EPILEPTICS' PERCEPTIONS OF THEIR CONDITION

SONIA ROOPNARAIN

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BY

SONIA ROOPNARAIN

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Supervisor: Prof PT Sibaya

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DECLARATION

I hereby declare that the work on: "Epileptics' Perceptions of Their Condition" is my own work, both in conception and in execution and that all the sources that I have used or quoted have been indicated and acknowledge by means of complete reference.

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Sonia Roopnarain Date

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ABSTRACT

There has been an increasing recognition on the part of physicians and others involved in the welfare of individuals with epilepsy, that seizures may be less disabling than their psychosocial correlates. There exists a lay propensity to discriminate against people with epilepsy, which, in turn, is the paramount source of the psychological and social burden that individuals with epilepsy have to endure. The objective of this study is to ascertain the psychosocial perceptions of epileptics towards their affliction. In essence, it is a study on the impact of epilepsy as a stigmatizing condition. The present investigation consists of four objectives.

- The first aim was to ascertain the perceptions of epileptics towards their condition.

- The second aim was to examine the psychosocial problems as reported by epileptics.

- The third aim was to find out what epileptics would like to recommend in this context.

- The fourth aim was to establish correlates of epileptics' perceptions, factors influencing perceptions, and whether these perceptions are influenced by certain variables in respect of the respondent.

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LIST OF ABBREVIATIONS

CNS	Central Nervous System
CT	Computerized Tomography
EEG	Electroencephalogram
EPICADEC	Epilepsy Care in Developing Countries
HSRC	Human Sciences Research Council
ILAE	International League Against Epilepsy
MRI	Magnetic Resonance Imaging
OPCS	Office for Population, Censuses, and Surveys
QoL	Quality of Life
Rs	Respondents
SANEL	South African National Epilepsy League
SPSS	Statistical Package for Social Sciences
TLE	Temporal Lobe Epilepsy
WHO	World Health Organization

CHAPTER ONE : INTRODUCTION

1.1 MOTIVATION FOR THE STUDY TO BE UNDERTAKEN

Epilepsy is a chronic brain disorder characterized by recurrent seizures due to excessive discharge of cerebral neurons. More than 10% of the population will experience a seizure at some time, and around 1% of the population has epilepsy (Hauser & Hersdoffer, 1990). It is a ubiquitous international disorder that knows no racial, class, gender, age or geographical boundaries, perhaps more so than any other medical condition. It is also one of the oldest disorders known to mankind with at least 3000 years of history since the earliest Babylonian and, later, Greek writings on the subject (Temkin, 1945).

There has been a growing realization that the social and psychological consequences of epilepsy are more debilitating than the seizures themselves. People with epilepsy have always suffered more from other people's perceptions and opinions of them, than from the illness itself (Scambler & Hopkins, 1986:26-43). So, one can understand the fear engendered by seeing a healthy human being suddenly struck, lying foaming and jerking, and then miraculously resurrected to life.

There are various problems with which a person with epilepsy has to deal with: the unpredictability of attacks, the psychological and social repercussions, and the reactions that other people have toward them. The social sequella of having epilepsy was relevant more than 2000 years ago when Hippocrates referred to the condition as the 'sacred disease' (Temkin, 1945). Since that time much was written on the social stigmatization of those with epilepsy. Even now, there is evidence that stigmatization persists (Betts, 1993).

The initial reaction to the diagnosis of epilepsy conjures up horrific images of the attacks and the stereotypes of people afflicted with the disorder. For many, a frightening mental collage emerges: uncertainty about the future, fear of the medication effects on the body

and mind, progressive mental or physical disability, unwanted disclosure of their secret, loss of driving and other privileges, and fear of losing their self-identity.
For many patients, however, the psychosocial impact of epilepsy is far greater than its neurological impact.

Aretaeus, in the 2nd Century AD, saw individuals with epilepsy as languid, spiritless, stupid, unsociable, and slow to learn from torpidity of the understanding and the senses (Guerrant, Anderson & Fischer, 1962). The need to dispel such misconceptions about epileptics has been the motivating factor for this research. Like most diseases, epilepsy entails medical as well as social definitions. The onset, course and prognosis of epilepsy might be largely universal, but the ways in which a culture handles its manifestations and consequences differ significantly. Once individuals experience symptoms suspicious for epilepsy, they are expected to turn to a biomedical facility for help and, after the diagnosis is confirmed, to follow a demanding treatment regimen.

However, little has been published about the views and perceptions of individuals afflicted with epilepsy. Little research has been carried out into the experiences of patients from different cultural backgrounds. Yet, knowledge of these processes as well as of the social and cultural context in which epilepsy is diagnosed, are vital determinants for support programs. A study of the psychosocial face of epilepsy is suggestive of numerous problems. This dissertation attempts to investigate how epileptics perceive their condition.

The researcher hopes to gain an insight of the wider psychological, social and cultural factors that impact on the lives of individuals with epilepsy. The study will be mainly based on the patients' perspectives and perceptions, since the exposure of their views is often lacking in public health research in developing countries (Jilek-Aall, Jilek, Kaaya, Mkombachepa & Hillary, 1997:783-95).

