy can hardly find worthwhile employment or a healthy spouse. Because of the belief that epilepsy may be contagious or caused by supernatural forces, epilepsy sufferers are shunned and feared by their fellow men, and they themselves are ashamed and frightened.

THE MAHENGE CLINIC FOR EPILEPSY

When an outpatient clinic for the treatment of epilepsy in the isolated population of the Pogoro in the interior of Tanzania was started by Dr Jilek-Aall, the senior author of the present article, 36 years ago, she noticed the miserable plight of the epilepsy sufferers and found that about 24% of the epileptic patients were suffering from manifest psychopathology (Aall-Jilek, 1965). She introduced phenobarbitone as anti-convulsive medication because of its known good effect in curbing the feared tonic-clonic seizures, and because this treatment is simple and affordable. Contrary to the prediction of many colleagues, the majority of patients turned out to be capable of taking their medication and visiting the clinic regularly. Although the Mahenge Clinic for Epilepsy has not always been able to provide enough medication and service throughout its 36 years of existence, the results of its epilepsy treatment have been very encouraging, not least in relation to manifest psychopathology (Jilek-Aall and Rwiza, 1992).

In 1990 the International Development Research Centre (IDRC) in Ottawa, Canada, funded a three

year joint Canada–Tanzania research project to study the epilepsy problem and the reasons for its unusual high prevalence in the Pogoro tribe living in a mountain area of Mahenge (prevalence rates of epilepsy between 11 per 1000 in the town of Mahenge and 125 per 1000 in one isolated village, were found) (Rwiza *et al.*, 1992). Because the Mahenge Epilepsy Clinic was part of the IDRC project, the clinic was significantly improved, and is now treating more than 700 patients. It has a permanent staff of one medical assistant, John Kaaya; a psychiatric nurse, Kalister Hillary, herself Pogoro and raised in Mahenge; and two visiting Tanzanian neurologists trained in Europe who are staff members of the Muhimbili University Hospital in Dar-es-Salaam, Professors Henry Rwiza and William Matuja.

In 1994, at the end of a three year research period, the authors undertook to explore if and how the project, through its treatment and education programmes, had influenced the local people's attitude towards epilepsy and if so, whether the patients' living standards and physical and mental well-being had improved. Besides looking at seizure control and re-examining the mental status of the patients, the authors carried out qualitative analyses research with selected focus groups of patients and non-affected people in the research area (Mahenge) and in a control community (Ruaha), located far enough away so as not to have been influenced by the Mahenge Epilepsy Clinic.

THE FIELD RESEARCH SETTING

Geographical and social environment

Mahenge consists of one small town surrounded by tiny villages and clusters of huts situated in a mountainous region about 500 km from the Indian Ocean with a population of about 20,000. Apart from government buildings, a newly constructed bank, a post office, a small police station, a prison and a government hospital, a few guest houses and small restaurants, there are several churches with a conglomerate of different people and races. The majority of the population, however, are subsistence farmers of the Pogoro tribe who may sell food products on the Mahenge market and buy the few household items they need in the small local stores. There are still children from remote villages who never go to school and most older Pogoro people can hardly read or write. Those who complete the local secondary school or the Capuchin priest seminary tend to emigrate from the area to seek employment elsewhere. Apart from a few generators there is no electricity, no TV and only a few transistor radios and tape-recorders. News from the outside world is rarely received as telephones seldom function, vehicles are few and most habitations are reachable only by foot or on bicycle. On weekends

the nights reverberate with modern African music in the town's small bars and restaurants and from the drums of the *goma*, traditional feasts, in the countryside. Beer and soft drinks are available but hardly affordable. At the *goma* men, seldom women, get drunk on *pombe*, a homemade brew. The Catholic church with local priests and nuns and its beautiful choirs and colourful festivities still attract most Pogoro people, but migrant workers in newly opened diamond and ruby mines are slowly bringing in different creeds and also AIDS and other modern illnesses.

Ruaha is a smaller community at the foothills of the Mahenge mountains, reachable only from Mahenge by a day long trek or by car on a treacherous and winding mountain road, which is impassable during the rainy seasons. Here, too, most inhabitants are subsistence farmers living in mud huts in small villages or family compounds. From the fertile hills and mountains the people come to Ruaha for the market and to the Catholic church and its dispensary which has been in operation since the Catholic Mission was established in Ruaha over 40 years ago. Modern education in small elementary schools is rudimentary and news from the outside world seldom reaches this isolated region. Curious young people wander off to Mahenge, the mines or other towns, seldom to return except when they meet with disaster such as contracting AIDS, TB, or other illnesses. Then they may come home to be cared for by their family and to be buried in their own villages.

