

**EPILEPSY: EXPLORING PSYCHOSOCIAL ASPECTS IN A SAMPLE
OF CLINIC ATTENDERS IN TWO BLACK TOWNSHIPS IN CAPE TOWN**

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ABSTRACT

There has been a growing realisation that the social and psychological consequences of epilepsy may be more debilitating than the seizures themselves. The present dissertation utilized the framework of a sociopsychological model in trying to gain an understanding of the consequences of having epilepsy. Twenty respondents attending the epileptic clinics of two day-hospitals located in the peri-urban townships of Guguletu and Nyanga in Cape Town were interviewed with the use of a semi-structured interview schedule. The interview explored aspects in the medical management of their illness including the use of indigenous forms of health care; vocational problems faced by respondents, personal adjustment to the seizures, and interpersonal relationship problems. Few respondents enjoyed good control over their seizures, yet none admitted to being dissatisfied with western treatment. Even so, there was mention of supernatural causative factors in the etiology of epilepsy and most respondents had at some time during the course of their illness consulted an indigenous healer. A major finding was a high rate of unemployment in the epileptic sample with dire secondary financial consequences. Further problems associated with having epilepsy included the unpredictable and potentially dangerous nature of epileptic attacks, the adjusting of their lifestyles, the experience of limited job and educational opportunities and social rejection especially because of a belief that epilepsy is contagious. Implications of the study include the need to provide a better understanding of the medical aspects of epilepsy to patients with every effort made to assist them to attain control over their seizures. There is a need to encourage open and free dialogue about cultural beliefs on the illness and its treatment while discouraging obviously erroneous and damaging beliefs. A need for practical assistance in the form of disability grants, access to a social worker and to the services of the South African National Epilepsy League was identified.

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OVERVIEW OF THE STUDY

Chapter 1 begins by defining epilepsy as it is understood medically. The chapter then shifts to focus on the treatment of epilepsy including a discussion of drug treatments, patient compliance to medication, and the role that cultural beliefs play in patient compliance.

In Chapter 2, the discussion shifts from the medical to the psychological and social aspects of the illness. Two models for understanding the psychosocial consequences of epilepsy are reviewed followed by a brief examination of the concept of stigma. The last part of this chapter consists of a literature review of three areas of psychosocial adjustment; namely, vocational adjustment, adjustment to seizures and interpersonal adjustment.

Chapter 3 brings focus to epilepsy in the context of Africa and looks at prevalence figures, common causes and beliefs about epilepsy, and indigenous healing practices in South Africa.

Chapter 4 sets out the research design of the study including the sampling strategy; criteria for inclusion of participants of the study; research procedure and interview schedule.

Chapter 5 presents the findings in descriptive form. Characteristics of the respondents are set out followed by a content analysis of the findings under the general headings of Medical Management, Alternative Sources of Health Care, Vocational Adjustment, Adjustment to Seizures and Interpersonal Adjustment.

In Chapter 6, the limitations of the research are noted. The findings are discussed and their implications. Some concluding remarks are offered pertaining to the interpretation of the findings.

CONTENTS

ABSTRACT	ii
ACKNOWLEDGEMENTS	iii
OVERVIEW OF THE STUDY	iv
CONTENTS	v
LIST OF TABLES	viii
CHAPTER 1 INTRODUCTION: MEDICAL ASPECTS OF EPILEPSY.	1
Epilepsy defined medically	1
The treatment of epilepsy with specific reference to developing countries	2
Pharmacological management	2
Compliance with drug treatment regimens	4
CHAPTER 2: PSYCHOSOCIAL ADJUSTMENT	7
Psychosocial concerns	7
The stigma of epilepsy	7
Two models for understanding psychosocial problems	8
Areas of psychosocial adjustment: review of the literature	9
Vocational adjustment	9
Financial status	10
Adjustment to seizures	11
Interpersonal adjustment	13
CHAPTER 3: EPILEPSY IN AFRICA	16
Prevalence and common causes	16
African beliefs on epilepsy and the cause of illness	17
Indigenous healing	19
Spiritual faith healing	20
Aspects in the treatment of epilepsy	21

CHAPTER 4: METHODOLOGY FOR THIS RESEARCH	23
Participants	23
Procedure	23
Interview schedule	24
CHAPTER 5: FINDINGS AND CONTENT ANALYSIS	26
Characteristics of respondents in the study	26
Medical management	29
Drug affordability	29
Drug type	29
Side effects	29
Frequency of seizures	29
Perceptions on the effectiveness of drug treatment	30
Reported patient compliance	31
Perceived causes of epilepsy	32
Alternative treatment sought for epilepsy	34
Indigenous healer consultation	34
Ancillary support	36
Vocational adjustment	36
Employed respondents	36
Loss of jobs because of epilepsy	37
Job-finding problems	37
Disclosure of illness	38
Financial problems	39
Daily activities	39
Adjustment to seizures	40
Impact of epilepsy	40
Problems attributed to having epilepsy	41
Disclosure of illness to others	43
Whether or not respondents speak freely about their epilepsy	43
Knowing about SANEL	44
Interpersonal adjustment	45
Respondents' Living Arrangements	45
Assistance from people in the household	45
Preference between going out and staying at home	46
Experience of rejection as a result of having epilepsy	47

CHAPTER 6: DISCUSSION AND CONCLUSIONS	49
The Findings	50
Medical management	50
Cultural beliefs and alternative sources of health care	54
Vocational adjustment	55
Adjustment to Seizures	58
Interpersonal Adjustment	60
CONCLUSIONS	62
APPENDIX A	64
APPENDIX B	67
REFERENCES	70

LIST OF TABLES

TABLE 1 :	Characteristics of the respondents in the study	28
TABLE 2 :	Seizure frequency	30
TABLE 3 :	Reported patient compliance in collecting and taking medication	31
TABLE 4 :	Causes attributed to epilepsy	33
TABLE 5 :	Alternative treatment options	34
TABLE 6 :	Respondents' living arrangements	45

CHAPTER I

INTRODUCTION : MEDICAL ASPECTS OF EPILEPSY

This dissertation explores the psychosocial problems associated with epilepsy as reported by epileptic persons attending two day-hospitals in the peri-urban Black townships of Guguletu and Nyanga.

The first chapter begins by defining epilepsy as it is understood medically. It then discusses the pharmacological treatment of epilepsy and raises issues specifically pertaining to medical treatment in developing countries. The chapter also examines the issue of patient compliance with drug treatment especially within the African context.

Epilepsy Defined Medically

Epilepsy is a chronic disorder in which symptoms are an expression of underlying abnormal neuronal discharges in the brain (Lishman, 1987). The current neurological trend describes epilepsy not as a single disease, but as a symptom of a wide variety of neurological disorders (Rodin, 1987; Shovron, 1990). Rodin (1987) suggests that the term 'the epilepsies' more aptly reflects the numerous seizure types and potential etiologies which characterize this condition.

A medical definition of the epilepsies sees them as being characterized by recurrent seizures which occur in an apparently spontaneous fashion. The seizures may be displayed in different forms depending upon the site of origin, extent, and speed of the electrical charges (Rodin, 1987). Hence, seizures may manifest as disturbances of behaviour, emotion, motor functioning, autonomic, or sensory functioning (Chadwick, 1990; Lishman, 1987).

The causes of epilepsy are as varied and complex as their manifestations (Scambler, 1989). Genetic factors undoubtedly play a part in etiology. Other significant causes are congenital malformations present at birth, brain tumours, head injury, drugs and toxins (e.g. alcohol), certain infectious diseases, acquired metabolic diseases, cerebrovascular disease and some degenerative disorders (Lishman, 1987). Attribution of cause is often impossible because of the multifactorial etiology of the disorder. Ultimately, as many as 60-70% of all epilepsies have no clear cause (Shovron, 1990).

Classification and terminology of the epilepsies have, not surprisingly, been problematic (Lishman, 1987). The International League Against Epilepsy (ILAE) has developed various classification schemes to assist in the medical diagnosis and categorization of the epilepsies. The most recent and increasingly accepted scheme is the Classification of the Epilepsies and Epileptic Syndromes and Related Seizure Disorders (1989). This more comprehensive and,

indeed, more complex classification is based on seizure type and EEG findings, as well as prognostic, pathophysiological and aetiological data (Shovron, 1990).

Kshirsagar & Shah (1992) point out that developing countries experience some difficulty in following the ILAE classification because of the unavailability of sophisticated instruments to diagnose a particular subtype of epilepsy. Rodin (1987) warns that preoccupation with subtypes or subclassifications carries a potential danger of overlooking a common, unifying theme underlying the multiple manifestations of the disorder. Rodin (1987) espouses a view of epilepsy as a dynamic process that can express itself in varying degrees of intensity at different times, rather than as discrete seizures of fixed origin. This proposed definition takes into account not only the ictal phenomena but also the interictal state of the patient (Rodin, 1987).

THE TREATMENT OF EPILEPSY WITH SPECIFIC REFERENCE TO DEVELOPING COUNTRIES

The treatment of epilepsy rests primarily on the administration of anticonvulsant medication, often over a period of many years. Significant advances in drug therapy have led to the development of new anticonvulsants which are especially effective for particular seizure types and which produce fewer adverse side-effects (Hermann & Whitman, 1991). These newer drugs, as well as some of the older, well-established drugs effectively control seizures in the majority of patients. Approximately 80% of patients presenting with epilepsy will have their seizures controlled with the use of appropriate medication (Rimmer & Richens, 1988).

An estimated 20% of epileptic seizures do not respond to drug therapy or are of an intractable type (Scambler, 1989). Surgery is occasionally used where seizures have been unresponsive to drug therapy and in cases of single discrete focal abnormality. Availability of surgical treatment in African countries is very limited due, in part, to the lack of adequate facilities (Osuntokun, 1978). Sometimes, patients can learn to control their seizures by avoiding obvious precipitants, such as alcohol or lack of sleep (see Scambler, 1989)

Pharmacological Management

The choice of a primary drug to treat a patient's epilepsy is determined by the type of seizures he or she suffers from, EEG findings and the patient's age (Kshirsagar & Shah 1992; Lishman, 1987). A patient's potential vulnerability to the undesirable side-effects of a drug is an important consideration in appropriate drug selection (Lishman, 1987).

The most widely used drugs for the treatment of generalised tonic-clonic (grand mal) seizures are phenytoin sodium (Epanutin), carbamazepine (Tegretol) and phenobarbitone (Lethyl).

Phenytoin is a highly effective anticonvulsant drug and the most widely used antiepileptic drug (Rimmer & Richens, 1988). However, its toxic effects and long term side-effects can be severe. Subtle long term effects on cognitive functioning affect concentration, memory and psychomotor speed (Lishman, 1987; Rimmer & Richens, 1988).

Carbamazepine is another widely used antiepileptic drug with a high degree of effectiveness yet low toxicity and fewer side-effects. It does, however, tend to be more expensive than phenytoin and phenobarbitone, sometimes by as much as 15 times. (Kshirsagar & Shah, 1992; Shorvon & Farmer, 1988). The most common dose-related adverse effects of carbamazepine are those that affect coordination (Rimmer & Richens, 1988).

Phenobarbitone was the first effective organic agent, introduced in 1912. Its advantages include a wide margin of safety and very low cost relative to other anticonvulsants (Lishman, 1987). In fact, it is the cheapest drug in many countries. (Shorvon & Farmer, 1988). The main side-effect of phenobarbitone is a tendency to induce somnolence or cause sedation (Gastaut & Osuntokun, 1976; Shorvon & Farmer, 1988).

An investigation of epilepsy services conducted by Le Roux & Rutherford (1992) at a Cape Town day-hospital serving the community of Heideveld found that the most commonly prescribed antiepileptic drug was phenytoin. Carbamazepine was used more frequently than phenobarbitone as a second choice. The authors speculated that this may be due to the many side-effects of phenobarbitone.

A common problem in the medical management of epilepsy is the inappropriate use of a variety of anticonvulsants, sometimes in combination with other drugs. Due to an increased awareness of the risks of toxicity and the dangers of drug interactions the practice of polytherapy goes against the current trend in modern medical practice of monotherapy (Rimmer & Richens, 1988). Monotherapy entails using the one most efficacious drug, with the fewest side effects, to control the patient's particular seizure type (Hermann & Whitman, 1991).

Advances in the pharmacokinetic knowledge of drugs have ensured that the drugs chosen for treatment and their dosage can be carefully monitored to ensure maximum efficacy with minimum side-effects (Rimmer & Richens, 1988). The levels of drugs present in an individual's blood can be carefully monitored and the dose adjusted to ensure that therapeutic levels are maintained. Similarly, the choice of drug can be altered to obtain maximal control of the seizures. It is evident, then, that drug treatment is a highly individual matter which needs to be carefully adjusted to the particular needs and responses of the patient (Lishman, 1987).

The above approaches to pharmacological management necessitate individualised attention and careful handling of the epileptic patient. In developing countries, the number of patients per

physician is often so high that the time a physician is able to devote to the individual needs of an epileptic patient is severely restricted (Shorvon & Farmer, 1988). Furthermore, in most developing countries - even in major centres - the technology to monitor drug dosage by estimating blood levels is not available (Osuntokun, 1978; Shorvon & Farmer, 1988).

The chronic nature of epilepsy necessitates a reliable long-term supply of drugs. In developing countries, a general lack in the availability of medical treatment for people with epilepsy remains a common and formidable problem (Shorvon & Farmer, 1988). Rural areas are most often affected in that the supply of drugs to health centres is often erratic. Shorvon & Farmer (1988) point out that the interruption of certain drug regimens such as phenobarbitone can have serious consequences including a severe exacerbation of seizures.

As previously mentioned, the choice of an appropriate drug should ideally be based on seizure type, EEG findings and the patient's age. However, at present in developing countries the major determinants of drug choice are the cost of the drug and its easy availability (Kshirsagar & Shah, 1992; Shorvon & Farmer, 1988).

Gastaut and Osuntokun (1976) propose that developing countries should not follow in the footsteps of industrialized countries which tend to accept and market a great variety of antiepileptic drugs, many of which are minor antiepileptics or even products with no substantial or proven antiepileptic properties. In order to avoid unnecessary expenditure on costly treatments, these authors suggest that only a small number of effective and harmless products with well-defined indications should be made available to physicians in developing countries. To this end, they suggest the usage of three major antiepileptics that act on all types of seizures except for petit mal absences. These are phenobarbitone, phenytoin and carbamazepine.

Even if drugs are available they are not always affordable to the epileptic person who is usually unemployed or earning a low income. In a study of Nigerian epileptic patients, most fell in a low income group and approximately one third of their sample had financial difficulty in purchasing drugs (Danesi, Odusote, Roberts & Adu, 1981).

Compliance With Drug Treatment Regimens

While there are logistical problems such as drug availability, supply and cost, equally important in terms of effective treatment is the epileptic person's view of the illness and medical treatment. It is generally accepted that the greatest single factor responsible for failure to control seizures is noncompliance (Rimmer & Richens, 1988; Shorvon & Farmer, 1988; Tettenborn & Kramer, 1992). Measuring 'drug compliance' amongst patients is notoriously difficult, and studies show that from one-third to one-half of patients do not follow suggested medical regimes (Hunt, Jordan, Irwin & Browner, 1989). The most effective method is to monitor levels of the drug in the blood (Rimmer & Richens, 1988).

Studies conducted in both developed and developing nations show that good patient compliance and successful treatment are dependent on the patients' acceptance and understanding of their disease (Goodridge & Shorvon, 1983). Drug treatment of epilepsy in Africans is effective if the patient can be convinced to take medication regularly according to instructions and to return for follow-up treatment. Thus, it is imperative to sell the idea of on-going treatment.

Some African patients' conception of western medical therapy combined with cultural beliefs and ideas about the cause of epilepsy make this a particularly difficult task. Shorvon & Farmer (1988) report that treatment is often sought on an inconsistent "on-off" basis, with medication taken for a short, well-defined period. Osuntokun (1978) notes that many patients stop taking medication of their own accord when they have been free of seizures for a few weeks despite emphasis that drugs can be stopped only at the discretion of the doctor.

Also common is the intermittent taking of drugs, for example, when a seizure seems imminent or directly after the crisis of a seizure. Such observations suggest that patients see the illness not as chronic but as occurring in acute outbursts. The concept of prophylactic treatment - i.e. long-term and regular use of drugs to prevent recurrence of seizures that may be absent - is foreign (Shorvon & Farmer, 1988). Unfulfilled expectations of an instant cure may lead to a general disillusionment with drug therapy (see Scambler, 1989) and perhaps experimentation with other forms of treatment.