Once the research has been conducted, its findings will be collected and analysed. The researcher will examine each of the factors, which serve as either barriers or facilitators to epilepsy. A close analysis of these factors will also determine how they are interrelated and their function in behavioural changes and social encouragement. Ultimately, it is intended that the research study initiates the design of culturally sensitive

epilepsy programmes, which will not only decrease social stigmatisation but also enhance social support to epileptics.

McLin and de Boer (1995:957-59) define stigma as the relation between the deviance of an individual and the devaluation society places on that particular deviance. These researchers point out that for stigmatization to be consistently effective, the stigmatized person must acquiesce or succumb to society's devaluation. But, people with epilepsy have not felt empowered to change the situation because they have taken for granted society's devaluation of them.

Westbrook et al. (1992:633-64) states that stigma theory was formulated to explain the behaviour, perceptions, beliefs, and the development of the social and psychological self of stigmatized persons. Broadly defined, stigmatized persons, are individuals who possess an attribute that others see as negative, unfavourable, or, in some way, unacceptable.

The social stigma attached to epilepsy can be one of its most debilitating accompaniments (Westbrook, Bauman & Shinaar, 1992:633-644). Although there has been improvement in the knowledge of epilepsy and attitudes towards it, children and adults afflicted with this illness continue to be stigmatised and discriminated against (Jensen & Dam, 1992:459-463). In fact, negative stereotypes of persons with epilepsy have been so deeply rooted in the society's belief system that they have become an accepted part of the concept of the disorder (Mc Lin & de Boer, 1995:957-59). McQueen and Swartz (1995:207-210) report on the experience of epilepsy in a rural South African village. They observe that stigma is essentially the feeling of being different, usually inferior, to others. According to these researchers, the argument offered by the 'orthodox viewpoint' of stigma is that it originates from outsiders, that is, persons who do not have epilepsy. These outsiders project a stigmatised image onto persons with epilepsy.

The 'hidden distress model' of stigma is the alternative model (Scambler & Hopkins, 1988:26-43). This model emphasizes making a distinction between enacted and felt stigma. Actual instances of discrimination endured by persons with epilepsy are referred to as enacted stigma. Felt stigma is chiefly the fear of meeting with enacted stigma.

Ryan et al. (1980) have claimed that many people with epilepsy in the United States do not feel stigmatized by their condition. They found, for example, that as many as 81% of those who had completed postal questionnaires felt that they had been treated fairly by employers. Approximately 70% felt they had been neither unduly restricted nor treated differently because of their seizures.

Livneh, Wilson, Duchesneau, Antonak and Richard (2001:533-544) reviewed the literature on the concept of psychosocial adaptation and impairment among persons with epilepsy. This literature focused on coping strategies and psychosocial adaptation. The article suggested that future research into self-coping skills and adaptation to epilepsy be undertaken.

Collings (1990:165-17) used a survey questionnaire to examine the association between social, psychological, and physical well -being in a sample of 392 British and Irish people with epilepsy living in the population. The sample was drawn from urban and rural epilepsy support groups in various regions and a hospital outpatients' population. Multiple regression analysis revealed that people's perceptions of their self and of their epilepsy were the most powerful predictors of overall well -being. It was emphasized that future research into psychosocial aspects of epilepsy should examine measures of people's subjective experience alongside sociodemographic indices.

These views are encapsulated by Kleinman et al.

> "Once this negative label is applied to a person with seizures that person bears the brunt of societal reactions that lower the sufferer's self- esteem, creating the inner sense of being discredited or discreditable, which over time spoils his or her identity" (A. Kleinman, Wang, Li, Cheng, Dai, Li & J. Kleinman, 1995:1319-1330).

Apart from the fact that there is an acute dearth of literature on attitudes towards epileptics, not much research has been conducted on the epileptics' self-perception. Where such research has been conducted in South Africa, it has been to a limited

extent. The researcher in this study attempts to synthesize some of these findings with the present research.

1.2 STATEMENT OF THE PROBLEM

Life with epilepsy generally involves more than adjustment to intermittent loss of control, long- term drug therapy and medical surveillance. People with epilepsy also have to learn to cope with a degree of public antipathy toward their condition. Indeed, many of those who have written of the psychosocial problems associated with epilepsy, have confidently asserted that these are almost always caused by public discrimination arising out of the perception of epilepsy as stigmatizing (Scambler &Hopkins, 1986:26-43).

The individual with epilepsy regards his/ her epileptic condition as a personal and social liability. In their world a fear of stigma associated with epilepsy predominates. The individual with epilepsy faces endless personal and social hindrances that have to be overcome. This study attempts to find answers to the following research questions: -

(i) How individuals with epilepsy perceive their condition?
(ii) What psychosocial problems they encounter?
(iii) How do we make life better for the affected?
(iv) What factors influence epileptics' perceptions of their condition?