RESEARCH DESIGN AND DATA COLLECTION (Yoddumern-Attig and Attig, 1984)

The research team

The research team consisted of:

- two moderators—in both locations there was one medical assistant and one local mental health nurse who spoke English and the local language;

- a principal investigator—main author, neuropsychiatrist, anthropologist, and specialist in tropical medicine, English speaking with a fair knowledge of the country's language, Swahili; and

- a participant observer—co-author, student nurse, non-involved observer and English speaking note-taker.

The focus groups, which consisted of six to 12 people, were selected to be as homogenous as possible, i.e. each group had participants under 24 or over 25 years of age, males or females, patients with epilepsy or controls. There were five patient and five control groups in Mahenge and four patient and three control groups in Ruaha. Meetings with each group were held in the Epilepsy Outpatient Clinic in Mahenge hospital and in a school room at the Catholic Mission in Ruaha.

Each session lasted about two hours and a tea break was planned but not always kept.

The groups were placed in a semicircle facing the team members who used a table for note-taking and instruction papers. The sessions were opened by a short orientation period in which the team members introduced themselves and explained the purpose of the gathering. Group members were then asked to give their name, age, and whatever personal information they choose to reveal. The participant observer wrote notes on each person's appearance, facial expression, and emotional state as well as describing the reaction to questions and to each other. She also noted physical and mental peculiarities such as burn scars, mutilations, nutritional state, tics, gestures, odd behaviour, etc. Both she and the principal investigator wrote down the responses immediately as they were understood or translated, using the prerecorded coding system (Appendix A). During evening hours they compared, discussed and ordered the field data according to Context and Recording Units. The Context and Recording Units as described in Appendix A were constructed before the field work took place and are based upon the main author's intimate knowledge of traditional beliefs on and treatment of epilepsy, gained during several years of medical work among the Pogoro people more than 30 years before the research, as well as on literature reviews and her previous publications related to epilepsy in Africa (Jilek, 1979; Jilek-Aall and Rwiza, 1992).

QUALITATIVE ANALYSIS

Communication problems due to sociocultural, psychological and other variables

The two nurses who knew most families in their communities encountered unexpected difficulties in organizing the groups. The patients in Mahenge who have been used to regular monthly visits to the Epilepsy Clinic since its foundation in 1960 were more willing than others to come for the groups, but were perplexed and showed ambivalent emotions when finding themselves obliged to deal with other epilepsy sufferers. Whenever epilepsy patients meet at the clinic entrance, they can be observed to politely exchange a few words, but in the clinic they look straight ahead or at the nurse. Untying the hidden medicine bottle from their clothing, they wait silently until the nurse has counted out the tablets and refilled the bottle, answering her questions as briefly as possible. When walking out they pass the waiting people, without looking right or left until they are far away from the hospital. Group discussion was to them a new and unexpected experience. In Mahenge and more so in Ruaha, participants at first sat stiffly and viewed each other with embarrassment. But soon curiosity would take over and even the most

timid ones listened attentively to those who dared to speak. After some time most patients would relax, become involved and help those who could not find words. Probably for the first time in their lives did they come out of their loneliness and experience the comfort of sharing their pain with fellow sufferers. At the end of a session they would often react with relief and excitement and thanked us with smiles. Some would ask when we could meet like this again. The greatest difficulty in communication was encountered with groups of women under the age of 24, whether patients or controls. In Pogoro tradition, young girls are expected to be shy and to say little or nothing at all, especially in front of strangers or older people. The girls in the groups appeared deeply embarrassed and would giggle when asked questions, looking down and hide their faces behind their scarfs. When coaxed, they said nothing or "I don't know". If they finally did give an answer they became further intimidated by wells of laughter from the other girls.

It was noticed that many persons without epilepsy refused to take part in control groups, more so in Ruaha than in Mahenge, and were quite suspicious of our motives. Some stated they did not want to deal with epilepsy or that they knew nothing about it. There was, however, a significant difference between the two locations in the true motivation for refusing. People in Mahenge, although certainly knowing about traditional beliefs and practices regarding epilepsy, disliked and felt embarrassed when asked to talk about such "old stuff" and would come up with answers they thought were more "modern", which indicates that they are no longer completely in their cultural tradition. Some people in Ruaha did not show up, hence smaller and fewer groups, or they displayed genuine fear when asked questions directly related to epilepsy, which indicates that they are still completely immersed in their culture. Traditional Pogoro people avoid even mentioning the word epilepsy for fear the spirit of *kifafa* (epilepsy) might become angry and take revenge upon the family of the disrespectful offender. It was, therefore, on many occasions necessary to modify or repeat some of the most sensitive questions, specifically those related to beliefs about causes of epilepsy, witchcraft practices, danger of epileptic attacks, blame for their occurrence, etc. People in rural environments are unaccustomed to talk about their feelings. Some of the questions in Context Units III and IV had to be combined or simplified as many people were unable to distinguish between their emotional reaction to epilepsy and the actual description of a seizure, or between the family's reaction and actions when facing an epileptic attack for the first time. The mediators, themselves local people, sometimes became too involved and would hesitate with certain questions or get irritated when people did not