Scambler (1987) notes that there have been surprisingly few attempts to explore patients' views on anticonvulsant medication. One such study by McQueen (1990) showed a high degree of compliance amongst a small sample of epileptic patients in the village of Mamre situated 48 km from Cape Town. That is, most respondents reported that they did not forget to take medication and, in general, felt that the medication did help and that they wanted to take it regularly. However, respondents had little information about the degree of seizure control that could be achieved from medication and accepted unsatisfactory seizure control. McQueen (1990) interpreted these findings as reflecting a general ignorance related to the medical aspects of epilepsy.

Good seizure control has far-reaching implications in enabling a person with epilepsy to lead a normal or near-normal life. One important illustration of the effects of poorly controlled seizures is that they limit the epileptic person's choice of occupations due to a variety of hazards within occupational settings (Tettenborn & Kramer, 1992).

Various strategies to improve patient compliance with antiepileptic drug therapy and, thus, improve seizure control have been suggested. Providing information and general counselling to patients on the various aspects of medical management could be effective and lead to a reduction in seizure frequency (Tettenborn & Kramer, 1992). These authors suggest that a

patient with newly diagnosed epilepsy should be involved in the decision-making process in selecting the medication prescribed to them.

Rimmer & Richens (1988) point out that the current trend towards monotherapy is an aid towards patient compliance. They advise that, whenever possible, drugs should be prescribed to be taken once or twice daily, rather than three to four times a day. Osuntokun (1978) reiterates that drug treatment regimens should be as simple as possible with cognisance of the fact that drug instructions are often printed in English and may, therefore, be incomprehensible (Shorvon & Farmer, 1988).

Some cultural beliefs about epilepsy and its causes provide little motivation for the use of western medical treatment. Shorvon & Farmer (1988) have emphasized that no epilepsy treatment should overlook the force of traditional medicine. Farrand (1984) further makes the point that although doctors treating Black patients within a western medical model may cure the symptoms of the illness, they ignore the traditional belief system within which the patient is functioning and fail to answer the crucial question of why the illness has occurred.

It has been suggested, then, that medical care of epileptics can be improved by an understanding of local cultural attitudes (Shorvon & Farmer, 1988). Farrand (1988) cites various authors in South Africa who have stressed the need to acknowledge, understand and utilize in treatment, the patient's model of illness and the discrepancies between it and the western medical model. Shorvon & Farmer (1988) see the most successful treatment programmes as those that work hand in hand with traditional medicine. In the next chapter psychosocial factors in epilepsy will be considered.

CHAPTER 2

PSYCHOSOCIAL ADJUSTMENT

The preceding chapter began with a discussion of some of the medical aspects of epilepsy including its definition and treatment. The focus now shifts to the psychosocial consequences of the illness including a discussion of the stigma which is so often associated with having epilepsy. Two models for understanding the psychosocial problems experienced by epileptics are examined. The chapter ends with a literature review of three areas of psychosocial adjustment: vocational adjustment, adjustment to seizures and interpersonal adjustment.

Psychosocial Concerns

In 1977 The Commission on Epilepsy stated that "possibly the least understood and most neglected aspects of epilepsy are the social, psychological and behavioural aspects that are so common" (cited in Levin, Banks & Berg 1988, p. 805). Yet, the most disabling aspects of epilepsy have been identified as not the seizures per se but the associated psychosocial problems (Collings, 1990a; Scambler, 1989).

Collings (1990a) points out that epilepsy is not unique among neurological and other physical disorders in having psychosocial consequences. However, it does seem that public conceptions are particularly negative and there is still a considerable stigma associated with the condition (Collings, 1990a).

Various authors have suggested that pure medical management of epilepsy may be insufficient to control the social consequences of the illness (Pond, 1981; Ryan, Kempner & Emlen, 1980). Scambler (1987) points out that physicians tend not to take the time to explore how their patients interpret their epilepsy and the impact it has on their lives.

The Stigma of Epilepsy

The threat of stigmatization is often very real to the epilepsy sufferer. The 'hidden distress model' formulated by Scambler and Hopkins (see Scambler, 1987; Scambler 1989; Scambler & Hopkins, 1988) offers a useful framework for understanding the epileptic person's experience of stigma. The model makes a distinction between 'enacted stigma' and 'felt stigma'.

Enacted stigma refers to actual instances of discrimination experienced by people with epilepsy that occur as a result of perceptions of their being somehow different from or inferior to 'normals'. Felt stigma is primarily the *fear* of meeting with enacted stigma and includes a sense of shame associated with 'being epileptic'. It usually follows after a person diagnosed with epilepsy learns to see her or his 'epileptic' status as socially undesirable.

Scambler & Hopkins (1988) have shown that the most common strategy for dealing with felt stigma is through secrecy and concealment. In not disclosing their condition to others, especially in personal relationships and in the work setting, people with epilepsy effectively reduce the opportunities for normal people to discriminate against them.

However, these authors suggest that felt stigma may be more disruptive to the quality of an epileptic's normal life than enacted stigma would be. This is because persons with epilepsy may need to go to great lengths to hide their epilepsy, often using avoidance or isolation tactics (see McQueen & Swartz, 1992). They also have to cope with the threat of their secret being exposed in several possible ways including an unexpected attack, being seen taking medication or a slip of the tongue in conversation. The threat of exposure may be a significant source of stress and anxiety in the life of an epileptic person who has chosen to hide his or her illness from others.

Two Models for Understanding Psychosocial Problems.

Collings (1990a; 1990b) identifies two models in the research literature which account for psychosocial problems associated with epilepsy. The first, referred to as the 'medical' model, recognises that non-medical problems are inevitably associated with epilepsy. It assumes that the severity of these problems varies according to the severity of the epilepsy. However, the mere diagnosis of epilepsy, irrespective of the severity of the disorder, has been shown to have psychological consequences for people with epilepsy (Griffin & Wyles, 1991; Scambler, 1987).

The second, theoretically more useful sociopsychological model, proposes that the psychosocial effects of epilepsy are mediated by other individual and social factors. These factors, according to a study by Ryan et al. (1980), include the degree to which the respondents feel handicapped by epilepsy, their perception of employment discrimination, their level of education and, to a lesser extent, their age and sex. In addition, Griffin & Wyles (1991) have emphasized the influence of personal perceptions of their epilepsy on the overall well-being of epileptic sufferers.

Collings (1990a) suggests that this model is more useful in its attempt to explore and understand the *experience* of having epilepsy. The present study uses the sociopsychological model as its framework to explore a variety of psychosocial consequences of epilepsy and the factors that mediate these consequences.

Areas of Psychosocial Adjustment: Review of the Literature

Vocational Adjustment

Vocational status in adults is recognized as a very important aspect of psychosocial adjustment (Dodrill, Batzel, Queisser & Temkin, 1980). Having a job has major significance with regard to feelings of satisfaction and productivity in the community (Dodrill, 1983). Self-esteem is maintained and enhanced by having meaningful employment or having some form of daily activity (Masland, 1985; Rodin, 1982).

In 1977, the Commission for the Control of Epilepsy and its Consequences stated that "employment is the single greatest problem facing the adult with epilepsy" (cited in Thompson & Oxley, 1988, p. 11). Both unemployment and underemployment are more frequent in people with epilepsy than in the general population (Dodrill, 1983; Griffin & Wyles, 1991; Masland 1985; Scambler, 1989). Estimates of prevalence rates in the literature vary widely from about 10% to 40% of sample populations (see review by Levin et al. 1988). Findings of local studies tend to support these high figures. For example, a study carried out at Heideveld Day Hospital (Cape Town) found that 61.3% of a small sample of epileptic patients attending this day-hospital was unemployed (Le Roux & Rutherford, 1992). In comparison, about 45% of the economically active population in South Africa is not employed (Business Day Reporter, 1993).

It is generally recognized that, although poor seizure control may be a contributory factor to employment problems in people with epilepsy, poor control does not adequately account for the difficulties experienced in obtaining or maintaining a job (Sands & Zalkind, 1972; Thompson & Oxley, 1988). Unemployment is reported to be widespread despite the demonstrated effectiveness of anticonvulsant drugs and relatively good seizure control that can be attained (Beresford, 1988; Thompson & Oxley, 1988).

A plethora of literature has shown that people with epilepsy are unable to find work or lose jobs because of employers' attitudes, prejudices and discriminatory practices (Chandra, 1988; Masland, 1985; Sands & Zalkind, 1972). Tettenborn & Kramer (1992) reiterate that many epileptic adults remain out of work not because they are unfit or unwilling to work but simply because potential employers are not prepared to hire or retain an individual with a seizure condition. Employees with epilepsy are viewed as 'less efficient' than others and, therefore, as 'poor investments' (see Scambler, 1987). Some of the problems that may be anticipated by potential employers are seizure attacks whilst on the job, putting in fewer hours of work, frequent hospitalization, hospital appointments, and high absenteeism. Epinews (December, 1992), a publication of the South African National Epilepsy League, reports that employer prejudice is based on fear which is rooted in ignorance.

Ryan et al. (1980) found that 46% of their sample of people with epilepsy felt they had encountered employment discrimination as a result of their epilepsy. As many as 22% felt they had been fired from one or more of their last four jobs for "an epilepsy-related reason". A similar finding was reported by Danesi (1984) who states that 47% of his sample of epileptic patients thought that employers generally discriminate against epilepsy. And yet, the Employment Commission of the International Bureau for Epilepsy (1989) has stated clearly that "neither the diagnosis of epilepsy nor the actual occurrence of seizures should disqualify a person from paid employment" (p. 411).

Negative attitudes and employment discrimination seem to have influenced the epileptic person's self-perceptions. Many epileptics perceive themselves at a disadvantage with respect to employability. Danesi (1984), for example, found that many rated their ability to work hard and their potential lower than those of non-epileptics. Only 46.1% thought that people with epilepsy contribute as much as others to society. Epinews ("Spreading The Light", 1992) refers to this phenomenon as a type of 'self-discrimination'; a phenomenon whereby epileptic sufferers tell themselves that they are incapable and cannot achieve. Such feelings may result from repeated experiences of enacted stigma which eventually erode the epileptic person's self-esteem to the extent that felt stigma dominates.

Scambler & Hopkins (1988) have explained the strategy of secrecy and concealment that is commonly used to deal with felt stigma. The Nigerian studies (Danesi et al. 1981; Danesi, 1984) reveal that most epileptics do not disclose their illness to employers. These findings are consistent with reports from the USA where it is estimated that one third of all people with epilepsy lie about their condition when applying for a job (see Scambler, 1987). Scambler & Hopkins (1988) found that although non-disclosure reduces vulnerability to stigmatization or discrimination, epileptic patients found living with the possibility of 'exposure' on the job highly stressful in itself.

In general epileptic people are less fulfilled or satisfied with their employment status; more specifically, with regard to job security, having a worthwhile job and having a job that fully utilizes their abilities. Dodrill (1983) cites a study by Perlam (1977) in which job counselling was rated higher in need than the need for better medical care.

Financial Status

An early social study by Danesi et al. (1981) found that a surprisingly large majority (90%) of their epileptic sample were employed, but most were engaged in low-paying jobs because of their poor educational achievement. This finding accords with a general observation that people with epilepsy are overrepresented in semi-skilled and unskilled jobs (Dodrill, 1983). Dodrill (1983) gives the impression that this is the case having taken into account the higher

prevalence of learning problems and mental handicap in epileptics compared to the general population.

Because of low income and high unemployment rates, epileptics are often dependent on others for financial security (Dodrill et al. 1980). Ultimately, the epileptic person's family is likely to carry their financial burden (see Thompson & Oxley, 1988). For example, epileptics in Tanzania, particularly those who were breadwinners prior to becoming epileptic, felt concerned about their inability to provide for their families and for themselves (Whyte 1991). In such cases, it was felt that the epileptic member would have to be fed and clothed by the family which may also have to finance treatment.

Epileptic persons also rely on federal subsidies or state disability grants. A study carried out in a small sample of epileptic patients at Heideveld Day Hospital reported that 74.2% received disability grants (Le Roux & Rutherford, 1992).

Adjustment to Seizures

Adjustment to seizures is an assessment of the epileptic person's acceptance of the seizure disorder. It explores their feelings and attitudes towards their seizures including whether they feel stigmatized by their condition. Further, it explores the effects that seizures have on their life including whether seizures are a source of any problems in their life. Masland (1985) believes that the person's own reaction to having the seizure disorder is the most significant factor in adjustment. Poor adjustment to epilepsy has been associated with increased scores on a scale of depression and of emotional adjustment (Hermann & Whitmann, 1991).

It has been frequently noted that people with epilepsy have difficulty coming to terms with their condition. A study by Dodrill et al. (1984) comparing the psychosocial problems faced by people with epilepsy in four western countries found that patients were resentful about the seizures and dreaded the possibility of an attack. They also feared that other people would find out about their condition. Shorvon & Farmer (1988) remark that persons with epilepsy would prefer to keep their illness secret from even their nearest neighbour.

Denial of one's epileptic condition is one manifestation of the difficulty in coming to terms with the illness. Danesi (1981), in a study of the social problems faced by epileptics in Nigeria, unexpectedly found that 24% of the sample of 113 patients denied being epileptics.

Interestingly, none of these patients had problems of social interaction but a few of them were scared of rejection.

Danesi (1984) reported similar findings in a later study. Of the 117 epileptic patients studied, 35.9% did not accept that they had epilepsy, and 23.9% would not accept the diagnosis even if they were told by a doctor. Among those who accepted the diagnosis, only 34.5% were willing

to disclose their condition to friends or employers, and only 41.8% were willing to be members of an epilepsy association. Most patients felt that members of the public do not understand epilepsy, fear it, and avoid contact with epileptic people (Danesi, 1984).

Non-acceptance of the diagnostic label of epilepsy and the fear of disclosing their epileptic condition appear to be closely linked to the epileptic persons' perception that they will be subjected to stigmatization and discrimination (see Levin et al. 1988). In a study conducted in the community of Mainre, McQueen (1990) found evidence for the existence of a sense of stigma amongst the respondents revealed in their use of language. Respondents avoided using terms which directly described their disorder, but instead used non-specific terminology such as 'becoming sick' to refer to their epileptic condition. The use of non-specific terms was seen as a strategy to avoid the stigma of being labelled 'epileptic'.

Collings (1990a) argues that although the stigma of epilepsy is well known, some people with epilepsy do tend to have irrational beliefs and fears about their condition that undoubtedly affect the way they feel about themselves. In a study exploring factors related to the well-being of persons with epilepsy, Collings (1990a) found that people's perceptions of themselves and of their epilepsy were strongly related to overall well-being.

The most important correlate of well-being was found to be 'self-image discrepancy', i.e., the discrepancy between perceived self now and anticipated self without epilepsy. Those who felt their self-image would not have been very much different if they did not have epilepsy tended to have high well-being, while those who felt their self-image would have been considerably different if they did not have epilepsy tended to have low well-being.

Collings (1990a) further asserts that some people with epilepsy have misconceptions about how they think their lives are restricted by their seizures. According to Tettenborn & Kramer (1992), the epileptic patient can go on being the person he or she was before the seizures started and continue leading the same lifestyle with only minor changes.

In South Africa, the main organization which concerns itself with the problems faced by people with epilepsy and their families is the South African National Epilepsy League (SANEL). SANEL provides therapeutic, educational, social and employment services to sufferers of epilepsy to enable these individuals to overcome barriers so that they can enjoy fulfilled lives.

Within the South African context of apartheid these services were initially not available to 'non-white' population groups until the 1970's. Presently, financial and personnel resources are very limited (see 23rd Annual Report; 1991-1992) making it difficult for the organisation to reach all communities and to make a significant impact in the communities that it does serve. For example, there is only one social worker of the SANEL branch office designated to service all the peri-urban Black townships of Cape Town.

Results of a SANEL survey in 1991 showed that of 1219 epileptic persons interviewed in the Western Cape area, only 11% had heard of SANEL; 4% had spoken to SANEL by phone and a mere 2% had visited SANEL personally.

Interpersonal Adjustment

Interpersonal adjustment refers to a person's ability to relate to other people, i.e. having close personal friends, having a sufficient number of social contacts, being able to interact socially, and being able to deal appropriately with the opposite sex (Dodrill et al. 1980). The area of interpersonal adjustment explores how well epileptic persons are integrated into the family and into society as a whole. It specifically assesses whether their epilepsy may have interfered with the forming or sustaining of interpersonal relationships.

Thompson & Oxley (1988) point out an increasing awareness that the ability to form and maintain friendships contributes to psychological stability and helps people cope with adverse life events. These authors assert that without an adequate social support system, people are at risk for psychological disturbance.

Problems of social adjustment faced by individuals with epilepsy are well-documented and varied. They include social isolation and withdrawal; difficulties finding a marriage partner; hurtful public opinion and hostility; avoidance by strangers; increased family stress and family relationship problems.

Epileptics have been found to be socially withdrawn and isolated (Levin et al. 1988) and scared of going out (McQueen, 1990; Thompson & Oxley, 1988), fearing accidents or embarrassment in public. This is particularly true if seizures are poorly controlled and therefore unpredictable.