1.3 AIMS OF THE INVESTIGATION

(i) To investigate the nature of epileptics' self-perception.
(ii) To examine psychosocial problems as reported by epileptics.
(iii) To outline epileptics' recommendations with regard to psychosocial problems.
(iv) To establish correlates of epileptics' perceptions and, factors influencing such perceptions.

1.4 HYPOTHESES

Hypothesis: 1

To find out whether individuals who perceived their epilepsy to be more severe and stigmatizing, had lower levels of perceived acceptance than those who had no such perceptions.

Hypothesis: 2

There will be no relationship between the psychosocial factors of epilepsy (namely, emotional, anxiety, self-esteem and social interaction, and cognitive-behavioural) and each of the following demographic variables:

- Age of the respondent
- Ethnic group of the respondent
- Home language of the respondent
- Educational level of the respondent
- Occupational level of the respondent

Hypothesis: 3

There will be no differences in the way epileptics' perceive,
their various recommendations.

Hypothesis: 4

There will be no relationship between each of the following demographic variables and the perception of epilepsy:

- Age of the respondent
- Gender of the respondent
- Ethnic group of the respondent
- Home language of the respondent
- Educational level of the respondent
- Occupational level of the respondent

1.5 DEFINITION OF TERMS

1.5.1 Perception

The term perception is used in this study to mean a belief about, or judgement of, or impression of, the subjective reality.

1.5.2 Epilepsy

The term epilepsy is used in this study to refer to a neurological disorder in which the patient suffers mild or severe convulsions with or without a loss of consciousness.

1.6. METHOD OF INVESTIGATION

1.6.1 THE RESEARCH PARADIGM

The empirical research that would be conducted will take the form of a field study. Quantitative data are needed to statistically test the hypotheses of the present study. Thus, at this stage, the researcher can stipulate that a quantitative research paradigm be conducted with the subjects. The researcher will compile and use a questionnaire as a measuring instrument, in order to elicit pertinent information from the patients.

Questionnaires will be used to obtain the following information from the respondents: biographical particulars (their age, socio-economic status, education, etc.), their opinions, beliefs and convictions (viz. about epileptics) and their attitudes (viz. towards epilepsy). The questionnaire schedule would be in the form of a Likert scale, which will consist of a collection of statements about the psychosocial aspects of epilepsy.

In respect of each statement, subjects have to indicate their degree of agreement or disagreement with its content on a five-point scale (e.g. strongly agree, agree, undecided, disagree, and strongly disagree). Multiple-choice items will be compiled in connection with biographical details (sex, age, marital status, etc.).

In a study of epilepsy, McQueen, Alison, Swartz and Leslie (1986:859-865), examined the psychosocial and medical consequences, including social stigma, of epilepsy. The study was based on interviews with 16 persons with epilepsy (ages 20-50, 75% male) in rural Mamre, South Africa. Respondents' indication of their feelings of being stigmatised was apparent in the language they used to describe the disease. They also expressed their desire to conceal knowledge of their affliction from others, particularly at their workplace. The epilepsy caused psychosocial problems, such as fear of leaving home unaccompanied, forgetfulness, and irritable moods. Hence, this study proved successful, since enhanced seizure control could be obtained with improved access to adequate medical care.

In another study by Jilek-Aal et al. (1986:783-795), the impact of the treatment and educational programmes of a 3-year Canada-Tanzania research project in Mahenge, Tanzania, was undertaken. The local people's attitudes toward epilepsy and epileptics' living standards, physical and mental well -being were examined through qualitative analysis of focus groups. Results of the analysis of the Mahenge focus group revealed a deficiency in systematic health education on epilepsy; a lack of government assistance for epilepsy care, and the erroneous belief that epilepsy was caused by angry spirits or witchcraft.

1.6.2 METHOD OF SAMPLING

The power of purposeful sampling depends on selecting a truly random and representative sample, which would permit confident generalization from the sample to a larger population. This results in information-rich cases (Patton, 1987). One of the most important characteristics of quantitative research is the requirement that the sample reflects the attributes of the target population, and hence conclusions that are drawn are pertinent to the whole population.

Random sampling is the ideal, most attractive sampling method conceptually (Huysamen, 1994:39). The researcher reports to a simple random sampling design to build a sample that is roughly representative of the population. With simple random sampling, each member of the population has the same chance of being included in the

sample and each sample of a population size has the same probability of being the sample chosen (Huysamen, 1994:39).

The research study sample would consist of 100 adult epilepsy patients (aged 12 years old and above) attending the Epilepsy Clinic at Wentworth Hospital. The age range of the patients to be selected for interviewing will reflect that of persons presumed to be able to provide personal information on their perceptions and experiences of being epileptic. Data on biographical variables with respect to the subjects would include- age, sex, race, socio economic status, type of epilepsy, general health, etc. The demographics of the sample will be spelt out later in chapter three.