answer. They had to be reminded of their role which they accepted with good humour.

GENERAL ANALYSIS OF THE FIELD DATA*

When observing the groups in the two communities the difference in appearance and behaviour was immediately apparent. Whereas people in Mahenge, with few exceptions, were well dressed and lively with little difference between patients and controls, the patients in Ruaha presented a miserable picture. With poor and dirty clothing, burns or scars, sores and physical ills, dull or sad expression, they contrasted sharply with the control groups there.

There was no significant difference in descriptions of an epileptic seizure. In both places many patients could describe an aura. As everywhere, patients with epilepsy often had to be told about their own seizures; most only knew because of post-ictal headache, fatigue or confusion, or because of a sore tongue, burns or other injuries.

The question about causes of epilepsy produced embarrassment and in Ruaha, much anxiety. Ten out of 27 patients responded with silence or with the uncommunicative "I don't know". An older man in a control group expressed it thus: "People used to believe that it was witchcraft, but nobody likes to talk about it, probably some would in privacy." Persons in Mahenge, especially control groups, who mentioned witchcraft or other traditional explanations would encounter protests or ridicule from other group members. The educating effort of the Mahenge Epilepsy Clinic was reflected in the explanations by clinic patients and controls, such as hereditary, repeated fever convulsions, brain damage, "natural" causes, fever, depression, and alcohol or drug abuse. In Ruaha people in all groups were afraid and cautious and would often not commit themselves to an explanation. The most frequent answer was "bewitchment" or "witchcraft", but some group members upon hearing this would react with anxious denial, e.g. "I never heard of such things". Helped by the mediators other traditional causes were mentioned such as punishment for wrong doing, contagion through contact with the saliva of a convulsing person, a "clan" affliction, answers indicating that people in Ruaha are still deeply steeped in the traditional beliefs about this "dangerous" affliction.

Older women, patients and controls, were in general more able to discuss feelings than others. When working on our field notes for the final analysis, we were astonished to discover that none of the patients or the controls in Ruaha had answered the question about their reaction to an epileptic seizure. We had recorded: "The group members were unable or unwilling to answer questions about feel-

ings" or "they did not understand the question and instead described the attack again". For the group of girls with epilepsy under the age of 24, our notes read: "Stunned silence. One girl age 10 stood up and said she wanted to go home. Others persuaded her to stay but nobody answered the question". Group participants in Mahenge were able to express feelings like shocked, startled, fear, wonder "why me?" and compassion yet the urge to run away. People were quick to add that in former years they would indeed have run away, but not nowadays. Some added that they knew how to protect a person in a seizure, i.e. getting sharp objects out of the way, loosen tight clothing and, unfortunately, putting something between the teeth of the convulsing person. More women than men expressed compassion and willingness to help an epileptic in seizure. In Ruaha seven out of 18 controls finally admitted something like shame or fear and most participants there eventually admitted that they would not touch a stranger having a seizure. This was demonstrated when a young boy happened to have a seizure outside the room where we held our meeting. The session was interrupted as people ran outside. Standing at a distance they would stare at the convulsing person, but only health workers from the dispensary were willing to carry the unconscious boy to a shady place.

Hospital workers in Mahenge know that people consult healers and try traditional medicine before coming for medical help. Participants in our groups denied this or hesitated to admit it and those who did inevitably commented that traditional healers could not successfully treat epilepsy and that sooner or later the patient would be taken to the hospital for medical help.