Low self-esteem among epileptic persons is common and may affect an individual's social presentation (Burden, 1981), and contribute to less fulfillment with respect to their family lives, their friendships and their marriages (Collings 1990a).

Families too may play a role in restricting the epileptic person's social activities and friendships by overprotecting their members who have epilepsy or by being constantly fearful and watchful over them (Pond, 1981; Scambler, 1987). Some epileptic members who have led very restricted social lives from an early age may have not had the opportunity to develop the necessary interpersonal skills to enable them to relate to others (e.g. Thompson & Oxley, 1988). Dependency is created and fostered by the perception that epileptics need a great deal of supervision and cannot be left on their own.

A supportive and caring family environment plays an important role in the social adjustment of a person with epilepsy. In Whyte's (1991) study several respondents (20%) said that epileptics

find sympathy, support or kindness from their families. Thompson & Oxley (1988) found that only 8% of their epileptic respondents reported difficulties with relationships between them and family members.

Clear differences between epileptics and non-epileptics have been demonstrated in the way in which they relate to others. In a study by Collings (1990a) of epileptic people in the United Kingdom, patients reported greater difficulties in social group situations, being with the opposite sex, being with familiar people, in one-to-one situations, in having conversations and when interacting with strangers.

In a different study in the U.K., Thompson & Oxley (1988) found that as many as 68% of their sample of 92 patients admitted having no personal friends and only 11% had a wide circle of friends. As many as 34% had never, as far as they could ascertain, formed a true friendship.

The findings on social adjustment of epileptic persons in Africa, in particular Nigeria, have been mixed. Osuntokun (1978) reported that epileptic persons in Nigeria have difficulties in making and keeping friends, in getting married and in retaining their spouses. In contrast, Danesi et al. (1981) reported that over 74% of their 113 epileptic subjects in a Lagos hospital experienced good social interaction; that is, they had many friends, mixed well with people, did not lose their spouses and did not have to change residence in spite of their epilepsy. Only about 25% showed poor social interaction ability. From this 25%, approximately 17% had lost friends or spouses because of epilepsy and felt rejected. The remaining 8% feared rejection and, thus, avoided making friends.

The authors conclude that despite the unfavourable attitude towards epilepsy in Nigeria, persons with epilepsy do not encounter major difficulties with social contacts. A relevant consideration within the Nigerian context is a strong family support system which reflects the extended family pattern (Danesi et al. 1981).

One other factor of importance that tends to limit the social interactions of epileptics to the extent of isolation is that epilepsy is considered a contagious disease in various parts of Africa (e.g. Awaritefe, 1989; Nkwi & Ndonko, 1989; Whyte, 1991). This belief often leads to fear, dread and avoidance of epileptic persons and their being treated as social outcasts.

In the small village of Maham in Cameroon where there is high incidence of epilepsy, the illness is believed to be transmitted by coming into contact with the foam that comes out of the epileptic's mouth either directly or through such agents as flies (Nkwi & Ndonko, 1989). These authors report that the epileptic person cannot participate in community activities; the epileptic male hardly ever finds a wife and the epileptic woman is likely to be 'given' to an elderly man with no request for a bridal price. Furthermore, contact is limited between the epileptic person

and his or her family and there is a separation of kitchen utensils, clothing and bed facilities between him or her and the rest of the family.

Similarly, studies in Tanzania (Whyte, 1991), Botswana (see Ben-Tovim, 1987) and Nigeria (Awaritefe, 1989) show a widespread belief that epilepsy is contagious, a belief held even ✓ amongst medical students. Awaritefe (1989) and Ben-Tovim (1987) have mentioned that any comprehensive program of help for people with epilepsy must take this belief into account.

The next chapter takes a more in-depth look at beliefs about epilepsy from various parts of Africa; the causal factors of epilepsy common to developing countries, and the use of indigenous healing methods for the treatment of illness.

CHAPTER 3

EPILEPSY IN AFRICA

Prevalence and Common Causes

Epilepsy is a common and well known condition in Africa. It is the most common disease of the nervous system in Africans apart from infections affecting the nervous system (Osuntokun, 1978). Epilepsy was cited as the neuropsychiatric condition that people were most familiar with in a study conducted in various Tanzanian communities (Whyte, 1991).

Prevalence figures in developing countries have varied widely but appear to lie between 4 and 10 per 1000 (see Shander & Shorvon, 1987). In South Africa it is estimated that at least 1 in 200 people have epilepsy, suggesting that there are over 190 000 people in the country with epilepsy ("Spreading The Light," 1992). In a survey of clinical records kept at the outpatient psychiatric clinic at Umtata Hospital in Transkei, epilepsy ranked as the third most common psychiatric disorder (Gijana & Louw, 1981).

It has been suggested that epilepsy is up to twice as prevalent in developing as in developed countries (see Kshirsagar & Shah, 1992; Shorvon & Farmer, 1988). Several factors could account for this claim including the younger age of developing country populations, the differing importance of various etiological factors and the effects of socio-economic factors (Shorvon & Farmer, 1988).

Common causes of epilepsy such as birth injury, childhood infections and head injuries due to motor vehicle accidents are all too frequent occurrences in developing countries (Chandra, 1988). A number of chronic infectious diseases result in epilepsy and are reported to be the most common cause of symptomatic epilepsy in Africans (Osuntokun, 1978). Cysticercosis, for example, is endemic in areas of Africa and is believed to be an important cause of epilepsy within Southern African population groups (see Kshirsagar & Shah, 1992; Osuntokun, 1978).

In recent years more cases of epilepsy secondary to tuberculoma have been detected (Kshirsagar & Shah, 1992). These authors cite 1989 World Health Organisation (WHO) statistics as showing that the risk of tuberculous infection is a hundred times higher in the developing countries.

Febrile convulsions occurring in childhood are another common etiological factor in African populations (Danesi, 1985; Osuntokun, 1978). Osuntokun (1978) reports that in the African child who is likely to be malnourished, febrile convulsions may possibly result in some brain damage, predisposing to recurrent seizures in childhood or later in life. Various researchers

have suggested that febrile convulsion predisposes to later development of temporal lobe epilepsy (see Danesi, 1985).

Poor antenatal and obstetric care in developing countries in Africa is responsible for a high frequency of birth injury to infants and, in turn, to a high frequency of epilepsy (Osuntokun, 1978; Shorvon & Farmer, 1988). Prolonged labour, for example, is believed to predispose to epilepsy especially of the temporal lobe type (Aird, Venturini & Spielman; cited in Osuntokun, 1978). In the Osuntokun et al. (1987) epidemiological study, birth trauma accounted for 3% of epileptic cases.

Post-traumatic epilepsy is becoming increasingly common in the developing countries in Africa. Osuntokun (1978) reports that Nigeria and East African countries have the highest rate in the world of car accidents per million-vehicle miles. Traumatic brain injury caused largely by assaults and motor vehicle accidents (MVAs) is far more common in Johannesburg than in the USA (Butchart et al. 1992).

Epilepsy in Africa and elsewhere is commonly seen as simply a physical or medical condition. Yet, as Tettenborn & Kramer (1992) point out, all the handicaps and sequelae of having epilepsy are psychosocial. Psychosocial consequences are slowly gaining recognition within the literature as being an essential part of the management of epileptic patients (McQueen, 1990).

African Beliefs On Epilepsy and The Cause of Illness

The stigma of epilepsy in African societies and elsewhere is well documented (e.g. Danesi et al. 1981; Danesi, 1984). As reported earlier, it is not uncommon to see epileptics treated as outcasts due to the popular misconception that the illness is infectious and can be transmitted by the person's saliva (see Awaritefe, Longe & Awaritefe, 1985; Ben-Tovim, 1987; Danesi et al. 1984; Osuntokun, 1978; Whyte, 1991).

Historically, epilepsy has typically been viewed as a form of spirit possession. In many African communities, for example, epilepsy is regarded as a sign of visitation by the devil and epileptics are believed to be "possessed" (Osuntokun, 1978). A study in Nigeria found that, after hereditary factors, "witchcraft" was the cause most commonly attributed to epilepsy by the lay populace (Awaritefe et al. 1985). The Shona of Zimbabwe (Gelfand, 1973) see it as the revenge of an aggrieved ancestral spirit (cited in Shorvon & Farmer, 1988). Alternatively, many regard the person with epilepsy as having been "struck by God" or as "the victim of an incurable and inherited disease" (Tettenborn & Kramer, 1992). In Tanzania, there is a belief that epilepsy may be associated with a worm which crawls up the spinal chord to the brain (see Whyte, 1991). Still others believe that it is due to the consumption of something harmful in utero (see Osuntokun, 1978).

Epileptic persons are insecure in their knowledge of the causes of epilepsy. In Nigeria (Danesi, 1984) it was found that among those who accepted that they had epilepsy, 65.5% did not know the cause. Twenty-five percent thought epilepsy is caused by brain damage; 7.2% thought epilepsy is infectious while a small fraction (5.4%) attributed the cause to evil spirit/witchcraft. Most of the patients were anxious to know more about epilepsy (Danesi, 1984).

Another study (Awaritefe et al. 1985) conducted in a sample of urban, educated, partly westernized Nigerians found that 25.5% of respondents did not know the causes of epilepsy. Only 8% mentioned brain damage as compared to 45.5% for heredity and 38% for witchcraft. The authors conclude that there is a general ignorance about the causes of epilepsy even among educated respondents.

Similarly, a study in Tanzania reported that of 196 respondents, 41 % did not know the cause for epilepsy. Some went on to suggest a cause anyway, with 29% suggesting a hereditary cause, 21% attributing cause to supernatural powers, 14% mentioning 'God's will/fate' and 8% suggesting a contagion as the cause of epilepsy (Whyte, 1991).

Individuals with epilepsy appear not to have adequate knowledge about the causes of epilepsy although some erroneous beliefs (e.g. that epilepsy is infectious) seem to have diminished. Unfortunately, patients who are not adequately informed about the various aspects of their illness are more likely to fall prey to myths and misconceptions that plague the illness (Collings, 1990a).

Witchcraft and sorcery are two significant and widespread supernatural causes of illness within traditional belief systems in Africa (see Farrand, 1988; Whyte, 1991). In both cases, illness is ascribed to "the covert action of an envious, affronted, or malicious human being who employs magical means to injure his victim" (Murdock, Wilson & Frederick, 1980; p.46; cited in Farrand, 1988).

One particular type of sorcery is known as 'idliso' and refers to the addition of noxious medicines including western poison to the victim's food or drink (Ngubane, 1977). The 'poison' is always administered by a person with malicious intent and occurs in situations of competition, jealousy and rivalry. Treatment is vital because it is believed that if no cure is found, idliso can cause death (Ngubane, 1977).

An illness which is attributed primarily to sorcery is the form of evil spirit possession known as 'ufufunyane'; plural: 'amafufunyane'. It is believed that sorcerers add soil from the graves of those who have died from the illness and ants to their harmful concoction which they place in the victim's food or in his/her path (Broster, 1982; Ngubane, 1977).

`Ufufunyane' is described as a type of mania or hysteria in which the victim is believed to be possessed by thousands of spirits of various races. Ngubane (1977) suggests that the notion of evil spirit possession is used among the Zulu as an idiom to deal with the increasing cases of psychoneurosis often associated with failure to cope with the changing social lifestyle brought about by industrialization.

Indigenous Healing

Similar to many other developing countries two distinct systems of health care exist in parallel in South Africa. Western, scientifically oriented medicine serves all population groups while the well-entrenched indigenous medicine enjoys support mainly among the South African Black population. The indigenous approach emphasises the supernatural cause of disease (Broster, 1982; Ngubane, 1977; Van Rensburg & Mans, 1982). Traditional views also recognize natural causes of illness and somatic symptoms more aptly treated by western medicine (Farrand, 1984; Wessels, 1985). Farrand (1984) reported that there was little agreement concerning the illnesses considered to be treatable by only western doctors and those seen to be treatable by indigenous healers.

The widespread belief in witchcraft and sorcery in Africa is borne out by findings from various parts of the continent. Thirty-eight percent of a sample of urban, educated, partly westernized Nigerians mentioned witchcraft as the cause of epilepsy (Awaritefe et al. 1985). Whyte (1991), in a Tanzanian study, found supernatural powers and, in particular, sorcery to be the most frequently cited cause of the neuro-psychiatric conditions examined in the study.

The indigenous healer or so-called `witchdoctor' plays a central role in curing and eliminating damage wrought by spirits, and in the prevention and eradication of the evil brought about by witchcraft. A distinction is made between the diviner/prophet known amongst the Xhosa as `igqira' and the herbalist known as `ixhwele'. The former share a close relationship with their ancestral spirits who are believed to endow them with special powers that include divination, dream interpretation and healing (Farrand, 1988; Van Rensburg and Mans, 1982).

The primary role of the `igqira' is to determine the cause of misfortune. (Farrand, 1988). By contrast, the herbalist concentrates on the treatment of the somatic symptoms with herbs and various ritual and ceremonial practices without necessarily being able to determine the source of the evil (Van Rensburg and Mans, 1982). For the purposes of the present thesis the term `indigenous healer' will be used to refer to both the diviner and the herbalist unless otherwise stated.

In South Africa, the strongest support for traditional medicine and the services of healers derives from rural areas (Van Rensburg & Mans, 1982). It is thought that urbanization of South African Blacks has initiated a process of transition from tribal medicine to modern

western-oriented health care through greater contact with western culture. Contributing to the greater use of western medicine are beliefs in Christianity which go against cultural beliefs in 'witchcraft'.

Farrand (1984) found that as many as 32.3% of Black psychiatric in-patients at a large modern hospital in the Witwatersand chose to consult a medical doctor alone for their presenting illness, as compared to only 12.3% who chose a traditional healer. Farrand (1984) attributes this trend away from total reliance on indigenous healers to the influence of western attitudes which strongly disapprove of traditional beliefs and practices and uphold western medicine as the only acceptable form of treatment.

Holdstock & Franks (n.d.), cited in Swartz (1986), however, provide evidence that equating urbanization and westernization with a diminishing belief in indigenous healers and witchcraft does not necessarily hold. Some patients, probably the largest group, resort to a combination of western and traditional services. They may first try the one, then the other; or perhaps resort to the services of a traditional healer in times of severe illness or dire need (Van Rensburg & Mans, 1982). Whyte (1991) also found support of the tendency to 'shuttle' between various types of treatment from respondents in her study held in various regions of Tanzania.

Shorvon & Farmer (1988) note with interest that many patients spend considerable amounts of money on obtaining traditional cures. In Nigeria, despite the fact that almost 90% of patients questioned recognized the effectiveness of medical treatment, a sizeable percentage (32.5%) would like to combine this with "native medicine" or "spiritual church healing" (Danesi 1984). Similarly, Farrand (1984) found that, although 32.3% of her sample Black psychiatric patients rejected indigenous healers, 40% said they would consult a medical doctor as well as a traditional healer and/or spiritual Zionist healer. These patients apparently reported that Black mine workers who become ill first go to a hospital. If there is no improvement in their condition, they then take this to mean that they should consult a traditional healer at home.

According to Farrand (1984) this finding lends support to the conclusion drawn elsewhere in Africa that the emergent urban Black has generated an informal model of treatment that relies on both western and traditional models of treatment. Farrand (1984) has suggested that treatment is a "two-stage process" in which the person first seeks a cure from the western doctor and then consults an indigenous healer to determine and alleviate the cause of the illness.

Spiritual 'Faith' Healing

Recently, growing numbers of Black South Africans are turning to a different group of indigenous healers - those who divine and heal within the framework of the African Independent Churches (Farrand, 1984; 1988). These churches enjoy a membership of over 4

million with members organized into numerous independent groups known as "amaZion". Within this framework, beliefs that are traditional to orthodox Christianity have been reinterpreted in terms of African beliefs and practices (Pauw, 1975; cited in Farrand, 1988). For example, God and Christ are seen as the ancestors of all people and sorcery and witchcraft are associated with Satan and his demons.

Zionists explicitly reject traditional healers in favour of their own prophetic healers known as 'amaprofita'; singular 'umprofita'. Farrand (1988) points out, however, that Zionist healers and traditional healers are very similar. While the former derive power from their ancestors, the latter derive power from the Holy Spirit. The 'diagnosis' of illness entails a trance-like state in which the prophet can "see" into the patient's head and ascertain the cause of the problem. Healing occurs during church services and includes prayer, laying on of hands, and the ingestion of holy water that has been prayed over or handled by the prophet and is used as an emetic.

In Farrand's (1984) study of the attitudes of Black psychiatric patients towards various forms of healing, an interesting finding was that the Zionist prophets were just as popular as traditional healers ('izangoma') as a treatment of choice. In accounting for this finding, Farrand (1984) has suggested that healing by the Zionist prophet within the context of a church movement may be more socially acceptable, cheaper, and more suited to an industrial urban environment than consulting a traditional healer.