1.6.3 THE METHOD OF DATA COLLECTION

The researcher would embark on a study sample at the Epilepsy Clinic at the Wentworth Hospital where data would be collected over a period of time. The collection of data is a crucial step in the execution of a good research design because the quality of research often rests upon the quality of data (Terreblanche & Durrheim, 1999). The data would be collected over a period of time. The head of the department of neurology would be contacted to enlist their support for the initiative, questionnaires would be administered, and the nature of the study would be explained. Regular visits to the Wentworth Hospital would be crucial to facilitate a compilation of a pre-selection list of patients.

The researcher has to ascertain the advantages and limitations of these methods and correlate their relevance to the research topic. Finally, a method that appears to be the most suitable and adequate needs to be selected for the research project.

1.6.4 PROCEDURES FOR THE ADMINISTRATION OF THE RESEARCH INSTRUMENT

Prior to the selection of the sample, permission to access medical records and to carry out the research was obtained from the Superintendent and the Head of the Department

of Neurology, at Wentworth Hospital, Durban[1]. Participation in the research was completely voluntary and informed consent.

The researcher provided participants with both an oral and written explanation of the purpose of the study, the research methods to be employed, the voluntary nature of the study and assurances that patient confidentiality would be protected. Confidentiality helps to legitimize the research process.

1.6.5 PROPOSED METHODS OF DATA ANALYSIS

The research design is made sufficiently flexible to permit a wide variety of analytic tools. The processes of analysis and interpretation involve disciplined study, creative insight, and careful attention to the purposes of the evaluation. The raw data was assembled, organized into specific categories according to each research aim, classified and edited. At this stage, analysis is left flexible to permit quantitative analysis of data.

1.7 ORGANIZATION OF THE STUDY

This study will be organized as follows:

1.7.1 CHAPTER ONE

This chapter consists of: motivation for investigation in this field, statement of the problem, definition of terms, methodology, aims of the study and a plan for the organization of the whole scientific report.

1.7.2 CHAPTER TWO

Chapter two provides a theoretical background to the study. This background considers and discusses the previous work done in this field:

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[1] See Annexure A, Letter Written to Wentworth Hospital.

(i) Studies on the nature of perceptions of epilepsy

(ii) Studies on the psychosocial problems as reported by epileptics

(iii) Studies on epileptics' recommendations

(iv) Studies on the factors influencing epileptics' perceptions

(v) Theory/ models on epilepsy and perception

1.7.3 CHAPTER THREE

This chapter details the research design and methodology of the study. The design and method of investigation are discussed in detail. Described in this chapter are data collection procedures, the selection of subjects, the procedure and research instrument, as well as a plan for organization and analysis of data.

1.7.4 CHAPTER FOUR

Chapter four concerns itself with the empirical investigation. It describes how fieldwork was carried out and the research instrument administered. This chapter also contains the analysis and interpretation of data. The hypotheses formulated/ postulated in chapter three are tested in this section.

1.7.5 CHAPTER FIVE

Chapter five presents the main findings of this investigation or study. This chapter concludes the research report by proposing recommendations.

CHAPTER TWO : LITERATURE REVIEW

2. INTRODUCTION

Epilepsy has long been used as a rich research terrain by social scientists interested in the experience of illness as a social phenomenon (Collings, 1990; Conrad, 1992; Good & Good, 1994; Jacoby, 1994; Kleinman et al., 1995; Mulder & Suurmeijer, 1977; Oliver, 1980; Scambler & Hopkins, 1986, 1990; Schneider & Conrad, 1986, West, 1979).

As suggested by Schneider and Conrad (1983) in their text, "Having Epilepsy", the reasons for using epilepsy as a research are varied. These include a larger degree of stigma potential associated with the disorder, and its overall low visibility as an illness. Thus, there is a substantial gap in some areas of the illness. Due to the sudden, unannounced seizure incidence, epilepsy must be consistently managed in a social setting. Managing epilepsy has been studied in great detail (Bastin, Stievenard & Vinchon, 1977; Jacoby, 1994; Kirchgassler, 1985; Scambler & Hopkins, 1986, 1990; Schneider & Conrad, 1980; Westbrook, Lauman & Shinnar, 1992).

There have been recent studies to differentiate the accepted categories of the epileptic experience, but there is still scope for more in-depth research investigations (Nijhof, 1988). This present study focuses on epileptics' self-perception and the extremely diverse and unique experiences that emerge from the affliction.

2.1 STUDIES ON PERCEPTIONS OF EPILEPSY

Many of those who have written of the psychosocial problems associated with epilepsy have confidently asserted that these are almost always caused by public discrimination and stigmatization (Faircloth, 1998:602-617; McQueen & Swartz, 1995:859-865). In the present study an acccunt is given of how people with epilepsy perceive their condition and of the different ways it can affect their lives. Some of the main implications of the growing social scientific literature on the perceptions of epilepsy are discussed.

A) PUBLIC PERCEPTIONS

It is evident from literature that epileptic phenomena are still interpreted in a negative and demoniac light in many third world communities (Temkin, 1945). A recent community study in Nigeria, found that after heredity, 'witchcraft' was the cause most commonly attributed to epilepsy by the lay populace (Awaritefe, Longe & Awaritefe, 1985:1-9).