Some, especially controls, insisted that nowadays epilepsy sufferers were advised to go directly to the Epilepsy Clinic. The impression gained was that healthy people are usually not interested in epilepsy and its problems and few know about whether an epilepsy sufferer goes to the clinic or not, except if they happen to have one in their family. Nine out of 27 controls had never seen an epileptic seizure although all group members knew of *kifafa*. In Ruaha questions about treatment of epilepsy were not taken well, each person waiting with apprehension for others to answer first. The controls, except for three older women, preferred to ignore the questions or pretended not to hear them. Patients and the three older women of the control group finally stated that epilepsy sufferers would be taken to a "witch doctor" (they did not use the word for traditional healer) who "can heal any illness" as one woman insisted. Some had half-heartedly taken the patient to a dispensary but few seemed to have faith in that kind of treatment. "This is an African illness", was one explanation. Tension lifted when we switched to inquiries about food restrictions. The groups became more lively, people laughed and

*For details see Appendix B.

discussed among themselves. Again there was a significant difference not so much between patients and controls, as between the two communities. As expected, women in general knew more about food than men, but except for one man and two women, the controls in Mahenge said there were no food restrictions for epilepsy sufferers. All group members in both locations agreed, however, that any kind of alcoholic beverage was taboo although it was admitted that some young men with epilepsy would still drink sometimes, especially at family feasts. Food restrictions were numerous in Ruaha and a few of these were still known but rarely observed among the patients in Mahenge. When listing food restrictions people in Ruaha could not tell the reasons for them, whereas patients in Mahenge came up with rational explanations, i.e. "epilepsy sufferers must not eat ripe bananas because the banana peelings are slippery, the epileptic could fall and have a seizure". The fish *kambali* should not be eaten because it is slimy like the saliva of the frothing epileptic, it slips from the hands, falls to the ground and flops about, like the convulsing person. Raw meat should not be eaten by epileptics because fresh blood can cause an attack (blood in the mouth from tongue bite?). The food restrictions most often mentioned were: *kambali*, or other small fish with "ugly" faces, ripe bananas, certain kinds of vegetables which get slimy when cooked, red pepper or *pili-pili*, and chicken, especially head and feet (often used in traditional medicine). One thin, obviously neglected woman patient in Ruaha said that a person with *kifafa* is not allowed to consume anything sweet like sugar cane or soft drinks, no chicken or goat meat, nor slippery vegetables or even cassava because "they have *shetani* (evil spirit) in them". She caused much laughter when adding "and even just the smell of alcohol feels like *shetani*".

What makes life so miserable for people with epilepsy in Pogoro culture are the restrictions they suffer because of the pervasive fear that *kifafa* is contagious. This is not necessarily understood in the medical sense but might mean that the evil spirit of *kifafa* can transfer from the convulsing person to bystander through contact with saliva or other excretions or simply through bodily contact. This fear and the conviction that *kifafa* is a punishment for some wrong doing which brings misfortune and shame to the whole family, leads to rejection and isolation of the epilepsy patient. In both localities controls admitted epilepsy sufferers are harshly treated. The patients, sharing the cultural belief, were painfully aware of each other's presence when dealing with these questions and tried to deny or minimize the negative behaviour they experience. But the dishevelled appearance, disfiguring burn scars, fresh burns, other wounds and physical ill health, so characteristic of the patients in Ruaha, told their own story. The sadness and fear reflected on their faces together with their timid behaviour bore witness to their suffering,

even when they refused to acknowledge it. They defended their loved ones or assured us that only other families and strangers are afraid of contagion and therefore run away instead of helping during a seizure. In Mahenge patients who admitted having had to eat and sleep alone assured us that the fear of contagion was now a thing of the past and only encountered in other localities. Restrictions nowadays were only for the protection of the afflicted, i.e. a *kifafa* sufferer should not sit close to the fire, fetch water or bath alone. Work and place restrictions in Mahenge were generally interpreted as protective only for the epilepsy sufferers themselves, in Ruaha protection was meant to be for the afflicted as well as for people close by. One boy in Mahenge and two girls in Ruaha said they could not play with the other children, "the children don't like me". Others said they were not allowed to take part in *goma* (traditional feasts) or other public gatherings. In Mahenge the rationale was "because there the epilepsy sufferer may be tempted to drink alcohol". People in patient groups would laugh, knowing that this was indeed often true. In Mahenge many patients stated that since they were in treatment at the Epilepsy Clinic and were free of seizures, they had no more work restrictions and were free to go any place. A few had even the courage to return to school, although the general consensus among patients and controls both in Mahenge and Ruaha was that people with epilepsy could not go to school, and most had not dared or not been allowed to return. The question of restrictions to marriage was another difficult topic. First of all, young boys and girls in Ruaha were too shy to answer. They only sniggered or said nothing. The group of women under 24 by now refused to deal with more questions and, after having thanked us politely, took their leave. The women over 25 in Ruaha were indifferent or non-committal; they all had children anyway. The controls both in Mahenge and in Ruaha agreed that it is difficult for an epilepsy sufferer to marry because they cannot look after children well, may be severely injured by falling in the fire when cooking, drown when fetching water or fishing, and epileptic mothers could perish while still having small children. Another reason mentioned was that couples with one or both partners having epilepsy have a greater chance of having children with epilepsy. Therefore, normal people hesitate to marry a person with epilepsy. For the same reason parents are unwilling to consent to such a marriage. Quite often epilepsy sufferers marry each other. In Mahenge people were more willing to discuss this. It was brought up that divorce was acceptable if the affliction had been hidden from the partner before marriage. Some epilepsy sufferers who had shown that they could well take care of themselves and were able to work normally had no difficulties in finding a marital partner, and even the partner's family would nowadays have few objections.