Aspects in the Treatment of Epilepsy

Many people with epilepsy, particularly those living in rural areas, simply do not know that epilepsy can be effectively treated with medication. Fisch & James (1992) found that most new epileptic patients at the Neurology Outpatients Department of Groote Schuur Hospital, Cape Town, present with recurrent rather than single attacks. The researchers suggest that patients appear only when the disease has become chronic due to ignorance or embarrassment about their condition.

For these and other reasons, indigenous healers are much more likely to be consulted initially than orthodox medical personnel (Shorvon & Farmer, 1988). Furthermore, many patients are likely to go from one traditional therapy to another before they finally wind up at a hospital (Danesi, in Shorvon & Farmer, 1988). Kshirsagar & Shah (1992) argue that patients commonly receive medical treatment only after valuable time has been lost and the disease has reached chronic proportions.

Whatever the circumstances, many Black patients arrive at the hospital with a clearly defined cultural explanation for their illness (Farrand, 1988). Such explanations are often ignored as

they are seen to have no place within the western scientifically based medical model of treatment.

The present study gives epileptic patients attending two Cape Town day-hospitals located in the Black townships of Guguletu and Nyanga an opportunity to express their cultural views and beliefs on the illness and its treatment. In addition, the study sees the need to explore the psychosocial concerns of epileptic persons (reviewed in the preceding chapter) as they pertain to this Cape Town sample of epileptic persons.

CHAPTER 4

METHODOLOGY FOR THIS RESEARCH

The study was an exploratory one aimed at determining the nature and scope of psychosocial problems experienced by epileptic out-patients. Permission to conduct the research at two day-hospitals serving the peri-urban Black townships of Guguletu and Nyanga was obtained from the then Medical Superintendent of the Day-Hospitals.

Participants

A sample of 20 persons aged between 21 and 55 years was selected on a convenience basis from a large number of patients attending the Epileptic Clinic at Guguletu and Nyanga Day-Hospitals. Epileptic Clinics are held once a week on a Wednesday morning from 8h:00 - 13h:00 at each of these day-hospitals. Ten epileptic patients at each day-hospital were selected for interviewing.

The day-hospital is a primary care facility aimed at providing basic health care to its surrounding community. It is a provider of follow-up treatment to patients that have been examined and diagnosed at one of the tertiary hospitals serving the greater Western Cape areas. These tertiary hospitals include Groote Schuur Hospital, Tygerberg Hospital and Valkenberg Psychiatric Hospital. Patients are often referred to the more accessible day-hospital in their community for long-term follow-up treatment.

The age range of patients that were selected for interviewing reflects that of persons presumed to be in the 'potentially employable' age group. Patients selected had to be exhibiting active seizures (i.e. at least one seizure in the past year) for which they were receiving treatment. Only those who had had epilepsy for at least three years were included in the study. Patients with a psychiatric illness, mental handicap or other chronic illness such as hypertension and diabetes were not accepted in the study.

Various clinical and biographical data were gleaned from the patients' day-hospital folders which, unfortunately, were not always complete. The data extracted from each folder consisted of diagnosis, frequency of seizures, sex, age, medication and changes in the patient's condition.

Procedure

Epileptic patients arrive at the day-hospital on a monthly basis to be examined and to receive anticonvulsant medication. After a patient had been seen by the doctor, his or her folder was handed to the researcher by the examining doctor or sister running the Epileptic Clinic. The folder was scanned for information regarding diagnosis of epilepsy, frequency and duration of

seizures, the patient's age and whether the patient was suffering from any other illnesses. Suitable patients were then approached by the researcher and permission to be interviewed on their illness was requested. The purpose of the study was briefly explained as well as how the information would be used. The interviews were all tape-recorded with the consent of the participants. Noone refused to be interviewed.

Interview Schedule

A semi-structured interview format was utilized. The interview schedule was available in both Xhosa and English (see Appendices A & B). All interviews with the exception of one were conducted in Xhosa and took from 40 minutes to just over one hour. Some of the questions were closed-ended and required a brief response, but the majority of questions were open-ended and were intended to elicit full and free descriptions of their problems and various cultural beliefs where relevant. The recorded interviews were transcribed from Xhosa into English. Transcribers were instructed to provide an exact transcription of the respondents' actual words.

Section A of the questionnaire ("Medical Management and Alternative Sources of Health Care") began by ascertaining the year of onset of their epilepsy, their type of epilepsy, a description of the seizures; their frequency and duration. Thereafter, the section explores their ideas on the causes of epilepsy; their need for medication and whether they feel it works; access and compliance to the medication.

In order to explore issues pertaining to compliance and whether epileptic patients in the study understand and accept the chronic nature of their illness they were asked: a) if they have trouble remembering when to collect their medication at the day-hospital; b) if they have trouble remembering to take their medication at home; c) how long they felt they would have to take medication and, d) if they felt that their epilepsy would improve with time or end.

While it is recognized that direct questioning is not an accurate method of assessing patient compliance, the emphasis in the present study was not on actual compliance per se, but on the patient's feelings and perceptions about their medication. Thus, broader issues were explored such as patients' treatment of choice, their feelings about the effectiveness of the medication and hence if they wanted to take drugs accurately and regularly.

Various authors have suggested that one way of improving compliance to drug therapy is to inform and counsel patients on the various (medical) aspects of their illness. Thus, epileptic patients in the present study were asked if they see anyone else other than a doctor for the treatment of their illness - perhaps a nurse, social worker or counsellor.

One of the aims of the study was to give patients an opportunity to express their cultural views and beliefs about their illness. To this end, they were asked what they thought caused epilepsy; what treatment they sought for their epilepsy and in particular, if they had ever sought the services of an indigenous healer. If so, they were asked about the circumstances surrounding the consultation, i.e. at what stage in the course of their illness, for what reasons, for how long, and whether they felt the treatment helped or not. Finally, they were asked what type of treatment they preferred between western medication and traditional forms of healing.

Section B. of the interview schedule ("Vocational Adjustment and Financial Status") looked at if patients were employed, the type of work they engaged in and if their epilepsy interfered with their work or ability to work. Job-finding problems and job-keeping difficulties were explored as well as financial concerns and whether (unemployed) respondents receive state Disability Grants or not.

Section C. of the interview ("Adjustment to Seizures") explored respondents' attitude towards seizures including if they felt ashamed or stigmatized by their condition, and any other adverse effects it had on their lives. Lastly, a question was posed about their knowledge of SANEL.

Section D ("Interpersonal Adjustment") concerned itself with how socially well-adjusted the respondent was, including if they were able to relate to others and had close personal friends. It also looked at the respondent's adjustment within the family.

CHAPTER 5

FINDINGS AND CONTENT ANALYSIS

Characteristics of Respondents in the Study

Sex and Age Distribution

Table 1 (page 28) describes the characteristics of the respondents. There were 10 males and 10 females. The mean age of the sample was 35.7 years (SD 7.8), with ages ranging from 26 to 55 years. The largest proportion of respondents (55%) were in the 31-40 age group.

Level of Education

The largest proportion of those who had attended school (45%) had primary school education (Sub A-Std V). Only 10% had completed secondary school with a matric certificate and none of the respondents had completed post-secondary education.

Marital Status

Seventeen respondents (85%) were single. Of these unmarried individuals, eight had children and nine had no children. Two patients (10%) were married, one of whom was married by Xhosa custom and tradition and not in the 'legal' western sense.

Employment Status

The majority of respondents (65%) were unemployed and not receiving a state Disability Grant.

Age at Onset of Seizures

The mean age at onset of seizures was 21.4 years, with a range of 7 - 44 years. The majority (35%) were between the ages of 11 and 20 when their epilepsy started.

Etiology

Twelve respondents in the sample said they knew of no known cause of their epilepsy. Of interest is that all 10 females fell within this group. Several of the respondents who could not discern a cause for their epilepsy reported sudden, unexpected onset of fits during school-going age. In at least one such case, genetic factors were a strong possibility as the respondent's sibling and niece also suffer from epilepsy. Six respondents had head injuries as the cause of

their epilepsy. All of these were male. Alcohol accounted for the cause of epilepsy in two respondents who were both male.

Symptoms and Type of Epilepsy

Seizure type was not documented in any of the folders that were examined. Respondents were asked if the doctor had ever told them what type of epilepsy they suffered from. All said that they had not been informed of their type of epilepsy. A few gave vague responses such as, 'they said it was fits'; 'they said it was epilepsy'. One person acknowledged that he may have been told but probably could not pronounce the name and therefore never remembered it.

Each respondent in the study was approached on the basis of attendance at the Epileptic Clinic for on-going, follow-up treatment of epilepsy. The diagnosis was therefore never questioned. Respondents were asked to describe what happens when they have a fit early in the interview schedule partly as a means of assessing whether they really knew what epilepsy is.

Features common to most of their accounts of an epileptic attack were blank or vacant staring, blurred vision, darkness in front of the eyes, dizziness, loss of consciousness (explained in various ways such as, 'I lose my mind'; 'I lose my senses'; 'I faint'; 'I have black-outs'; 'my mind goes blank') falling to the ground, convulsions, foaming at the mouth and biting of the tongue. Many respondents reported feeling disoriented and confused for a period of time after the attack until they 'regained their senses'. Headache and body weakness or fatigue were other features common to the time period following an attack. Less commonly cited features of an epileptic attack were urinating, stiffening of the hands and arms, screaming and distorting facial features.

The description of epileptic attacks given by most respondents appears to fit that of generalized tonic-clonic seizures (i.e. 'grand mal' epilepsy). However, due to the detailed clinical knowledge and sophistication required to make accurate diagnoses of the different types of epilepsy (see Lishman, 1987), the researcher felt it inappropriate to make further judgements on seizure type solely on the basis of descriptions given by respondents.

Table 1

Characteristics of the Respondents in the Study

Characteristics	n	Percentage
Sex		
Males	10	50
Females	10	50
Age in Years		
21 - 30	6	30
31 - 40	11	55
41 - 50	1	5
51 - 60	2	10
Level of education		
No education	1	5
Primary school (Sub A - Std. 5)	9	45
Secondary school (Not completed)	7	35
Secondary school (Std. 6 - Matric)	2	10
Currently studying (Matric)	1	5
Post-Secondary including university	0	0
Marital status		
Single	17	85
Married	2	10
Widowed	1	5
Employment Status		
Employed	2	10
Unemployed / Disability Grant	4	20
Unemployed / No Disability Grant	13	65
Student	1	5
Age at Onset		
Below 10	4	20
11 - 20	7	35
21 - 30	4	20
31 - 40	3	15
Above 40	2	10
Etiology		
No discernible cause	12	60
Post - traumatic	6	30
Alcohol	2	10

MEDICAL MANAGEMENT

Drug Affordability

Patients are administered medication on a monthly basis and are charged a fee of R6.00 on each visit to the day-hospital for medical treatment. Most patients (85%) claimed responsibility for paying for their own medication although over half of the unemployed respondents who do not receive disability grants reported that they have difficulty actually paying the fee. At least five patients admitted that 'nobody pays'. Four patients (20%) are partially or fully assisted by a family member in paying for medication.

Drug Type

The names of the drugs prescribed to patients were gleaned from their folders because the patients themselves did not know the names of their medication. Only two patients were able to give the names of their pills.

The most commonly prescribed drug to patients was phenytoin sodium (Epanutin) - the most widely used and well-researched antiepileptic drug (Rimmer & Richens, 1988). It was prescribed to 70% of the patient sample. The second most frequently prescribed drug was phenobarbitone, prescribed to 50% of the patient sample. The least prescribed drug (30% of cases) was carbamazepine (Tetgretol), perhaps due to its cost relative to the other two.

A relatively large proportion of patients (40%) were prescribed more than one drug. This practice goes against current opinion on drug management which has shown no significant advantages of polytherapy over monotherapy.

Side Effects

Just below one-half (45%) of patients reported that they experience side-effects from the medication. The most commonly cited side-effects were dizziness, drowsiness and headache. More idiosyncratic responses to medication included regular visits to the toilet, constipation, stomach pain and burning sensation of the eyes. No clear relationship linking side-effects to particular drugs could be established.

Frequency of Seizures

Seizure frequency is an important characteristic of epilepsy and may be used to evaluate the effectiveness of treatment programmes.

Table 2

Seizure Frequency

Number of Seizures	n	Percentage (%)
Total suppression of seizures on treatment	2	10
One a year or less often	2	10
Three to four a year	1	5
One to three a month	11	55
One to two a week	4	20

As shown in Table 2, the majority of patients (55%) have seizures occurring between one and three times a month. A mere 10% (i.e. two respondents) in the present study reported full control over seizures if they take their medication accurately and regularly.

No relationship could be determined between frequency of seizures and degree of compliance due to the less than ideal method of assessing patient compliance used in the study.

Furthermore, several patients found it difficult to give an estimation of the frequency of their seizures as they felt the number varies a great deal from one month to the next. Whereas one month they may suffer a lot of attacks, at other times they may enjoy relative freedom from seizures.

Perceptions on the Effectiveness of Drug Treatment

The majority of respondents in the study do not enjoy full seizure control with as many as 55% experiencing two to three seizures in one month, as has been shown. Even so, all respondents, with the exception of one, reported that the medication was of help.

Respondents maintained that medication was particularly helpful in two ways. Firstly, several mentioned that if they complied with treatment regimens (i.e. if they remembered to take the correct number of pills at the prescribed times on a daily basis), they did not get attacks. Thus, good compliance on their parts was felt to result in total suppression of seizures. Secondly, others acknowledged that even if total suppression of seizures was not achieved, medication did seem to reduce the number of seizures they had. This was expressed in various ways by such statements as: (When I've taken my medication)... 'I stay a long time before I get a fit' or 'there is some relief but it does not get completely right', or 'I don't get fits so often'.

The sole patient who believed that medication did not help was disgruntled with the fact that he gets fits even when he is using medication. He was not the only one who felt this way. Although others generally felt positive that medication helped, some of them went on to express other sentiments about the medication. One patient, for example, felt confused that he still gets seizures on treatment. Another acknowledged that her epilepsy had improved on treatment but expressed dissatisfaction that the condition had not been cured as she still gets seizures.

Reported Patient Compliance

Patients that remember to collect their medication were defined as those who, according to their reports, had not defaulted on their monthly appointment at the day-hospital for three consecutive months prior to the interview. Likewise, patients who remember to take their their medication at home were those who reportedly had not forgotten to take their medication on a daily basis for the past three months.

Table 3

Reported Patient Compliance in Collecting and Taking Medication

Number of Patients That ...	n	Percentage (%)
Remember to collect pills*	12	60
Do not remember to collect pills	8	40
Remember to take pills at home	7	35
Do not remember to take pills at home	13	65

*See above text for definition

Table 3 contrasts the number of respondents who reported that they remember to collect their pills from the day-hospital and take them at home with those who forget. Respondents who do not always remember to collect their medication cited various reasons for not doing so including: making a mistake about the appointment date, not feeling well enough to travel to the day-hospital due to a seizure the day before, and forgetfulness.

The main reason for not taking medication at home seemed to be forgetfulness. Despite their apparent intentions to take medication as directed, some do forget at times and need to be reminded by those who live with them. One respondent felt the need to experiment to see what would happen if she stopped taking her medication. Two respondents were not able to follow

proper instructions regarding the times they were supposed to take their medication. One respondent mentioned that he would sometimes sleep over at a friend's without having planned to do so and would, therefore, not have his medication with him.

Most respondents (85%) reported that they did not know how long they would have to continue to take medication. Most of these respondents went on to indicate that they were relying on the the doctor to inform them if and when medication was no longer necessary. A small number of respondents (15%) indicated that they would have to take medication for life.

Just over half of the respondents believe that their illness will get better in time or will actually end. Such perceptions were reportedly based on having experienced a reduction of seizures since the onset of their epilepsy or having faith in the ability of doctors to cure epilepsy.

Several were doubtful or did not know whether their illness would improve or end in time. Their response in this regard seemed to be based on the length of time that they had been suffering from epilepsy. For example, one patient responded, "I am old... I am 50-something, and I was 12 years when I first got epilepsy. I don't think it will ever get better or go away".

One respondent indicated that if people take their medication regularly, they can enjoy full control over seizures. In this way, she felt that the illness does improve or 'end'. She appeared to understand that seizure suppression could be achieved with regular use of medication for life. It is of interest that this particular respondent has previously been a volunteer group facilitator for SANEL. Her exposure to this organisation may account for her generally accurate ideas regarding medical and other aspects of epilepsy.