A number of studies have examined lay beliefs and attitudes concerning epilepsy. Experience in the United States demonstrates that public education can change attitudes and perceptions. Perhaps the most influential study is the sequence of surveys undertaken at five-year intervals since 1949 by the American Institute of Public Opinion (Caveness & Gallup, 1980:509-518). The latest report, of the 1979 survey, indicates that 95% of American adults are familiar with the word epilepsy, and that, 63% of these adults have known someone with epilepsy and 59% have actually witnessed an epileptic seizure. Taken together, the surveys show a gradual increase in public awareness of what epilepsy is and how it is caused. For instance, in 1949 only 59% of respondents disputed that epilepsy is a form of 'insanity', compared with 92% in 1979.

These surveys by Caveness et al. (1980) also suggest a growing public acceptance toward epilepsy. Changing responses to two particular questionnaire items illustrate this trend. Respondents were asked: 'Would you object to having any of your children in school or at play associate with persons who sometimes had seizures (fits)?' Twenty five per cent replied 'yes' in 1949, 17% in 1954, 18% in 1959, 13% in 1964, 9% in 1969, 5% in 1974, and 6% in 1979.The second question was: 'Do you think epileptics should be employed in jobs like other people?' Thirty five percent said 'no' in 1949, 22% in 1954, 11% in 1959, 9% in 1964, 12% in 1969, 8% in 1974, and 9% in 1979. In each of the seven surveys 'liberal ' responses were most prevalent in the better - educated, professional, younger and urban sectors of the population.

While the balance of the evidence available in Europe, as well as in the US, would seem to support this indication of enhanced lay knowledge and tolerance of epilepsy since the war, there are three qualifications that need to be made. Firstly, many of the relevant studies have relied, like Caveness, on questionnaires, which, as an instrument of

research, have several limitations. A key limitation is that not all questions can be reasonably answered within the framework of a finite number of choices.

Secondly, a few of the studies have produced findings at variance with those of Caveness. To take a single example, Bagley's British survey, which utilized a social distance scale, suggested that there is still considerable public antagonism towards people with epilepsy (Bagley, 1972:33-45). One of his findings was that people with epilepsy are often more rejected than those with cerebral palsy or mental illness. Interestingly, an American study carried out a decade later, and also using a social distance scale, reported that people with epilepsy are less often rejected than those with cerebral palsy or mental illness (Albrecht, Walker & Levy, 1982:1319-27). Axiomatically, caution is required in interpreting apparently inconsistent results such as these.

The third qualification is probably the most important. It is well known that the relationship between beliefs and attitudes on the one hand, and behaviour on the other, is a precarious one. Even if it is accepted that the public is generally better informed and less hostile towards epilepsy today than it was a generation ago, it does not follow that discrimination based on stigma, is necessarily diminished or dying out. There is, in fact, abundant anecdotal evidence of episodes of stigmatization, but there is no solid European or American evidence concerning either prevalence of these episodes or of the degree of risk of stigmatization faced by people with epilepsy.

Hayden, Penna & Buchanan (1992:191-197) examined the epileptic patients' perceptions of their condition. Their study also explored related medical problems, factors triggering seizures, and the relation of epilepsy and pregnancy in 517 people (aged 18 mo-89 years) with epilepsy. The study revealed matters pertaining to driving, the unpredictability of seizures, the lack of employment, learning and cognitive difficulties, as well as psychosocial issues as major concerns to respondents. The relationship between stress and seizure control was highlighted. Of 272 female respondents over the age 12 years, many reported an exacerbation of seizures in association with menstruation. Most female respondents reported no problems with epilepsy during pregnancy, although there were reports of increased seizures and other medical problems.

B) SELF- PERCEPTIONS

Research has been conducted on the self- perceptions of epileptics. Ryan et al. (1980:433-444) have claimed that many people with epilepsy in the United States do not feel stigmatized by their condition. They found, for example, that as many as 81% of those who completed postal questionnaires, felt that they had been treated fairly by employers. Approximately 70% felt they had been neither unduly restricted nor treated differently because of their seizures. It may be significant, however, that the index of 'perceived stigma' used by Ryan et al contained several items enquiring whether or not respondents have actually experienced discrimination based on stigma.

The comment by Blaxter (1976), arising out of her general survey of disability in Britain, is pertinent:

> "Epilepsy came into a special category. In fact, none of the sample's epileptics gave any evidence at all that they had experienced any social stigma, but each one expressed surprise and gratitude at this and told generalized stories about the problems which epileptics 'usually' faced".