RESULTS

Mahenge

Study results in Mahenge include the following.

1. Traditional beliefs regarding epilepsy which created fear of, and discrimination against, epilepsy sufferers, have weakened.
2. The attitude and behaviour toward epilepsy sufferers has changed for the better because people have seen the improvement of seizures through medical treatment. People now say that *kifafa* cannot be an "African affliction" since Western medicines from the hospital are effective (medical instead of magical treatment). During the field research in Mahenge in 1992, people saw how epileptic patients, hitherto discriminated, became the centre of attention; a room in the rundown old Mahenge hospital was painted and prepared for their examination and treatment; a brand new electric power generator was installed for the Epilepsy Clinic and later donated to the hospital; and African and foreign physicians occupied themselves with the epilepsy sufferers, bringing supplies of medicines and other goods.
3. Fear upon witnessing an epileptic seizure has diminished, an indication that the Epilepsy Clinic's health education and practical advice how to handle a convulsing person has penetrated the local population. Patients, their families and friends, village chiefs and all health professionals were invited to cooperate and received education on medical causes and treatment of seizure disorders.
4. The physical and mental improvement patients attending the clinic experienced has also improved their functioning, self-confidence, and outlook on life. This is reflected in greater acceptance into family and community, which has significantly improved their quality of life.
5. The popular outlook regarding epilepsy in Mahenge is optimistic, except for realistic concerns of securing adequate medication supplies for the Epilepsy Clinic. During group sessions, further actions to improve the lot of the epilepsy sufferers were suggested by group participants, such as special teachers to help epileptic children in school or special classes, better funding for the clinic, and more education and consultation from expert health personnel. The recent formation of an Epilepsy Society in Mahenge testifies to the increasing willingness of the general population to take actions to improve the lot of those who suffer from epilepsy. The participation of epileptic patients in these actions demonstrates their readiness to assume responsibility for their own rehabilitation and for the improvement of their quality of life.

Ruaha

Study results in Ruaha include the following.

1. Because of lack of government assistance, the church dispensary in Ruaha has always had to charge for parts of medication cost. But for the physically weak and often mentally disabled epilepsy sufferers in Ruaha, earning money is nearly impossible and their families, being quite poor themselves, are not inclined to pay for long term treatment.
2. Frequent change of personnel at the understaffed dispensary leads to lack of continuity. Therefore, medical treatment of epilepsy sufferers is often sporadic and may consequently cause severe withdrawal seizures. Confidence in medical treatment remains very low and is not increasing.
3. No systematic health education on epilepsy has been provided in Ruaha.
4. The belief that epilepsy is caused by angry spirits or witchcraft prevails and people in Ruaha are therefore unwilling to discuss the epilepsy problem in their community. Both patients and controls are at a loss to suggest any actions for future improvements. Most persons suffering from epilepsy as well as their families appear to have given up any hope of improvement from medical treatment and the epilepsy sufferers have resigned themselves to the miserable lot assigned to them by their society.

SUMMARY

Two rural communities in the interior of Tanzania were investigated for changes in attitude towards epilepsy and possible improvement in living standard and well-being. The majority of the people belong to the same tribe and culture and have an unusually high prevalence of epilepsy. In one community, Mahenge, a medical outpatient clinic for epilepsy connected to the regional government hospital, has been in operation since 1960 and its function improved as the result of a three year research project on epilepsy from 1990 to 1994, whereas the other more isolated community, Ruaha, has only a small nongovernment dispensary with limited resources. The four weeks of field work in 1994 which consisted of re-evaluation of 260 project patients at the Epilepsy Clinic in Mahenge included the conduction of selected focus group discussions with patients and controls in both communities. The results of the focus group discussions in the two communities have been analysed in this paper.

CONCLUSION

Epilepsy patients and controls in the one community, Mahenge, gave similar responses to the ques-

tionnaires used during group discussions on epilepsy, and likewise the responses of patients and controls in the other community, Ruaha, were very similar. However, the responses obtained from both epilepsy patients and controls in Mahenge differed significantly from the responses obtained from patients and controls in Ruaha.