Perceived Causes of Epilepsy

The question about causation was an open one; respondents were asked to name several causes which they thought might be operative. Most respondents stated that they did not know the cause of epilepsy, but went on to give suggestions anyway. Their responses have been grouped into eight categories and are shown in Table 4 together with the frequencies with which the various causes were mentioned. Witchcraft and sorcery were combined to form one category because the difference was often not clear from respondents' explanations. Broster (1982) has mentioned that the two are often closely associated in the minds of people with a blurred distinction in certain cases.

As shown in Table 4 (page 33), the response 'Don't know' was most often given to the question regarding the cause of epilepsy (38.78%), however, most respondents went on to suggest a cause regardless. Only three respondents said they did not know the cause of epilepsy and, further, could not offer any suggestions regarding its cause.

The most frequently mentioned explanation for epilepsy involved physical phenomena, the most common being an injury to the head. Some respondents implicated the brain but were vague in their explanations. For example, 'a nerve in the brain is disturbed', or, 'the problem is an open space in the brain between the medulla and I don't know what'. Other mentioned causes of a physical nature were gall ('inyongo') and burns. Physical causes constituted 20.41% of all suggestions.

Witchcraft and sorcery constituted the second most frequently mentioned cause of epilepsy (16.33%). Although not seen from the table, 'idliso' and 'bewitchment' were most often cited within this category. The motives behind these acts were said to be a dislike for the respondent and/or jealousy and envy of their progress at school or in life in general. The people who were thought to command these acts were not mentioned except in one case where a jealous neighbour was implicated. Indigenous healers were seen to be primarily responsible for effecting such acts with one respondent explaining that they travel at night by plane from Transkei to come and bewitch people in Cape Town and then return the following day.

Table 4

Causes Attributed to Epilepsy

Perceived Cause	Number of times mentioned	Percentage (%)
Do not know	19	38.78
Physical	10	20.41
Witchcraft/Sorcery	8	16.33
Psychological and Social Problems	5	10.2
Substance Abuse	3	6.12
Diet	2	4.08
Heredity	1	2.04
Worm	1	2.04
Total	49	100

Average number of causes per person: 2.45

Within this category one person mentioned 'ukutwasa' as a cause for epilepsy. 'Ukutwasa' is a form of ancestral spirit possession when a person receives a 'calling' to be a diviner ('igqira'). Yet another patient said that epilepsy is caused by 'amafufunyane' which he explained to be 'ants placed in the inside of a body'.

Psychological and social problems were the next most commonly cited cause of epilepsy and included 'worrying'; 'thinking too much'; 'troubles'; 'nerves'; and 'stress' due to family conflict.

Less frequently mentioned causes were substance abuse involving alcohol; heredity, a worm which deposits its 'dirt' in the brain; and dietary causes. As regards dietary causes, one respondent mentioned unhealthy eating as a perceived cause of epilepsy and another stated that if one loves meat and eats too much of it, this can cause epilepsy.

Alternative Treatment Sought for Epilepsy

Table 5

Alternative Treatment Options

Treatment Type	Number of Respondents	Percentage (%)
Indigenous Healer Only	11	55
Spiritual faith Healer Only	0	0
Indigenous Healer and Faith Healer	2	10
Other	7	35

Table 5 shows that 65% of the respondents in the study have sought alternative treatment to the western medical type, the majority having consulted an indigenous healer.

Two respondents had seen both an indigenous healer and a faith healer. One of these respondents seemed to have been desperately seeking an end to his fits when he turned to 'the churches'. He explained that he was treated by a certain 'Father M.' who 'places his hands on you and then every illness in you is cured'. Unfortunately, in his case, the treatment was not successful. The second respondent reported greater success in treatment administered by 'the Christian people of Zion'. He was given (holy) water which he used as an emetic and was prayed for.

Indigenous Healer Consultation

Four respondents mentioned that they were on medication at the time of going to see an indigenous healer. One respondent stated that he had started treatment with a doctor, then sought consultation with an indigenous healer to see if he could help, eventually coming back to the doctor.

The reasons for seeking consultation with an indigenous healer were varied. Two respondents stated that they were seeking a cure for their illness. One of them reasoned that since he was not born with epilepsy, surely a cure was possible. He mentioned, in addition, wanting to augment the effectiveness of treatment by combining indigenous healing methods with western medication. The other respondent who sought a cure for his epilepsy wanted 'this thing that gives me fits to come out'.

One respondent consulted an indigenous healer to determine the cause of his epilepsy. Four respondents sought the services of an indigenous healer because they felt their epilepsy had stemmed from a deliberate act of sorcery ('idliso') or bewitchment by 'other people'.

One respondent went to see an indigenous healer due to the severity of her attacks which she described as 'constant'. Another went because he was trying his luck in what he referred to as 'trial and error'.

Seven respondents mentioned being taken to see an indigenous healer by a parent, grandparent, aunt and in one case, a spouse. When they were asked if they would go of their own volition, most stated that they would not.

Respondents had seen an indigenous healer for a varying number of visits and length of time. Some had gone only once, others twice, and yet others had gone 'many times' during the course of their illness. Only one respondent was reportedly still seeing an indigenous healer at the time that the interviews were conducted. This respondent felt that the combined effect of western medication and Xhosa medicines had improved her epilepsy.

The most frequently mentioned reason for *not* seeking the services of an indigenous healer was due to a belief in Christianity. This was expressed in various ways: 'I trust in God'; 'at home we believe in the Bible, praying and laying hands (on an ill person)'; 'at home we don't believe in people like witchdoctors, we are people of God'.

One respondent saw no reason to consult an indigenous healer because his epilepsy had a clearly established cause: head injury. He did, however, mention that those who contracted epilepsy from 'amafufunyane' should seek the services of an indigenous healer.

All respondents who had consulted an indigenous healer, with the exception of one respondent, stated that the treatment they received did not help. Generally, they saw no improvement in their condition as they still got fits, with one patient complaining that his condition even worsened when seeing a healer. The one exception, who takes both western medication and traditional medicines, stated that she could not ascertain which of the two forms of treatment was providing her with relief from seizures but believed it was the combined effect of the two.

Ancillary Support

Three respondents have seen a social worker during the course of their illness. One respondent had been referred to a social worker in unclear circumstances; the second saw a social worker for non-medical related issues, and the third previously mentioned SANEL volunteer had evidently received information and counselling on medical and other aspects of epilepsy.

VOCATIONAL ADJUSTMENT

Two of the 20 interviewed respondents were in full-time employ in the open labour market - one male and one female. The majority of patients (i.e. 17) were unemployed and there was one student. Of these unemployed persons, four were receiving a state grant awarded to people with physical or mental disability deemed unfit for full-time employ in the open labour market. This grant is known as the Disability Grant (D.G.) and precludes one from employment in the open labour market. The student was also receiving a Disability Grant. The majority of unemployed respondents (13) were not receiving a D.G.; some had never had a grant and some had been receiving a D.G. which had been subsequently withdrawn.

A new policy ruling in 1992 concerning the administration of disability grants saw the withdrawal of grants from many people with epilepsy. Whereas before, epileptic patients were granted disability allowance on the basis of their unfitness for formal employment, the new ruling states that an epileptic is fit to work unless her or his epilepsy is coupled with some other debilitating handicap such as mental retardation or psychiatric illness (Dr Mbombo, personal communication, October 1992).

Employed Respondents

The one employed male respondent is 27 years old with a Std 9 education. He works as a labourer at a motor spares outlet. He has been employed in this job for two years and earns an income of R 700.00 a month.

This respondent reported that his first epileptic attack occurred at the workplace but that he has had no subsequent attacks at work. His seizures are reportedly well-controlled and do not interfere with his work aside from having to be absent one day a month in order to fetch medication at the day-hospital. He reported that his employer does not find this absenteeism a problem as he brings a letter from the doctor after each visit.

When he had his first attack, he was taken to hospital by his employer, who advised him to stop drinking alcohol. He reported that at no time did his employer suggest that he quit the job as a result of the onset of epilepsy. He further stated that he has not been absent from work due to seizures per se and that he works the same number of hours as do other employees.

The one employed female respondent is 30 years old with a Std 10 (matric) education. She works as a cleaner at a clothing factory, a job she held for seven years. She reported that her epilepsy started when she was still at school several years before she started working. Her epileptic seizures are reportedly well-controlled although she has suffered the occasional attack at work, occurring about once a year. Such attacks apparently elicit special attention being shown to her for the duration of her illness, whereafter things return to normal. She reported that, in general, such attacks have not caused any problems with her employers. She explained that the way in which epilepsy affected her work is by having to take an entire day off work each month to fetch medication at the day-hospital because of the lengthy procedure at the day-hospital. She further reported that recently her employer had asked that she take only half a day's leave for day-hospital visits. She reported that aside from 'that special day' when she has a fit at work, she is treated the same as any other worker.

Loss of Jobs Because of Epilepsy

Although two respondents were employed in the open labour market at the time that the study was conducted, at least 13 of the unemployed respondents had held jobs in the past. Of these 13, ten were employed at the time of the onset of their epilepsy. Nine of these ten respondents reported that they had lost or quit their job for a reason that was either directly or indirectly related to their epilepsy.

At least five respondents reported being told by their employers that they were no longer fit to work because of their epilepsy. Some of the reasons for dismissal were reportedly that they would be 'a problem' to, or 'make trouble' for, the employer and co-workers; that the respondent was in danger of being injured by domestic machinery and had no one to supervise her; that the employee showed a high rate of absenteeism.

At least three respondents stopped working of their own accord. One such respondent explained that her epileptic fits, which occurred only at night, affected her ability to effectively carry out her daytime duties as a domestic worker. Her body was often stiff and her tongue would be injured from having sustained a bite making it impossible for her to eat. Another respondent reported feelings of shame and humiliation from having epileptic fits in front of other staff members at her work place.

Job Finding Problems

Thirteen of the 18 unemployed respondents reported that they have actively sought employment after the onset of their epilepsy. In at least eight cases, their problem in securing a job seemed to be related to their epileptic condition. In this regard, a few respondents reported that they were not hired because potential employers anticipated that they were going to have

seizures at work. Some respondents were vague and reported that they were not finding a job 'because I have fits'.

There were other 'epilepsy-related' reasons for not finding a job. One respondent speculated that perhaps would-be employers were deterred by his scarred face which is a result of injuries from falls during seizures. He felt that probably would-be employers view him as a 'skollie' (somebody of disreputable character) and, therefore, as somebody who is going to steal from them. One respondent who had applied to an education department for a teaching post on numerous occasions speculated that her failure to secure a post may be due to the fact that a certain member of the selection panel for the posts had attended teacher's training college with her and, thus, knows of her epileptic condition. She speculated that this one member may then disclose her epilepsy to the rest of the group resulting in her application being turned down.

At least two respondents seemed to cast doubt on their potential to work because of their epilepsy. One of them mentioned that perhaps he was too weak to work hard and the other feared that he would not be able to work effectively or do heavy-duty work because of his illness. Such perceptions are likely to have influenced their ability to secure employment.

Other reasons for not finding a job were *not* related to the respondent's epileptic condition. At least three reported job scarcity as the reason for their inability to find work. Another respondent mentioned that he lacked transport money to enable him to look for a job.

Disclosure of Illness

Half of the respondents were asked if they had disclosed their illness to potential employers when seeking a job. They reported more often that they do *not* tell potential employers of their epileptic condition. Two such respondents said that initially they did disclose their illness but had stopped this practice because of their failure to secure a job.

The most commonly reported reason for non-disclosure of their epileptic condition was a feeling that they would undoubtedly not get the job if the would-be employers knew. For example, one respondent said he found it ludicrous to announce before-hand that he has fits. He felt it is better to tell employers once inside the job when they are in a better position to accommodate him. Another respondent explained that when applying for a job she deliberately writes that she does not suffer from any illnesses in the section of the application form enquiring on the applicant's health. She reported that one should only disclose the illness when one has been appointed for the job. One respondent lamented that even though he hides the illness from would-be employers he ends up losing the job anyway when they see that he has epileptic fits.

Financial Problems

As reported previously, only two of the 20 respondents were employed and of the 18 unemployed respondents, only five were recipients of state disability grants. This meant that 13 respondents (65%) effectively had no source of income.

All but two respondents reported that they worry about money. Not surprisingly, most respondents reported the source of their financial problems to be the lack of full-time employment.

The reasons that respondents gave in accounting for their worry about money were varied. Six respondents mentioned that in addition to providing for their own needs, they had either one or more children to support. As one respondent put it, 'whatever circumstances I am in, I have children to support'. In most cases financial support included meeting their educational needs for fees, books and uniforms.

Various other needs were reported which respondents felt they could not meet due a lack of money. These were, food (e.g. 'I am not eating well. '), clothing (e.g. 'Sometimes I get clothes from people; I cannot buy myself clothes'), housing (e.g. 'I want to build a house; I want to get my wife to return and build a house, with me having money'), and rent (e.g. 'We do not even have money for rent').

Four respondents reported that they are financially dependent on family members, usually parents, but also siblings. In two cases the supporting parents are pensioners and in one case the supporting mother is herself sickly with asthma.

Interestingly, the two employed respondents also reported that they worry about money. In both cases, the money they receive is apparently not sufficient to cover all their responsibilities.

The two respondents who reported that they do *not* worry about money both receive a disability grant. One respondent mentioned that although this 'money from the government' is helpful, there are still things that he cannot afford such as supporting a wife and a family which he hopes to do in the future.

Daily Activities

The 18 respondents who are not employed spend their days pursuing a variety of activities. Most of the women reported that they spend their day doing household chores such as cleaning, washing, ironing and various other 'odd jobs' in their homes. Two of these respondents in addition to house work take care of a baby in one case and in the other case, small children from the neighbourhood. Three women reported that they do not do anything in particular but just 'sit at home'.

Many of the unemployed men seemed to spend their days pursuing activities outside of the home. As one respondent put it, his blood must not lie stagnant in his veins and it is not good to be passive. Thus, he does a variety of activities such as visiting friends, physical training, boxing, listening to music and gardening. Another male respondent helps his father who is a herbalist and runs errands for him. Another respondent takes on odd jobs requested by neighbours, but mostly visits friends. Various other activities such as gardening, washing of cars, searching for a job were reported as daily activities. Finally, one male respondent is a student and spends his day at college.

Twelve respondents (60%) reported that their illness has interfered (or currently interferes) with the pursuit of such activities which they enjoy. As regards the female respondents who reported that they enjoy cleaning, cooking, washing and other household activities, it would seem that their illness in general does not stop them from initiating or pursuing such tasks but epileptic attacks hinder them from completing the task in hand. One female respondent who reported that the epilepsy stops her from sewing explained that her hands continually feel dry and her fingers have stiffened since the onset of her epilepsy, making it laborious for her to sew.

ADJUSTMENT TO SEIZURES

Impact of Epilepsy

In reporting what it is like to have epilepsy, the immediate response of at least 12 respondents was a negative remark such as, 'it is bad to have this illness'; 'your life is not alright'; 'it's not a nice thing'; 'on the whole there is nothing good about having epilepsy'. Respondents then elaborated on such remarks, bringing out various aspects of the illness which they disliked or resented.

Four respondents reported that epilepsy is a danger to their lives because of the unpredictable and uncontrollable nature of attacks. Potentially hazardous situations in which it could place the sufferer included a sudden attack while crossing the road or merely walking on the side of the road in busy traffic conditions; falling from a seizure whilst working on a roof top; or sustaining a burn while handling or washing with hot water in a bucket.

Six respondents disliked epilepsy because they felt the illness had restricted them from pursuing certain activities or restricted their movements in general. For example, one respondent reported that he was a builder by profession who had worked on many construction sites. However, since he got the illness he has not been able to do 'a lot of things' in his profession and has been reportedly fired from jobs.

Another respondent mentioned that he used to be a keen soccer player. He had stopped playing the sport because increased adrenalin and becoming 'hot' apparently triggered seizures. One respondent explained that he refrains from pursuing certain activities because, 'your common-sense is telling you that whilst you are doing something you might have an attack'. Another respondent shared his view that when a person has epilepsy he cannot 'loiter around', but has to 'stay in one place'.

Two respondents felt that epilepsy is 'very hurtful' because it results in social rejection. One attributed perceived rejection to his status as a 'patient' or sickly person. He felt that others viewed and treated him as a sick person and, therefore, avoided him or did not include him in social activities for fear that he would let them down. The other respondent reported that people avoid epileptic sufferers because they think the illness will be passed on to them through the epileptics' falling and belching.

Another two respondents particularly resented the loss of consciousness that accompanies seizures and the disorientation thereafter; and the loss of control over one's thoughts, speech and actions. One explained, 'it's like you don't have a mind... you are mindless... not in your right senses; when you get up you wonder what happened... where you are... the people will explain what happened to you'. Body weakness and fatigue were also mentioned as a reason for disliking epilepsy. One respondent felt epilepsy was 'hurtful' because people who are not aware of her illness may be at a loss as to what to do when she has an attack in their presence.