This suggests that it may be useful to distinguish between actually experiencing stigmatization, and expecting, or fearing it. In their British community study, Scambler and Hopkins (1986:26-43) found that while only a third of their sample could recall ever having experienced enacted stigma at all, even in the form of casual ridicule, nearly 90% reported suffering intermittently from felt stigma. They suggest that when the diagnosis of epilepsy is communicated to the people, they quickly learn to see their status as 'epileptics' as socially undesirable. Typically, they develop a 'special view of the world' in which felt stigma predominates. When 'activated' by 'situational stimuli'- witnessed seizures, for example-this 'special view of the world' predisposes them above all else to conceal their condition and its medical label from others, to try to 'pass' as normal (Goffman, 1968).

Most of the literature supports the view that popular reactions to epilepsy have mellowed in the last generation. People are now better informed and their attitudes toward

epilepsy less inimical. It would be unwise to assume, however, that discrimination based on the perception of epilepsy as stigma, is largely a thing of the past.

2.2 STUDIES ON THE PSYCHOSOCIAL PROBLEMS AS REPORTED BY EPILEPTICS

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, 1988:805). Yet, the most debilitating 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, Kemper & Emlen, 1980). Scambler 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.

Ratele (1996) examined the psychosocial face of epilepsy and the impact on the mental health of the epileptic. The traditional African cultural/ belief environment which ordinarily influences African lives, is assumed as possibly influencing, to a greater degree, the psychosocial lives of persons with epilepsy and was taken into account in the study.

The results reveal a statistically significant association between seizure frequency and psychosocial adjustment. The ability to handle social situations has been found to be related significantly to seizure frequency. 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 also a need to

encourage open and free dialogue about cultural beliefs on the illness and its treatment while discouraging obviously erroneous and damaging beliefs[2].

Beuninck (1991) examined the psychosocial implications of epilepsy among Blacks. This study aimed to formulate tentative conclusions regarding effective assistance for the psychosocial problems surrounding epilepsy. This was an exploratory investigation consisting of mainly a questionnaire. The test sample consisted of 50 epileptics from Peloni hospital in Bloemfontein, South Africa. The perceptions of the research group had been obtained regarding the psychosocial implications of epilepsy within the following three contexts: the psychological implications, the social welfare implications, and other related implications.

The results revealed that the research group had problems with their psychological functioning. Identified problem areas were - depression, anxiety, fears, aggression and cognitive functioning. Other problems included the effect of epilepsy on social interaction, family interaction, self-image, and work and financial status. Recommendations for improved psychosocial functioning of the epileptic were made.

Van Wyk (1993) examined the aggravating effect of epilepsy and stigma among adolescents in Pretoria. The main aim of this research was to study the experiential world of the adolescent with epilepsy and to determine the aggravating effect this condition has on his/her life. The qualitative research method was used. Interviews were conducted with three subjects; these discussions were tape-recorded and documented in writing. The recordings were phenomenologically analysed and conclusions drawn from these findings were compared to those of previous literature.

The findings revealed that the adolescent with epilepsy views his/her life as potentially limiting and restricting in three facets, namely; his/her body, mind and that of the prejudiced community. Disclosures by the subjects revealed that these adolescents experience intense frustration, which find expression in fluctuating feelings of anger and/or depression.

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[2] Whilst many academics, researchers have focused on the HIV/AIDS socio-cultural myths, research on

While, Perfile (1997) explored the psychosocial aspects of epilepsy in a sample attending a clinic in two Black townships in Cape Town. This study utilized the framework of a sociopsychological model in trying to gain an understanding 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 seizures and interpersonal relationship problems. Few respondents enjoyed good control over their seizures. Supernatural causative factors in the etiology of epilepsy also surfaced. A major finding was the high rate of unemployment in the epileptic sample with dire secondary financial consequences.

Implications of the study include the need to provide patients with a better understanding of the medical aspects of epilepsy and to assist them to attain control over their seizures. There was also a need to encourage open and free dialogue about cultural beliefs of 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 (SANEL) was also identified.

Eidhin and McLeavey (2001) in their study aimed to investigate the relationship between perceived acceptance, stigma and severity in a population with epilepsy. The relationship between negative self-perception and epilepsy has been addressed in a number of studies, but little is known about any association between epilepsy and perceived acceptance. The aim of this study was to investigate if perceived acceptance by others, correlates with perceived stigma, perceived severity and a variety of factors associated with epilepsy.

Approximately 52 individuals (aged 18-64 years) with a diagnosis of epilepsy attending an outpatient clinic participated in the study. Participants completed questionnaires measuring aspects of epilepsy as well as perception of stigma, severity and acceptance by others. Results showed that the type of epilepsy was significantly correlated with

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epilepsy should not be neglected.

perception of stigma. Significant negative correlations were found between perceived stigma and perceived acceptance and between duration of epilepsy and perceived acceptance. It was concluded that perception of acceptance is related to the way in which the individual leamed to cope with the diagnosis of epilepsy.

Newton and Gero (1984) reported on a study on the epilepsies among rural African epileptic patients in Transkei. At the time of the study there were no reported studies of the epilepsies in African rural areas in South Africa. However, according to Cosnett (1973, cited in Newton & Gero, 1984), the epilepsies accounted for 20% of the neurological admissions to Edendale Hospital, Pietermaritzburg.