The qualitative analyses of selected focus group discussions in the two communities confirmed the empirical impression that the regular medical epilepsy treatment which had gone on since 1960 and the epilepsy research project in Mahenge have positively influenced the attitude towards epilepsy among the local population. In Ruaha, where epilepsy treatment has only been sporadic, people still have the same negative attitude towards epilepsy as people in Mahenge used to have before the Epilepsy Clinic was organized there some 36 years ago.

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APPENDIX A

Prerecorded Coding System

<i>Context Unit I</i>	<i>Epileptic patient</i>	<i>Examples</i>
Recording units	1.1 Appearance and behaviour	Difference in appearance between patients and controls
	1.2 Types of seizures	1.1 Neglected, physical and mental ill health
	1.3 Description of seizures	1.2 Differences between epileptic seizures and other seizures, i.e. febrile convulsions
		1.3 Patients subjective understanding
		What other people say about seizures
<i>Context Unit II</i>	<i>Causes of epilepsy</i>	
Recording Units	2.1 Most frequent explanation	2.1 Hereditary, supernatural, contagious disease
	2.2 Traditional causes	2.2 Witchcraft, punishment for wrongdoings, revenge by spirits or people, spells, possession
	2.3 Medical explanation	2.3 Brain disease, head trauma, malaria, other physical or mental causes
<i>Context Unit III</i>	<i>Reaction to epilepsy</i>	
Recording Units	3.1 Individual reactions	3.1 Shock, fear, guilt, anger, depression etc.
	3.2 Family reaction	3.2 Shame, trying to hide illness, rituals etc.
	3.3 Community reaction	3.3 Rejection, avoidance, indifference, acceptance
<i>Context Unit IV</i>	<i>Treatment of epilepsy</i>	
Recording Units	4.1 Traditional	4.1 Healer for herbal medicine, rituals for patient and family; food and other taboos
	4.2 Biomedical	4.2 Hospital, dispensary, Epilepsy Clinic
	4.3 Combination	4.3. What is tried first? How, together?
<i>Context Unit V</i>	<i>Restrictions</i>	
Recording Units	5.1 Food and drink	5.1 Vegetables, meat, fish, fruits, beverages
	5.2 Family restrictions	5.2 Isolation because of fear of contagion; hiding
	5.3 Place and work	5.3 School, workplace, market, church, feasts
	5.4 Marriage	5.4 Restrictions from partner, from family
<i>Context Unit VI</i>	<i>Changes in attitude</i>	
Recording Units	6.1 Changes in patients	Feels helped; personal outlook, quality of life
	6.2 Changes in family	More accepted re: closeness, marriage etc.
	6.3 Changes in community	Is community willing to help? More now than before?

APPENDIX B

Summary Of Group Discussions With Epileptic Patients In Mahenge And Ruaha

	MAHENGE	RUAHA
<i>Context Unit I</i>	<i>Group I: (7 males over 25)</i>	<i>Group I: (5 males over 25)</i>
Recording Unit 1.1: Appearance and behaviour	5: well dressed, communicative; 2 spoke English 2: communicated poorly; depressed	1: well dressed, communicative 4: neglected, shy, communicated poorly; of these 2 were physically ill and 2 had severe burn scars
	<i>Group II: (12 females over 25)</i> 7: well dressed, communicative, friendly 5: shy, suspicious, sad; 3 of these had old burn scars	<i>Group II: (7 females over 25)</i> 1: well dressed, communicative 2: neglected, shy, no eye contact 4: friendly but not spontaneous 4: women had severe burn scars
	<i>Group III: (8 males under 25)</i> 5: well dressed, communicative, alert, friendly, and proud 2: depressed but communicative 1: looked dull, neglected, communicated poorly	<i>Group III: (8 males under 25)</i> All poorly dressed and neglected 4: physically ill, sad, quiet 2: communicative, friendly 2: depressed, severe burn scars on head
	<i>Group IV: (7 females under 25)</i> 4: well dressed, communicative, lively, frequent smiles 3: shy, self-absorbed, quiet	<i>Group IV: (7 females under 25)</i> All poorly dressed, neglected, shy, communicated poorly 3: severe burn scars 5: small stature, underdeveloped
Recording Unit 1.2: Types of seizures	All participants in all groups knew the difference between febrile convulsions and epilepsy Most described tonic-clonic seizures and post-ictal symptoms	All patients in all groups (except for 3 young girls who gave no answers) knew the difference between febrile convulsions and epilepsy Seizures poorly described
	<i>Group I: (7 males over 25)</i> 4: unaware of own seizures, but described post-ictal symptoms 3: felt dizzy before seizure	<i>Group I: (5 males over 25)</i> 2: unaware of seizures 3: described aura (rumbling in stomach, chest pain, dream) None described post-ictal symptoms
	<i>Group II: (12 females over 25)</i> 9: unaware of own seizures but described post-ictal symptoms 1: seizure starts with hearing voices 1: seizure starts with confusion, head nodding	<i>Group II: (7 females over 25)</i> 4: unaware of seizures 1: partial seizure without loss of consciousness 1: seizure starts with running, then falling 1: seizure starts with confusion
Recording Unit 1.2: Types of seizure	<i>Group III: (8 males under 25)</i> 5: unaware of own seizures, but described post-ictal symptoms 2: described aura (double vision, flash of light)	<i>Group III: (8 males under 25)</i> 7: unaware of own seizure, but described post-ictal symptoms 1: seizure starts with running, then falling