Two respondents seemed resentful about the fact that they did not expect or anticipate such an illness to befall them, hence, 'I did not expect to be like this'. The feelings that were associated with their epilepsy were reportedly embarrassment (e.g. 'it's embarrassing - you can be dressed well and fall in the road...'; humiliation (e.g. 'I don't know what kind of illness this is because you can easily urinate on yourself'); shame (e.g. 'others try to overcome the shame of having epilepsy by getting into booze'); feeling shy and exposed.

Only one respondent did not give a negative report about what it is like to have epilepsy. This respondent said she did not really know what it is like to have epilepsy as she had never given the question much thought. She went on to report that epilepsy had not affected her life in any significant way because she is capable of doing things and because she is working.

Problems Attributed to Having Epilepsy

Over half (11) of the respondents in the sample reported financial difficulties primarily associated with a loss or lack of employment as the main problem which their epilepsy had caused. Many of these respondents reported that they 'struggle' or 'suffer' because they are unable to provide for themselves and, in some cases, for their children as well.

Two respondents reported that they starve because they have no money for food. One of the two explained that starvation is now a precipitant of her fits ('if you have not eaten your fits start all over again'). The other expressed a fear that he would resort to stealing for food, 'because, you see, when you're hungry you will take something which belongs to someone else, and steal it, and eat it because you are hungry. You will be caught and locked up as though you are a thief, but you did it because of hunger'.

Epilepsy was seen as the cause of being unable to take advantage of job opportunities, being unable to pursue educational opportunities, and opportunities in other spheres of life. Hence, 'I think I would have done a lot of things in my life... but this illness prevents me from grabbing opportunities which come my way'.

Five respondents reported that epilepsy had impeded their educational progress. For example, 'I would have gone to school and furthered my studies... It (her life) would have been better'. Two of the five had quit schooling before reaching Std 10 due to epileptic attacks that affected their classroom performance, the writing of exams and social functioning at school.

One respondent actually completed Std 10 and had aspired to do nursing, medicine, teaching or social work but had not applied because 'she knows she got epilepsy'. On further probing, she explained that she was uncertain as to which discipline would accept and accommodate her epileptic problem and ultimately she feared being rejected and, thus, never applied.

One respondent was forced to quit a teacher's training course due to the disruption caused by seizures during lectures. She lamented that some of her former school-mates were now nurses at the day-hospital which she attends for treatment of her epilepsy.

There were various other problems whose cause was attributed to having epilepsy. One respondent pointed to his face, scarred by falls during epileptic attacks. A lack of friends was reported by one respondent who has become 'scared' that he will not fit in amongst people and also fearful of their knowing about his condition. Forgetfulness was a reported problem for one respondent and another complained of hearing problems which reportedly have occurred since she started having epilepsy. One respondent was worried about her child's perplexed and confused reaction to her epileptic attacks.

Three respondents reported that epilepsy has not caused any problems for them. One such respondent explained that he is able to treat himself by keeping 'up-to-date with his medication'; he feels like somebody who does not have epilepsy. The other respondent who is employed reported that epilepsy does not affect his life in any significant way except for having to come to

the day-hospital regularly for medication. The third respondent explained that she does anything she wishes to do in spite of having epilepsy and is just as able to go out and 'communicate' with people as she is to sit at home.

Because of the problems cited above, 16 respondents (80%) reported that their lives would have been different if they did not have epilepsy. Three respondents (15%) said their lives would *not* have been any different and one respondent (5%) gave a tangential response to the question.

Disclosure of Illness to Others

Eight of the 20 respondents reported that they *do* mind people knowing that they have epilepsy; ten did *not* mind and two were non-committal, i.e. sometimes they did mind and other times they did not mind.

Those who *did* mind people knowing gave their reasons. These included feelings of shame about having epilepsy particularly because of the belief that the illness is infectious; and being the brunt of insults and jokes about the illness, or being fearful that this could occur. One respondent felt that epilepsy is her guarded 'secret' and that if others knew, it would smear her name, spoil her reputation and disrupt things for her. Two respondents did not elaborate much as to why they mind if others know that they have epilepsy. One such respondent simply said that he minds because 'its not something good'.

Three respondents mentioned in addition that, even though they do mind others knowing about their illness, such an attitude is not helpful because they have the illness, they cannot rid themselves of it, and they cannot hide it.

The reasons given for *not* minding others knowing about their epileptic condition were varied. One respondent felt he should not hide his epilepsy so that others are in a position to provide him with help when he falls ill. Another reported that he does not mind because he did not bring the illness upon himself; getting epilepsy was something over which he had no control. Similarly, another reported that she is not afraid to tell others about her epilepsy because it is a fact of (her) life and others would eventually find out anyway and, perhaps, wonder why she had not told them in the event of getting an attack in their midst. Several communicated a non-caring attitude about the reaction of others to their epileptic condition.

Whether Or Not Respondents 'Speak Freely' About Their Epilepsy

Fourteen respondents reported that they speak freely about their epilepsy, and six reported that

they do *not* speak freely about their epilepsy. It would seem that even though eight respondents previously reported that they mind people knowing that they have epilepsy, for certain reasons, some do speak freely about it anyway. These reasons are pursued in the discussion.

A few respondents apparently 'speak freely' about their epilepsy in the sense that they explain the nature of their illness to others and when it befell them. Others 'speak freely' only if the subject arises, or if someone specifically asks about their illness, or in the event that they experience a fit in front of a person. Two respondents reported that they speak freely about their epilepsy because it is an unchangeable fact of their lives that has happened and which they feel they cannot hide.

Six respondents reported that they *do not* speak freely about their illness. For one respondent the reason given was to prevent the possibility of people gossiping about him and, hence, arousing his anger and a situation in which he would cause harm to somebody. Another reported that she does not speak freely about her epilepsy because of the belief that epileptic people can infect others with their illness.

Knowing About SANEL

Fifteen respondents (75%) reported that they did *not* know SANEL while five respondents (25%) reported that they did know of SANEL. One respondent was very familiar with SANEL having originally established contact with the organisation through a visiting social worker and eventually become a volunteer for SANEL. She said she had learnt to sew through her contact with the organisation and had been on various social trips organised by SANEL which she had found enjoyable.

Another respondent had made contact with a social worker at SANEL in trying to organize herself a bursary to further her studies. She went on to say that the social worker concerned was very busy as she was the only one catering for all of those living in the township and was, therefore, unable to maintain contact with her and unable to assist her. Yet another respondent had had contact with a SANEL social worker in the past and, through this contact, had visited and sung to groups of other epileptic persons. One respondent said that SANEL had helped him obtain a Medicalert bracelet and felt that he should go back to the social worker as he had lost the bracelet. One other respondent vaguely remembered that he had had some contact with SANEL in the past but could not remember the details.

INTERPERSONAL ADJUSTMENT

Table 6

Respondents' Living Arrangements

Living Arrangement	Marital status
	Unmarried
Family Home with Parents	10
Sibling(s)	6
Other Relatives	2
Total	18
	Married
Own Home	1
Son	1
Total	2

Table 6 shows the people with whom the respondents live. Eighteen of the 20 respondents in the present study were not married; this includes one widow. At least ten of these 18 unmarried individuals, aged between 30 and 45 years, reported that they live in the family home with one or both parents, siblings, nieces, nephews and their own children.

Assistance From People in the Household.

Sixteen respondents (80%) reported that they receive help from the people they live with in dealing with their epilepsy, while four respondents (20%) said that they do not.

Seven respondents reported that family members remind them to take their medication. Ten reported that when they have a seizure, family members take off their shoes, tight clothing and dentures, and dab their face or forehead with a wet cloth. Another fairly commonly reported form of help (n = 7) was to lay down the epileptic member to rest or sleep. One respondent explained that he is made to sleep on his side so that he can easily release the foam that comes out of his mouth and avoid choking.

Five respondents reported that family members assist them by setting alight or burning a piece of cloth (and in one case, a cigarette), putting out the flame, and allowing it to emit smoke. They then pass the smoke-filled rag under the patient's nose for them to inhale. Two of the five respondents who receive such help reported that the practice of inhaling smoke helped them to overcome their seizure, with one reporting that he feels the fit 'lifting' away.

One respondent, however, said this practice was of no help to him and another remarked about it, 'we are Africans... we do these things that we don't really know about'.

Another reported form of help ($n = 5$) was the placing of an object including a piece of cloth, handkerchief and peg in the mouth of the epileptic person to prevent them from biting their tongue during a seizure. Other, less common ways that family members help their epileptic member were by beating them on the chest whilst calling out their name or hitting them on the stomach because of a belief that something 'dirty' in the stomach must be emitted. Also reported was the stretching out of the epileptic member's fingers or hand during or after a seizure.

More indirect forms of assistance were, reportedly, providing financial support to their epileptic member, providing and preparing food for their sick member, removing him or her from potentially hazardous situations at the onset of a fit, and watching over him or her in social situations away from home.

Eight respondents (45%) reported 'feeling different' in the home because of their epileptic symptoms which set them apart from other 'normal' members in the family.

Preference Between Going Out and Staying at Home

Eleven respondents (55%), eight of them women, reported that they prefer staying at home rather than going out to meet people. Seven respondents (35%) reportedly prefer the opposite. Two respondents reported that they enjoy doing both and have no preference for either one above the other.

The fear of experiencing an epileptic attack away from home was again stated as the primary reason for staying at home. This fear was expressed in various ways such as, 'I get discouraged by the thought that this illness could attack me while I'm on my way somewhere, alone, with nobody to help me', and, 'I stay at home because I know I've got fits'. Embarrassing public reactions to symptoms of the aura preceding seizures or to the seizures themselves, such as laughter and running away were another reported reason for staying indoors.

Many of those who prefer going out engage in social activities such as card games, soccer and

music which bring them into regular contact with others. At least two such respondents mentioned that they are not afraid of having fits away from home because one of them trusts that people will help him when necessary and the other places his trust in Jesus and God. One other respondent felt strongly that epileptic fits were not going to stop her from socializing and communicating with others because, as she explained, 'I don't think it (the epilepsy) can stop me from communicating with people because communication is what's needed'.

Experience of Rejection As a Result of Having Epilepsy

Nine respondents (45%) reported that they have indeed felt rejected by someone because that person knew of their epileptic condition. Four of these who have felt rejected because of their epilepsy attributed rejection specifically to a belief apparently held by people that epilepsy is contagious. One such respondent said that many people do not want to socialize with him and even run away from him because they think that he could infect them. He explained, 'they say so... that it is passed on... but I don't really know how because I got it (epilepsy) from an injury'.

Similarly, another respondent reported that he had stopped telling people who are not close friends about his illness because he had learnt that people run away from him or avoid him when informed. He explained the way in which epilepsy is believed to be passed on:

"They say when you get an attack, sometimes you get wind which you release in a belch; they say *that* is when you can infect other people. Then people get scared of you, they avoid you and your company".

A third respondent who complained that people run away from her because they believe they can get infected by her epilepsy also reported that the illness is thought to be passed on by the action of belching during or after a seizure. One respondent reported that her friends in the neighbourhood and people with whom she attended school have turned against her because, 'they say if they walk around with us (epileptics), this thing is infectious'.

Three respondents reported having been rejected by a boyfriend and one by his wife because of their seizure condition. This respondent, whose wife apparently deserted him with the children, left saying that 'she's not going to live with somebody like this; when she first accepted me I was not like this'.

Two respondents whose boyfriends apparently abandoned them have children by these men. One of the respondents reported that her boyfriend ran away after he learnt that she had epilepsy. The other left following the birth of their third child which coincided with a time when the

respondent's seizures became more severe.

The other respondent said she is uncertain as to why her boyfriend left but is particularly perturbed that he shows no concern for the welfare of his child and does not provide any financial support.

Eleven respondents have reportedly not felt rejected by someone as a result of knowledge of their epileptic condition. One mentioned that even a previous girlfriend knew of his illness and yet viewed him as a 'normal person'. Another stated that people generally talk to him and that he also sits around and chats freely with others.

One respondent reported that, although she has not felt rejected by friends, she has, however, been made fun of, laughed at and been the subject of gossip because of her illness especially while still attending school.

One respondent who has not felt rejected mentioned another reaction that people have towards her epilepsy, which is that of pity for her. This, she said, makes her heart sore as she has not deliberately brought the illness upon herself. A few other respondents mentioned some difficulty in dealing with the reactions of others to their illness because, as they explained, they do not purposefully or intentionally bring the illness upon themselves. In most cases, they seem to feel they have no control over its occurrence.

Most of the respondents (65%) reported having only one or two friendships rather than lots of friends. Respondents seemed to prefer having one or two trusted friends who know about their epilepsy and treat them normally in spite of it, and are able to provide help when necessary. Lack of sensitivity to their condition and negative reactions were factors that tended to limit respondents' friendships to just one or two. Of those who apparently have lots of friends (35%), one mentioned that most of these friends do not know that he has epilepsy.

CHAPTER 6

DISCUSSION AND CONCLUSIONS

The present research has explored the experience of having epilepsy amongst persons attending day-hospitals in the peri-urban Black townships of Guguletu and Nyanga. Kleinman (1988) comments that local cultural orientations shape our understanding and treatment of illness. The approach used in the study necessitated an examination of cultural beliefs of the nature, cause and treatment of epilepsy. There were, however, limitations to the study worth mentioning from the outset.

A non-random selection of only a small number of respondents who constitute 'attenders' of their local day-hospital was conducted. This sampling technique appeared to be the most practical and least time-consuming in gaining access to African epileptic sufferers. Choosing subjects randomly was not possible because not many patients met the criteria for inclusion in the study. Applying a random sampling technique to those who did qualify would have proved too time-consuming.

The conclusions that can be drawn from the study are, therefore, not generalisable beyond the scope of African epileptic persons living in Nyanga and Guguletu who use the services of the day-hospital in their respective communities. As such, the sample is a biased one and may be atypical or not completely representative of African epileptic sufferers. In fact, the sample may not even be typical of clinic 'attenders' as selection was not random.

A semi-structured individual interview was conducted to elicit information from respondents. It is recognised that a single interview is inadequate to tap the entirety of people's views, attitudes and beliefs on epilepsy. Attitudes are complex phenomena subject to incoherences, contradictions, nuances, vagueness and change. Again, practical considerations of time and the scope of the research necessitated only one interview.

As regards the interview process itself, it was apparent in many cases that respondents were not used to being questioned to such a degree on the non-medical aspects of their illness, particularly with the use of open-ended questions. The tendency, especially at the initial stages of the interview, was to give a brief response and to then pause in anticipation of the next question. Respondents needed a great deal of prompting with verbal and non-verbal cues in order to expand on their answers and to elicit greater detail and depth.

The above problem was compounded by the fact that the researcher is conversant, but not fluent,

in Xhosa. This led to some difficulty in pursuing interesting leads or eliciting fuller explanations and descriptions of phenomena, thus, compromising the potential richness of the data. In order to limit the effect of a language barrier to a minimum, interviews were recorded and later translated and transcribed from Xhosa to English with the aid of three fluent Xhosa-speakers.

In introducing myself to respondents I told respondents that I was a researcher but did not give an indication of my professional identity. In several instances respondents referred to me as 'social worker' or 'nurse'. Such references implied that I was perceived as a member of the western-oriented health profession. This perception could have influenced their responses particularly on questions enquiring on their traditional beliefs on the causes of epilepsy and their treatment preference between western and indigenous methods of healing. Respondents may have felt obliged to reply to such questions in ways that showed that they accept and utilize western medicine whilst distancing themselves from indigenous beliefs for fear of criticism or admonishment.

Analysing and recording the responses from open-ended questions proved to be sometimes difficult due to the complexity of people's attitudes. Respondents qualified their answers or gave responses that could not be simply pegged into discrete categories. For example, on being asked if a respondent had ever felt rejected by someone because of his or her epilepsy, one person said she had felt rejected when having a seizure in the company of others, but otherwise at any other time had not felt rejected. An essentially content analytic methodology as used in this study does not easily deal with contradictions or complexities of this nature.

The Findings

Medical Management

Many of the problems faced by epileptic patients to be mentioned in the ensuing discussion may arise from the poor control of seizures. Medical management is, thus, a critical factor in influencing the psychosocial well-being of epileptic sufferers.

The drug most commonly prescribed to patients was phenytoin sodium (Epanutin) - the gold standard in epilepsy treatment - prescribed to 70% of the patients. This finding is highly comparable to that reported in a study of epileptic patient services at another Cape Town day-hospital. At Heideveld Day-Hospital, phenytoin sodium was prescribed to 80% of the sample of epileptic patients. Phenobarbitone was used more frequently than carbamazepine in this study, possibly because it tends to be the cheapest antiepileptic drug in many countries (Shorvon & Farmer, 1988).