The first aim of the study was to interview and examine epileptic patients in a rural community in Transkei so as to classify them by using clinical and electrocephalographic (EEG) criteria. The second aim was to gain some understanding of the sociocultural background of the patients. The results and discussion, according to the aims, were divided in two sections, namely, medical aspects and sociocultural background.

The sample was made up of 158 epileptic patients from the Nguni tribe. Fifty of these were inpatients at the Umzimkulu Psychiatric Hospital. The remaining 108 patients attended neuropsychiatric clinics at hospitals in Umtata, Lusikisiki and Rietvlei. Interviews were carried out with the assistance of a Xhosa interpreter and a relative if one was available. Each interview was based upon a questionnaire.

A formal neurological examination of all patients was done. An experienced technician using a 16-channel Beckman Accutrace 200 EEG recorded EEG's in 104 patients. The EEG's were recorded during rest, hyperventilation, and intermittent photic stimulation.

Each of these phases lasted about 10 minutes. A lack of facilities limited the carrying out of other investigations, for example, serological tests for syphilis. Some of the questionnaires were not completed. Twenty-eight patients were not oriented for time, person and place. Some questions, for example, the one on the impact of the disorder on marriage, were not relevant to all patients. A few patients refused to answer some of

the questions. Therefore, the percentages were based on the number of patients who answered each question.

Newton and Gero (1984) report that epileptics are generally accepted by the Nguni people, and that less than 20% of the patients were ostracized whereas, in the Semokwe district in Zimbabwe, 44% of the adults were rejected by their community. Also, the disease was explained by an in-depth examination of its traditional causes, that is, the difference between witchcraft and ancestors.

The literature review on the topic thus far, has focused on reports published by several researchers in South Africa. The availability of literature or research evidence related to knowledge of and attitudes towards epilepsy in South Africa does exist, as depicted by a review of the literature. However, studies on epileptics' perceptions towards epilepsy are non-existent. The literature that follows focuses on the psychosocial aspects of epilepsy in other countries.

A study by Alvarado, Ivanovic-Zuvic, Candia, Mendez, Ibarra and Alarcon (1992) on the psychosocial evaluation of adults with epilepsy in Chile, revealed that several psychosocial disorders were observed in epileptic persons. For example, there was the presence of depressive disorders in children, which was treated with barbiturates. The social withdrawal and ostracism that prevailed in epileptic persons reflected failed attempts at coping with the disease. Low self-esteem and dependency may have been attributed not only to social prejudice and societal attitudes, but also to epileptics' own fears and misunderstandings about the nature of the disease.

Frith, Harris and Beran (1994) conducted a study on the management, and attitudes towards epilepsy by a group of general practitioners in Sydney. They concluded that epilepsy, if not well controlled, can adversely affect self-esteem, work, daily activities (such as sport and driving), and relations with family, friends and the community.

Also, lack of attention paid by doctors to empathize with patients, explaining their condition and its treatment, and assisting them in maintaining a normal quality of life and

work causes patients to become dissatisfied with their care[3]. Hence, doctors' attitudes towards patient care can contribute to the epilepsy sufferer's lack of self-esteem and difficulty in adjusting to a chronic problem (Frith et al., 1994).

Suurmeijer, Reuvekamp and Aldenkamp (2001) investigated the social functioning, and quality of life of epileptics. From the records of 4 outpatient clinics, 210 epileptics were randomly selected. During their visit to the outpatient clinic, they completed a questionnaire assessing health perceptions and social and psychological functioning. Additional information about their medical and psychological status was gathered from the patient files.

Results show that, in decreasing order of importance, psychological distress, loneliness, adjustment and coping, and stigma perception appeared to contribute most significantly to the outcome quality of life (QoL) as judged by the patients themselves, regardless of their physical status. In the final model, none of the clinical variables (onset, seizure frequency, side -effects of anti-epileptic drugs) contributed significantly with the patients' QoL judgement.

More importantly, the effect of other variables such as seizure frequency and health perceptions, medication and side effects, life fulfilment, self-esteem, and mastery is mediated by these variables. Because all of the variance in QoL of the patients was explained by the psychosocial variables included in this study, the study recommends that health professionals should be aware of the significance of the psychosocial functioning of patients and the role it plays in the achievement of good QoL.

Lau, Lee, Philip and Wong (2001) examined the psychosocial adjustment of people with epilepsy in a Chinese cultural context. Fifty patients with epilepsy completed The Washington Psychosocial Inventory, the Coping Inventory for Stressful Situations, and a questionnaire that assessed their psychosocial difficulties and coping styles.

Multiple regression procedure was used to examine the strength of various medical and social factors in predicting the psychosocial adjustment problems of these participants.

[3] This is especially evident at state hospitals where there are limited resources and budgetary constraints.

Social factors, such as self-perception and coping strategies, were more powerful predictors of psychosocial adjustment in people with epilepsy than the medical factors associated with epilepsy.