Appendix B—Continued

1: feels head turning left; salivation

Group IV: (7 females under 25)

4: unaware of own seizures, but described post-ictal symptoms
2: described aura (irritation in throat, visual hallucinations)
1: no answer

Group IV: (7 females under 25)

4: unable or unwilling to answer
1: headache and palpitations before seizure
1: seizure starts with dizziness
1: describes aura (dryness of throat)

Context Unit II
Recording Unit 2.1–2.3:
Causes of epilepsy

Group I: (7 males over 25)

All agreed: epilepsy could be “inherited”
2: witchcraft
Other causes mentioned by all: wind, God, “coming by itself” other illness, i.e. malaria

Group I: (5 males over 25)

All hesitant, anxious, uneasy
2: witchcraft or sorcery
2: “bad luck”
1: “don’t know”

Group II: (12 females over 25)

3: fever or febrile convulsions
5: probably witchcraft
1: “don’t know”
Other causes mentioned by several: hereditary, brain disturbance, depression, tension

Group II: (7 females over 25)

All hesitant, anxious, uneasy
5: witchcraft or sorcery
Other causes mentioned by several: malaria, “other illnesses”

Group III: (8 males under 25)

2: febrile convulsions
2: febrile convulsions or witchcraft
1: witchcraft
Other causes mentioned by several: hereditary, germ in the brain, brain disturbance, illness like malaria

Group III: (8 males under 25)

All hesitant, anxious, uneasy
5: witchcraft or sorcery
3: “don’t know”

Group IV: (7 females under 25)

1: personal problems, tension
1: probably witchcraft or magic toad
5: “don’t know”

Group IV: (7 females under 25)

All scared, whispered among themselves something about witchcraft
4: decided on “witchcraft”
3: would say nothing

Context Unit III
Recording Unit 3.1:
Reaction to epilepsy

Group I: (7 males over 25)

All embarrassed; a few expressed feelings like: worrying, fear, sorrow

Group I: (5 males over 25)

3: “don’t remember”
2: “don’t know”

Group II: (12 females over 25)

6: feeling scared
3: not afraid
2: worried and sad (“why me?” “It was like a bad dream”)

Group II: (7 females over 25)

All unable to describe emotions; did not comprehend question; gave only seizure description again

Context Unit III
Recording Unit 3.1:
Reaction to epilepsy

Group III: (8 males under 25)

4: feeling fear
2: sad because had to leave school
2: shock, despair, depression

Group III: (8 males under 25)

All unable to describe emotions; gave only seizure description

Group IV: (7 females under 25)

All giggled and hid their faces; too shy to answer

Group IV: (7 females under 25)

Stunned silence; no answers; 1 girl age 9 wanted to leave

Appendix B—Continued

Context Unit IV

Recording Unit 4.1–4.3:

Treatment of epilepsy

Group I: (7 males over 25)

4: family arranged traditional treatment, later took them to epilepsy clinic

1: no family action, self-referral to epilepsy clinic

2: no answer

Group II: (12 females over 25)

5: family arranged traditional treatment, later took them to epilepsy clinic

7: taken to epilepsy clinic by family

Group III: (8 males under 25)

4: family arranged traditional treatment, later took them to epilepsy clinic

4: taken to epilepsy clinic by family

Group IV: (7 females under 25)1: family arranged traditional treatment
5: eventually taken to epilepsy clinic by family

1: taken to epilepsy clinic by family

Context Unit V

Recording Unit 5.1:

Restrictions of foods and drinks

Group I: (7 males over 25)

None knew any food restrictions; all

agreed: should avoid alcoholic beverages

Group II: (12 females over 25)