The three drugs most frequently prescribed to respondents in the present study have been recommended for primary usage in developing countries because of their effectiveness in treating almost all seizure types (Gastaut & Osuntokun, 1976).

Respondents generally did not know the names of the pills prescribed to them. There are several possible reasons to account for this finding. Doctors who treat epileptic patients and prescribe their medication may not inform the patients of the names of the pills they give out.

Shorvon & Farmer (1988) have noted that in developing countries the number of patients per physician is often so high that the time a physician is able to devote to the individual needs of an epileptic patient is severely restricted. It is possible that at busy day-hospitals such as Gugelutu and Nyanga, physicians tend not to supply patients with information regarding the name and type of medication they prescribe, preferring to concentrate on achieving control of their illness.

Alternatively, as one patient pointed out, perhaps they are indeed informed of the medication prescribed to them but do not remember the name because of the unfamiliarity of medical terms especially in a second language.

A third possibility is that their lack of knowledge of the names of pills prescribed to them is reflective of a broader lack of understanding of their illness in general. This possibility will be explored further in relation to other findings.

Several respondents cannot afford to pay the R 6.00 levy on medication. This finding is understandable in light of the fact that a significant percentage were unemployed and not receiving a state disability grant due to their epileptic condition. A similar finding was reported by Danesi et al. (1981) in Nigeria, who found that one third of their sample of epileptic patients earned low incomes and had some financial difficulty in purchasing drugs. The findings appear to confirm that drugs are not always affordable to the epileptic person who is usually unemployed or earning a low income (Shorvon & Farmer, 1988).

This finding has a serious implication in that some epileptics may not feel at ease about returning regularly to the day-hospital because they cannot afford the medication fee or because of a debt they have incurred. It seems that the health care system does allow for some flexibility in paying the medication fee. It is suggested that patients should be seen by the day-hospital social worker for assistance with this and other problems as will be further expounded upon later in this discussion.

Although most epilepsies can be controlled with the use of appropriate medication, the majority

of respondents in the study did not enjoy full seizure control. This finding is partly a result of the selection criterion. Even so, as many as 55% reportedly experience one to three seizures in one month. Shorvon (1990) recorded lower figures (i.e. better control) for developing countries. Shorvon (1990) estimated that of patients receiving treatment for generalised tonic-clonic seizures, 25% have seizures occurring at a frequency of more than one per month. It is important to question the validity of figures obtained in the present study as many of the patients found it difficult to pin-point the frequency of seizures per month and stated that it tended to vary.

Even so, it would seem that many respondents have not seen the full benefits of western medicine. By implication, a primary line of intervention that seems to be indicated is the achievement of better control over seizures.

The literature suggests that the most important factor responsible for poor seizure control is non-compliance. Although most respondents remember to collect their medication from the day-hospital every month, only a third reported that they remember to take their medication regularly at home. Despite their apparent intentions to take their medication as directed, most do forget at times and need to be reminded by those who live with them. It has been noted that memory problems are not an uncommon associated feature of epilepsy.

Two respondents reported that they were unable to follow instructions pertaining to the times they are meant to take their pills. This finding highlights the importance of Osuntokun's (1978) suggestion that drug treatment regimens should be as simple as possible. Whenever possible, drugs should be prescribed to be taken as few times as possible in the day (Rimmer & Richens, 1988). Fortunately, instructions on medication packets are printed in Xhosa, English and Afrikaans which means that they are comprehensible to respondents who were mostly literate.

Despite the lack of achievement of full seizure control reported by the majority of respondents, most perceived the medication to be helpful. The illness was seen to be treatable with medication; however, a few respondents expressed confusion and dissatisfaction that the medication does not, in fact, cure their condition. The apparent concern was that they still get epilepsy even though they take the medication. Similar sentiments about epilepsy were expressed by community health workers in Khayelitsha and Nyanga in Binedell's (1993) study. Specifically, it was felt that western medicine was unable to provide a cure for epilepsy resulting in disillusionment and loss of confidence in medication. For these and other reasons, respondents appeared motivated to seek other forms of treatment particularly indigenous methods of healing.

Most respondents appeared to have no idea as to how long they would have to continue to take tablets for their epilepsy and expressed a reliance on the doctor's discretion in this regard. Most

had faith that their illness would either get better or that eventually they would stop having seizures.

Here, I noted a lack of understanding of certain aspects of epilepsy, namely, the concept of their illness being a chronic and, often times, life-long illness. As a consequence they seemed not to understand that the nature of their illness may entail the taking of drugs on a prophylactic basis for a long time - perhaps even well after seizures have stopped. Even though it may be good practice to rely on the doctor's decision regarding the termination of drug treatment, it is argued that patients should be equipped with sufficient information about their illness to enable them to be active participants in this decision.

Studies in both developed and developing countries have shown that good patient compliance and successful treatment are dependent on adequate knowledge and understanding of the illness (Goodridge & Shorvon, 1983). Only one respondent displayed accurate ideas on the treatment aspects of epilepsy in saying that full seizure control could be achieved by taking medication regularly for life. This particular respondent had previously been a volunteer group facilitator for SANEL. It would seem that her exposure to the organisation has resulted in the gaining of sound knowledge and information on her illness.

Various authors have suggested that one way of improving compliance to drug therapy is to inform and counsel patients on the various aspects of their illness (e.g. Tettenborn & Kramer, 1992). Most respondents in the study have not seen anyone other than a doctor for the treatment of their epilepsy. As suggested earlier, the doctor is likely to focus on the purely medical aspects of managing the illness, and may be too pressured to provide counsel and information on epilepsy in general. Respondents' awareness and education about their illness are sadly lacking.

Within the context of primary health care, the community health worker and to a large extent the social worker can be primary agents in providing education to epileptics, their families and community members. The study has identified a host of psychosocial problems associated with having epilepsy, yet very few epileptics actually get to enjoy the services of a social worker.

It is suggested that all (new) epileptic patients presenting at the day-hospital should as a matter of protocol be referred to the day-hospital social workers for the appropriate management of social problems relating to their illness including vital education on various aspects of epilepsy. In addition, the day-hospital social worker may provide the link to the services of SANEL which remain unknown to most Guguletu and Nyanga day-hospital epileptic patients. Evidently this recommendation would need full investigation taking into account the time and financial constraints of day-hospital social workers.

Cultural Beliefs and Alternative Sources of Health Care

Studies in various parts of Africa have identified a strong and fairly widespread belief in witchcraft and sorcery as causes of epilepsy. Respondents initially said that they did not know the causes of epilepsy but, on encouragement, were able to offer some ideas.

The cause of epilepsy was most often attributed to physical phenomena such as head injury, gall ('inyongo') and burns. This finding is understandable in light of the fact that for many of the respondents, the onset of epilepsy followed a physical injury especially to the head.

Witchcraft and sorcery constituted the next most frequently mentioned cause, with 'idliso' and 'bewitchment' being most often cited as specific causal factors. 'Ukutwasa' and 'amafufunyane' were also mentioned.

Although respondents willingly shared cultural views and ideas on the causes of epilepsy, I gained the clinical impression that there was a subtle wish to distance themselves from such beliefs. The causal explanation was often accompanied by a statement indicating that they personally do not believe in such. As mentioned earlier, an influencing factor in this regard may have been their perception of me as somebody aligned to the western health care system. Farrand (1988) comments that cultural views are often seen to have no place within the western scientifically based medical model of treatment, a factor which could have made respondents reluctant to express such views. Furthermore, the interviews were conducted at the day-hospital, an evident feature of the western medical system.

Binedell (1993) found some indications that community health workers in Khayelitsha and Nyanga respect and accommodate people's cultural beliefs about ill-health and their preferences regarding treatment. There was evidence in Binedell's (1993) study to suggest that community health workers do not discourage a family from consulting a traditional healer, so long as they also sought the advice of a doctor.

Most respondents in the present study have consulted an indigenous healer at some stage for the treatment of their epilepsy. Reasons for the consultation included the seeking of a cure for their illness, the seeking of a cause, and to eliminate or cure the negative effects of an act of sorcery or bewitchment. Zionist faith healers have, in addition, been consulted by two respondents.

Again, it was my clinical impression that respondents seemed to be distancing themselves from identifying indigenous healing forms as viable forms of treatment. Several respondents mentioned being taken to see an indigenous healer by a family member and stated that they would not go of

their own volition. All but one respondent stated a preference for medical treatment over indigenous healing and all respondents who had consulted an indigenous healer felt that the treatment given did not help.

Even so, that most of these clinic-attending respondents have at one time or another consulted an indigenous healer for the treatment of their epilepsy appears to lend support to observations made by various authors. The literature suggests that (African) patients tend to resort to a combination of western and traditional services or 'shuttle' between the two (e.g. Farrand, 1984; Holdstock and Franks, n.d., cited in Swartz, 1986; Whyte, 1991.)

At the time the study was conducted only one patient was still seeing an indigenous healer for the treatment of her epilepsy while simultaneously using western medication. As mentioned earlier, most respondents have serious doubts about the efficacy of indigenous treatment methods for epilepsy and prefer western drugs. These findings possibly indicate a diminishing belief in and reliance on traditional health care.

However, it is important to note that the sample of respondents is a biased one representing clinic-attenders. These people are not likely to be prime supporters of other forms of treatment by virtue of the fact that they come to the clinic every month to collect medication. This particular issue would have to be addressed in a sample of non-clinic attending epileptic patients in the community for more valid findings.

Rather than discouraging cultural beliefs about ill-health and people's apparent need to seek other forms of treatment, the findings of the study suggest that open and free dialogue is needed about such beliefs; after all, they influence compliance with the ingestion of western medicines. There appears to be a need for closer links between professionals working within the medical model and those using indigenous healing methods.

Vocational Adjustment

Findings indicated that an overwhelming 90% of the epileptic respondents in the present study were not employed. The lack of money (secondary to unemployment) and its far-reaching consequences was the most commonly expressed concern of the epileptic persons interviewed. Financial problems seemed to represent the most difficult aspect of coping for them, particularly if epilepsy developed in a breadwinner. This finding clearly supports the assertion by The Commission for the Control of Epilepsy and its Consequences that unemployment is the single greatest problem facing the adult with epilepsy.

The high unemployment figure amongst epileptics in the present study (90%) compared to that of the general population (45%; Business Day Reporter, 1993) appears to lend support to the literature which has shown unemployment to be more frequent in people with epilepsy. The percentage of unemployed persons in the present study was much higher than that cited in two other Cape Town hospitals.

The unemployment figure in a sample of mainly so-called Coloured (65% of sample) and Black (20.6% of sample) epileptic out-patients attending Groote Schuur Hospital was found to be 41.3% (Fisch & James, 1992). The percentage in a sample of "Coloured" epileptic patients attending Heideveld Day-Hospital was 61.3 % (Le Roux & Rutherford, 1992).

A countrywide survey of 1660 Blacks conducted by the Human Resources Research Council (HSRC) concluded that between 5% and 10% of Blacks were unemployed and living at levels of severe deprivation (cited in Business Day Reporter, 1993). Thus, the unemployment figure found in the present study far exceeds the proposed rate of unemployment amongst South African Blacks in general.

The two respondents who were in full-time employ were both working in unskilled jobs in spite of the fact that one of them has an important secondary school qualification known as Matric. According to a previous study conducted in Nigeria, epileptic persons are overrepresented in the semi-skilled and unskilled employment sectors largely because of poor educational achievement (Danesi et al. 1981). It is difficult to account for this one respondent's unskilled job as a cleaner considering her educational qualifications. More information is needed to ascertain the circumstances surrounding the choice of her job including whether or not she made job applications elsewhere and if so, on what basis she was turned down.

Of note is that both employed respondents reported well-controlled epileptic seizures which have little or no effect on their worklives. Their illness entails monthly visits to the day-hospital to collect medication. In both cases suitable arrangements have been arrived at with their employers concerning these monthly visits. They have reportedly not experienced any prejudice or discrimination at the workplace by their employers who are aware of their epileptic condition. It is argued that these respondents do not appear to manifest the 'problems' that are typically anticipated by employers with regards to epileptics, such as frequent seizure attacks on the job, working fewer hours, regular absenteeism and frequent hospitalization (see Scambler, 1987). However, caution should be exercised in drawing any conclusion from this finding since the number of employed respondents is so small.

Several respondents who had previously held jobs had been less fortunate in retaining their jobs

after the onset of their epilepsy. As many as 45% felt that they had lost their job for a reason that was related their illness. While it is difficult to determine with any degree of certainty if their loss of a job was a result of employer discriminatory practice, it seemed that in many cases respondents perceived it as such. Respondents reported that because of their 'epileptic status', employers rendered them unfit to work; a burden to the employer or to co-workers; or a danger to themselves.

Finding a job appears to be as difficult as, if not more difficult than, retaining one. Many of the unemployed respondents would like to be working and have actively looked for work in spite of their epileptic condition. Their perception is that they are being denied the opportunity of work 'because of the epilepsy' or 'because they have fits'.

The low educational achievement of many respondents is likely to contribute to the difficulty in their becoming employed (e.g. Danesi et al. 1981). One other disadvantage that Black South Africans have to contend with is that, because of the lower standard of their system of education, they more often do unskilled work than Coloureds or Whites. Epilepsy may be more of a barrier to jobs for unskilled workers than to jobs for white-collar workers because the occurrence of seizures in the unskilled work environment (usually a factory, construction site, etc.) has potentially far more serious or dangerous consequences than having a fit in a white-collar, office environment. By implication, Black epileptic persons appear to be restricted from those areas in which they are best qualified to apply.

It was a subjective observation that two respondents seemed to have developed paranoid ideas regarding the reasons for not finding a job, which may be the result of repeated rejection by would-be employers. Another two respondents seemed to cast doubt on their potential to work, thinking themselves too weak or not capable of heavy-duty labour. This finding seems to be an example of 'self-discrimination' - a form of discrimination that epileptics impose on themselves, making them feel that they are incapable and cannot achieve (Epinews, December 1992).

Given the respondents' reported problems in finding a job, it was not surprising to find that most, by now, do not disclose their illness to would-be employers when looking for a job. Respondents choose not to disclose their illness for fear of encountering discrimination. This fear is the felt stigma suggested by Scambler and Hopkins (1987; 1988) in their 'hidden distress model'. It would appear that the felt stigma portrayed by respondents in the present study was indeed justified in that many had reportedly encountered actual instances of discrimination by would-be employers (i.e. enacted stigma).

Currently in South Africa, the government is cutting back on health expenditure and within this

process 'a few' epileptics are being announced fit for work, particularly if they do not present with any other major disorder. Once withdrawn, the reinstatement of the D.G. occurs on an individual case basis only following the outcome of a work assessment or the 'stiff recommendation' of a social worker, psychologist or doctor's report (I. Daniels, Western Cape Director of SANEL, personal communication, May 26th 1993).

Unemployed respondents who have had their disability grants withdrawn were bitter and resentful about this. They complained that although they were supposedly 'fit to work' and were, therefore, forced to seek employment, they were not able to find work, ironically, because of their epileptic condition. One such respondent taunted, 'If they say I'm fit for work, let them find me a job!'

Clearly, the current situation regarding disability grants is frustrating to epileptic persons. Although some would prefer to work rather than receive a grant, their inability to find jobs makes them dependent on the grant. The present depressed economic climate resulting in job scarcity probably most affects those with disabilities. It is suggested that the policy on the administration of grants to epileptics be reviewed as it seems to be currently working to their disfavour. An organisation like SANEL which has as its goal the interests of epileptic persons may be in a position to make recommendations to the Government regarding the appropriate policy management of disability grants to epileptics.

As many as 65% of the respondents in the study have no source of income and most of the respondents, including the two employed respondents, appear to have financial problems. Respondents complained of not being able to meet basic needs of food, clothing, housing and providing for their children. Research has indicated that epileptic persons are often dependent on others, especially on their families, for financial support (Dodrill et al. 1980; Thompson & Oxley, 1988; Whyte, 1991). In the present study, at least four respondents reported being solely dependent financially on family.

Adjustment To Seizures

In the present study, respondents reported many negative aspects of having epilepsy that they have to cope with. These include: the unpredictable and potentially dangerous aspect of having an attack any time and anywhere (n=8); that epilepsy imposes restrictions on certain activities and on one's social movements (n=6); that epilepsy causes body weakness (n=1); that epilepsy results in fewer job and educational opportunities (n=5); that seizures are embarrassing and humiliating (n=2); that epilepsy results in social rejection (n=2) and that epilepsy causes a temporary loss of contact with reality (n=2).

It has been frequently noted in the literature that people with epilepsy are generally unwilling to disclose their illness to others and may come to fear that other people will find out about their condition (Danesi, 1984; Dodrill et al. 1984; Levin et al. 1988; Shorvon & Farmer, 1988). In the present study, as many as 40% of the respondents said that they mind about others knowing that they have epilepsy. The illness was associated with feelings of shame especially because it is considered by some to be infectious; with being made fun of, laughed at, or insulted; and with loss of dignity and respect. Thus, many epileptics seem to perceive their illness as socially undesirable.