No food restrictions any more; traditionally, should not eat fish, “smells badly”; all agreed: no pepper, no cigarettes, alcohol should be avoided

Group III: (8 males under 25)

None knew of any food restrictions; all agreed: red pepper, cigarettes and alcohol should be avoided

Group IV: (7 females under 25)

3: no food restrictions

2: no *kambali* fish

2: no chicken

1: no cassava

Recording Unit 5.2:

Family restrictions

Group I: (7 males over 25)

2: isolated by family, but not anymore

5: no isolation, family helpful

Group I: (5 males over 25)

3: family arranged traditional treatment, later took them to dispensary

2: no family action, self-referral to dispensary

Group II: (7 females over 25)

5: family arranged traditional treatment, later took them to dispensary

2: no answer

1: no treatment

Group III: (8 males under 25)

None answered: appeared scared and suspicious

Afraid of disapproval?

Group IV: (7 females under 25)4: family arranged traditional treatment
2: taken to Mahenge hospital for burns, no epilepsy treatment

1: family first tried traditional treatment, then dispensary

Group I: (5 males over 25)

1: no food restrictions

2: no *kambali* fish or other fish with “ugly faces”

2: no fish, no ripe bananas

All agreed: alcohol should be avoided

Group II: (7 females over 25)

1: no food restrictions

4: no dried fish, especially no *kambali* fish

2: no bitter tomatoes, ripe bananas, eggs, chicken

All agreed: alcohol should be avoided

Group III: (8 males under 25)7: no *kambali* fish, no slippery vegetables, no ripe bananas

1: no chicken head and feet, no pork or goat meat

All agreed: alcohol and cigarettes should be avoided

Group IV: (7 females under 25)

All agreed on the following restrictions:

no *kambali* fish, slippery vegetables, sugar cane, red pepper, and alcohol*Group I:* (5 males over 25)

3: isolation because people think epileptic is contagious

2: “nobody is afraid”—no more comments

Appendix B—Continued

	<p><i>Group II: (12 females over 25)</i> 3: isolated by family 9: no isolation, family helpful</p>	<p><i>Group II: (7 females over 25)</i> Consensus isolation because people afraid of contagion; have to eat and sleep alone; family ashamed; tries to hide the epileptic member</p>
	<p><i>Group III: (8 males under 25)</i> All had been isolated, but not any more; family not afraid, but strangers afraid of frothing saliva during seizure</p>	<p><i>Group III: (8 males under 25)</i> All looked uncomfortable and sad 4: isolated; family afraid of epileptic member 4: gave no answer</p>
	<p><i>Group IV: (7 females under 25)</i> Much giggling; no clear answers; all denied isolation by family members</p>	<p><i>Group IV: (7 females under 25)</i> 3: not allowed to play with other youngsters 4: no answers, shy and anxious</p>
Recording Unit 5.3–5.4: Restrictions of place, work, and marriage	<p><i>Group I: (7 males over 25)</i> None have work restrictions can go any place 6: had to leave school because of epilepsy All agreed: no restriction on marriage</p>	<p><i>Group I: (5 males over 25)</i> All said they should not be close to fire and water, but have to cook and fish because family not helping 1: confined to home All agreed: no marriage restrictions</p>
	<p><i>Group II: (12 females over 25)</i> 2: restricted from cooking 10: restricted from market, church and feasts when seizures expected 7: had to leave school because of epilepsy All agreed: no restriction on marriage</p>	<p><i>Group II: (7 females over 25)</i> All said they should not be close to fire and water, but have to cook and fish because family not helping 5: family keep them away from public places None would discuss marriage restrictions</p>
Recording Unit 5.3–5.4: Restrictions of place, work and marriage	<p><i>Group III: (8 males under 25)</i> 5: restricted from being close to fire and water; should not walk alone All had to leave school because of epilepsy; all agreed: no restriction on marriage</p>	<p><i>Group III: (8 males under 25)</i> 2: no restrictions 1: has to be accompanied all the time All had to leave school because of epilepsy; none would discuss marriage restrictions</p>
	<p><i>Group IV: (7 females under 25)</i> 4: restrictions in going to public places All restricted from being close to fire and water; all had to leave school because of epilepsy; no restriction on marriage if epilepsy controlled on medication</p>	<p><i>Group IV: (7 females under 25)</i> 2: not allowed to play with other youngsters 4: not allowed to be close to fire and water All had to leave school because of epilepsy; none would discuss marriage restrictions</p>
CONTROLS	<p>Controls not presented because there was no significant difference in the answers between patients and controls in the same location</p>	