Even so, a large number of respondents 'speak freely' about their illness because epilepsy is an illness that is not easily concealed and is an inescapable fact of their lives. Hence, some are forced to explain to others the nature of their illness and when it befell them; either when the subject arises or at any other time.

Because of the unpredictable nature of epileptic attacks, many respondents felt they were prone to or at risk of accidents and injuries, and felt restricted in pursuing certain activities. As many as 60% of the respondents reported that their epilepsy prevents them from doing the things that they enjoy. Collings (1990a) argues that some epileptic people fall prey to irrational beliefs and fears about their condition and may have misconceptions about the limitations that they think seizures impose on their lifestyle.

Current opinion suggests that epilepsy may entail only minor changes to one's lifestyle (Tettenborn & Kramer, 1992) yet the findings seem to indicate that epilepsy is imposing significant restrictions on respondents' lives. Furthermore, most respondents felt their lives would have been different if they did not have epilepsy, implying that epilepsy has entailed important changes in their life course or lifestyle. An important consideration in the present findings is that for many of the respondents, their epilepsy is not properly controlled on medication.

Respondents reported that the illness had in various ways thwarted their life ambitions and aspirations and, in so doing, prevented them from attaining their goals. Felt stigma (i.e. the fear of enacted stigma) was clearly a factor in the case of a respondent who would have liked to have furthered her studies after matric but failed to make the relevant applications because she feared rejection.

It is suggested that education is needed to inform epileptic persons of exactly what precautions and restrictions to their lifestyle are necessary and what restrictions are in fact unfounded. Further, epileptic persons may benefit from being informed of their rights, especially to a full education and employment so that they do not fall prey to discrimination by uninformed individuals, or to their own self-discrimination. Tettenborn & Kramer (1992) believe that one of

the primary goals of patient care for persons with epilepsy is to help them lead an independent life with as few restrictions as possible.

It is encouraging that there is an organisation in South Africa such as SANEL that concerns itself with the welfare of epileptic persons. However, the majority of respondents (75%) said that they did not know of SANEL. This finding will have to be further investigated as it may be owing to a number of possibilities including how well SANEL advertises its services in the day-hospitals in Black townships.

Interpersonal Adjustment

Most respondents are not married and still live in the family home. This finding seems to indicate that epileptic persons may be more dependent on their families for accommodation than non-epileptics, perhaps because they are usually not financially independent. The finding must, however, be treated with caution considering that it is not an uncommon feature in Black township settings to find multigeneration families living under the same roof. Ultimately, only a few unmarried individuals may be able to afford a home of their own.

Respondents also rely on their families for practical assistance in handling epileptic attacks. One atypical form of help reported by a few respondents is the inhalation of smoke through the nostrils, generated usually by burning a piece of cloth and dousing the flame. This practice provides some relief from seizures for some respondents and not for others. No record of this practice was found in the literature.

The findings suggest that respondents rely on their families for financial support, accommodation and practical help in dealing with their seizures. It was interesting to note, however, that in spite of the help provided by their families, as many as 45% of the respondents felt they do not fit in, in the home or they feel somehow different.

Studies conducted in Nigeria exploring the epileptic person's ability to make and keep friends have yielded mixed results (e.g. Danesi et al. 1981; Osuntokun, 1978). Findings of the present study indicate that most of the respondents have only one or two friendships rather than a lot of friends and acquaintances. In most cases, respondents had deliberately limited their friendships to one or two trusted friends due to negative experiences with people. Some of the mentioned attributes of these trusted friends were that they know of the respondent's illness and can provide help when necessary, and they treat the respondent like a normal person making him or her feel accepted as one of them.

Several researchers have noted that epileptic persons are scared of going out alone, particularly if their seizures are poorly controlled and, therefore, unpredictable. Epileptics fear embarrassment and are prone to accidents and injuries (McQueen, 1990; Thompson & Oxley, 1988). Findings of the present study appear to lend further support to these reports in that most respondents, and especially female respondents, indicated a preference for staying at home as opposed to going out. The primary reason underlying this preference was the fear of experiencing an epileptic attack while away from home.

As many as 45% of the epileptic respondents have felt rejected by someone because of their epileptic condition. Nearly half of these attributed rejection to the apparently fairly widespread belief that epilepsy is infectious. The infectious agent was explained to be the wind which is released in a belch during an epileptic seizure. The finding is consistent with reports elsewhere in Africa on the belief in the contagious nature of epilepsy (Awaritefe, 1989; Ben-Towim, 1987; Nkwi & Ndonko, 1989).

This belief is a cause for concern because its consequences are evidently damaging to the welfare of epileptics. While it is insensitive and not always desirable to interfere with people's (cultural) beliefs, when such beliefs are clearly erroneous and have far-reaching adverse implications as in this instance, it is suggested that providing basic education or factual information to the community is vital.

Several respondents reported that their boyfriend and, in most cases, also the father of their child(ren) had abandoned them because of their epilepsy. It would appear that epilepsy places considerable strain on close interpersonal relationships to the extent that some people opt out of the relationship, sometimes abandoning their responsibilities as care-givers to children.

A few respondents reported having a particular interest or hobby which brings them into social contact with others. For such people, having seizures in public was not a primary concern. Participation or involvement in a social activity, hobby or special interest may be an important factor in promoting a healthy attitude towards having a seizure disorder and, in particular, in preventing being socially handicapped by one's illness. It is argued that what may be more important than the degree of seizure control in determining whether or not epileptic persons are socially handicapped by their disorder is their *attitude* towards their epilepsy.

In this regard, one respondent stated that she likes Jonty Rhodes' 'style' in that he is a sportsman

despite having epilepsy¹. In elaborating she said, 'As a sportsman, you don't feel as though you have epilepsy... you don't feel that epilepsy because you've got something to do... there is something that he's doing on the side'. She then went on to advise people with epilepsy to engage themselves in some activity in order that they are not socially incapacitated by their illness.

CONCLUSIONS

In conclusion, the research has documented several social and psychological problems faced by epileptic persons presenting at two local day-hospitals. There are confounding factors that make the findings of the study difficult to interpret. Firstly, it is difficult to tease out the extent to which the psychosocial problems identified in the study are attributable to the respondents' epilepsy and how much are, in fact, attributable to the socioeconomic conditions pertaining in general to Blacks living in townships.

Take, for example, the issue of dependency on families for accommodation. It has been noted in the discussion that multigeneration families are a common feature of African households and that most young single Blacks may not be able to afford a house of their own. At best it can be said that epilepsy limits their opportunities or chances of owning a house of their own.

Likewise, the educational system for Blacks in general is inferior and as a result, their job opportunities are limited to lower levels of the employment hierarchy. Again, at best it can be said that epilepsy exacerbates job-finding problems that pertain to all Blacks.

Secondly, epilepsy may present as an easy target on to which respondents are able to blame all their misfortunes. In other words, epilepsy may provide a powerful explanation for everything negative or difficult in their lives. Indeed, many of the respondents felt their lives would have been different if they did not have epilepsy. This manner of reasoning tends to result in low well-being (Collings, 1990a). Difficult socioeconomic circumstances may be so entwined with the respondents' experience of their epilepsy that they cannot effectively separate the two.

The above confounding factor highlights a broader limitation of the present study, namely, that it deals with people's perceptions which may differ from reality. The aim of the study was to describe and, therefore, bring awareness of the psychosocial problems experienced by epileptic

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. Jonty Rhodes is a well-known South African sportsman who, despite having epilepsy, has excelled and won competitions in a number of sports.

patients attending two day-hospitals located in Black townships. Further research possibilities that could splinter off this study are plentiful.

It is suggested that the study is used as a basis from which to generate hypotheses that are subjected to experimental conditions of investigation. For example, it was the respondents' perception that potential employers show prejudice against employing epileptics. One could possibly investigate the reality of this perception by the use of 'dummy' applications. Another research possibility in this area is to investigate what role the epileptic persons felt stigma plays in limiting employment and educational opportunities for them.

Many epileptics in the present study have imposed restrictions on their lifestyle. One could possibly investigate how necessary such restrictions are by comparing the quality of life or well-being amongst those who lead relatively unrestricted or normal lives to those who lead fairly restricted lifestyles.

A useful study would investigate the reasons that the services of SANEL appear largely unknown to township communities, and ways to counter this problem.

In summary, the study explored the psychosocial consequences of epilepsy from a premise that such consequences are mediated by factors other than the severity of seizures. Methodological problems including a small, non-random sample of epileptic respondents limit the generalizability of the findings. Respondents reported social and psychological problems with respect to occupation, finances, education, interpersonal relations, and lifestyle. The study gives suggestions for further investigation to validate some of the findings.

APPENDIX A

INTERVIEW SCHEDULE (ENGLISH)

Name:.....Date:.....Age:..... Sex:.....

Address:.....Education:.....Occupation:.....

Marital Status:

A. MEDICAL AND TRADITIONAL MANAGEMENT

This section explores how respondents understand their illness: ideas of what causes epilepsy, its possible duration, access to medication and their views on medical treatment. It also asks whether the respondent has consulted an indigenous healer for treatment; their views underlying consultation and treatment preference.

1. When did your epilepsy start?
2. What type of epilepsy is it?
3. How often do you get the fits? What happens when you get a fit?
4. What do you know about epilepsy - who gets it? What causes it?
5. What kind of treatment do you take for your epilepsy?
6. Where do you get the medicine from? How often? Who collects the medication? Who pays for it?
7. Do you often have trouble remembering when to take your medicine?
8. How long will you have to take the medication for? Will it ever get better?
9. Does the medicine seem to help? If so: In what way? Have you noticed any side-effects?
10. Do you see anyone else for your treatment other than a doctor, sister or nurse - e.g. social worker, counsellor?
11. Have you ever seen (do you see) an indigenous healer to treat your illness? If so - explore:
 - (i) when in course of illness;
 - (ii) duration of consultation;

(iii) reason for consultation and whether it helped.

12. What type of treatment do you prefer?

B. VOCATIONAL ADJUSTMENT AND FINANCIAL STATUS

This section attempts to find out whether respondents are employed, the type of work they engage in and whether their illness has interfered with their work. Job-finding problems were explored as well as financial status and access to a state grant.

1. What do you do for a living? If unemployed - what do you do during the day? How do you spend your time?

2. How do you find the job/work?

3. Has your illness interfered with your work in any way?

Possibilities: frequent absence from work
 frequent attacks at work
 frequent visits to clinic
 fewer productive hours at work

4. Have you had problems finding a job because of epilepsy?

5. Do your employers know of your illness?

6. Have you ever been dismissed from a job because of your illness?

7. Do you worry about money? Is this related to your having epilepsy?

8. Do you receive a Disability Grant?

B. ADJUSTMENT TO SEIZURES

This section attempts to gain an understanding of what it is like for the respondents to have epilepsy; their attitude towards seizures including whether they feel stigmatized by their condition. The section also explores effects it has on their life and problems it causes for them.

1. What is it like to have epilepsy?

2. What problems has the epilepsy caused for you?
3. What do you dislike most about having epilepsy?
4. Do you mind people knowing you have epilepsy?
5. Do you talk freely to others about your epilepsy?
6. Do you know anyone else with epilepsy?
7. What type of things do you enjoy doing?
8. Does the epilepsy stop you from doing these things or anything else you'd like to be doing?
9. How do you feel your life would be different if you didn't have epilepsy?
10. Do you know about SANEL?

C. INTERPERSONAL ADJUSTMENT

The following questions attempt to find out how socially well-adjusted the patient is - i.e. how well he or she is integrated into the family and society and, more specifically, how the epilepsy may have interfered with interpersonal relationships.

1. With whom do you live?- details of family and others in the home.
2. Do you get any help from people you live with in dealing with your epilepsy?
e.g. reminding you to take medication; helping you when you are about to experience a fit /during or after a fit; collecting medication for you at Day Hospital.
3. Do you feel you fit in well at home, or do you feel somehow different?
4. Are you the type of person who enjoys going out to meet people or do you prefer to stay at home? If latter, is it because of your illness?
5. Are you the type of person with lots of friends and acquaintances or just 1 or 2 friendships?
6. Have you ever felt rejected by someone because they know you have epilepsy?

INTERVIEW SCHEDULE (XHOSA)

Igama:.....Umhla:.....Iminyaka:.....Ubuni.....

Idilesi:.....Ibanga Lemfundo:.....Umsebenzi:..

Uhlobo Lomtshato:.....

A. MEDICAL MANAGEMENT

1. Waqala nini ukuba nesisifo sokuwa?
2. Luhlobo luni lwesifo sokuwa?
3. Usifumana kangaphi esisifo / uwa amaxesha amangaphi?
Kwenzeka ntoni xa usiba nefits?
4. Wazi ntoni ngesifo sokuwa - sifunyanwa ngobani?
Sibangwa yintoni?
5. Hlobo luni loncedo olufumanayo ngesisifo sakho sokuwa?
6. Uwathatha phi amayeza? Kanga phi? Ngubani okulandela amayeza? Ahlawulwa ngubani?
7. Ukhe ubenengxaki yokukhumbula amaxesha okuthabata amayeza?
8. Uzakusebenzisa amayeza de kube nini? Sakuze sibe nobungcono (isifo)?
9. Ingaba amayeza ayakunceda? Ukuba kunjalo: Njani? Kukho nto okhe wayiqaphela?
10. Ukhona omnye umuntu ofumana kuye unyango ngaphandle kuka gqirha, sista okanye unesi, unontlalo-ntle, umcebisi?
11. Wakhe (uya ya) wabonana nosiyazi/ixhwele ukunyanga esisifo sakho? Ukuba kunjalo - tyatyadula:
 - (i) Bekuba ngelishesha lokugula.
 - (ii) Amathuba okundwendwela.
 - (iii) Unobangela woku ndwendwela.
 - (iv) Uye wancedakala
12. Lulu phi uhlobo lonyango olukhethayo?

B. VOCATIONAL ADJUSTMENT

1. Wenza ntoni ukuze uphile / uphumelele?
 Ukuba uyaphangela - wenza ntoni emini?
 Ulichitha njani ixesha lakho?
2. Uwufumana njani umsebenzi / impangelo?
3. Ingaba ukugula kwakho kuyaphazamisana nomsebenzi wakho?
 Ukuba kunjalo :
 - (i) Soloko ungabiko emsebenzini?
 - (ii) Soloko uhlaselwa (kukugula) emsebenzini?
 - (iii) Soloko uquqa ekliniki?
 - (iv) Usebenza iyure ezimbalwa emsebenzini?
4. Wakhe wanengxaki yokufumana umsebenzi ngenxa yesifo sokuwa?
5. Umqashi waho uyazi ukuba unesifo sokuwa?
6. Ukhe wagxothwa emsebenzini ngenxa yokugula kwakho?
7. Uyazihlupha ngemali? Ingaba lengxaki inxulumene nokuba nesifo sokuwa?
8. Uyayifumana i-"Granti"?

C. ADJUSTMENT TO SEIZURES

1. Ingaba kunjani ukuba nesifo sokuwa?
2. Ngxaki zini esikufake kizo esi sifo sokuwa?
3. Yintoni oyithiye gqitha kuba unesisifo sokuwa?
4. Uyakhala xa abantu besazi ukuba unesifo sokuwa?
7. Zinto zini othanda ukuzenza?
8. Singaba esisifo sokuwa siyakuthintela ungabi nakuzenza ezizinto okanye into engenye ubungathanda ukuyenza?

9. Uziva ngathi ubomi bakho bebunokuba nomahluko ukuba ubungenaso isifo sokuwa?
10. Uyayazi na i-SANEL?

D. INTERPERSONAL ADJUSTMENT

1. Uhlala nabani? Chaza abantu bekhaya kunye nabanye abantu ohlala nabo.
2. Ingaba uyalufumana uncedo kubantu ohlala nabo ngokuphatelana/ngokunxulumene nesisifo sakho sokuwa?
Umz. (i) ukukukhumbuza usele anayeza;
(ii) ukukunceda ngexesha uzaku qalis ukuwa okanye xa usiwa okanye emva kokuwa;
(iii) ukukulandela amayeza e "Day Hospital".
3. Uzifumana ukwimo efanelekileyo ekhaya, okanye uziva uhlelekile?
4. Uluhlobo lomntu oluthanda ukuphuma udibane nabantu okanye ukhetha ukuzihlalela ekhaya?
Ukuba uhlala ekhaya ingaba kungenxa yokugula kwakho?
5. Uluhlobo lomntu olunabahlobo abaninzi nokuqhelanisa okanye unomhlobo omnye, okanye ababili?
6. Ukhe waziva ulahliwe / ungamkelwanga ngumntu kuba ekwazi ukuba unesifo sokuwa?

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