These findings show that psychosocial maladjustment is a significant issue for people with epilepsy in Hong Kong. The emerging importance of social factors as predictors of psychosocial adjustment in epilepsy, as compared with medical factors, highlights the need for developing tailored counselling therapy and social support groups for people with epilepsy.

Mielke, Sebit and Adamolekun (2000) conducted a pilot study on the impact of epilepsy on the quality of life of epileptics in Zimbabwe. This study examined the psychosocial functioning levels in epileptics residing in Zimbabwe, their self-perceptions and those of their caregivers. Data were collected from 38 epileptic patients (age 8-56 years) residing in urban Zimbabwe and attending either a community-based support group or a specialized epilepsy clinic.

Results show that 36 respondents did not perceive themselves to have sufficient cognitive impairment to interfere with social functioning, work performance, or relationships with others. However, ¾ of caregivers and 2/3 of respondents felt that functioning was mildly to moderately reduced, particularly in the areas of solving daily problems and speed of thinking. A quarter of the respondents experienced problems in relationships with others and almost a fifth of the respondents reported more than four areas of reduced functioning. About 2/3 of the respondents reported sexual functioning as not applicable, although only 4 respondents were aged <15 years. Findings suggest that there is a significant need for selected groups of epileptics in Zimbabwe to receive attention concerning psychosocial abilities.

Jilek-Aal, Jilek, Kaaya, Mkombachepa and Hillary (1997:783-795) conducted a psychosocial study of epilepsy in Africa. This article focused on the psychosociocultural aspects and indigenous concepts of epilepsy. It also exposed popular attitudes towards epileptics, and social status of these sufferers in a Tanzanian tribal population. The authors presented a comparative analysis of focus group discussions conducted with epileptics and with matched controls in two isolated communities.

In one community (Mahenge), a clinic for epilepsy has been operating for over 36 years, with a public education component during the last four years. Whereas in the other community (Ruaha), epileptics have only been sporadically treated in a small mission dispensary. These people have thus had little opportunity to learn about the nature and modern treatment of convulsive disorders.

The responses obtained in focus group discussions reflect the significant change in notions about the illness, in the attitude toward epileptics and in the social status of epileptics in Mahenge. The people of Ruaha, however, still regard epilepsy as a typical "African" affliction fraught with supernatural danger and not effectively treatable by modern medicine.

AREAS OF PSYCHOSOCIAL ADJUSTMENT

Among some of the studies conducted on the psychosocial aspects of epilepsy, there are a number of aspects that are related. Among these aspects are the following:

A) Vocational Adjustment

Vocational status in adults is recognized as a very important aspect of psychosocial adjustment (Dodrill, Batzel, Queisser & Temkin, 1980). Material advances are taking place in the areas of education and employment. In 1976, Rodin, Shapiro and Lennox observed that 7.4% of the epileptic children attending their clinic had been rejected by their schools; 25.8% were receiving special education. In the United States, legislation now makes it illegal for epileptic children to be refused appropriate education.

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, 1987). In 1977, the Commission for the Control of Epilepsy and its Consequences stated, "employment is the single greatest problem facing the adult with epilepsy" (cited in Thompson & Oxley, 1988, p.11). Both unemployment and underemployment are more prevalent among people with epilepsy than in the general

population (Dodrill, 1983; Griffin & Whyles, 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 are unemployed (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 they lose jobs because of employers' attitudes, prejudices and discriminatory practices (Chandra, 1988; Masland, 1985; Sands & Zalkind, 1972). Tettenborn and Kramer (1992) reiterate that many epileptic adults remain out of work, not because they are unfit or unwilling to work but simply because prospective 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 (SANEL), 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. A similar finding was reported by Danesi (1984) who stated, 47% of his sample of epileptic patients

thought that employers generally discriminate against epilepsy. Yet, the Employment Commission of the International Bureau for Epilepsy (1989) has stated clearly that 'neither the diagnosis nor the actual occurrence of seizures should disqualify a person from 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 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 that eventually erode the epileptics' self-esteem to the extent that felt stigma dominates.

Scambler and Hopkins (1988) have explained the strategy of secrecy and concealment that is commonly used to deal with felt stigma. They have found that although concealing their epileptic status reduces vulnerability to stigmatization or discrimination; epileptic patients found living with the possibility of 'exposure' on the job highly stressful in itself. 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 (Scambler, 1987).

B) EDUCATION

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 concurs with a general observation that people with epilepsy are over represented in semi-skilled jobs

(Dodrill, 1983). According to Dodrill (1983), this is a result of 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 epileptics' family are likely to carry their financial burden (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 themselves (Whye, 1991). In such cases, it was felt that the epileptic member would have to be fed and clothed by the family that may also have to finance treatment for epilepsy. Epileptics 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 and Rutherford, 1992).

Chaplin, Wester and Tomson (1998:299-303) examined the employment experiences of 245 outpatients with epilepsy, as part of a study into the rehabilitation needs of epileptics. Results of questionnaires revealed that 9% of the sample were unemployed and a further 16% were in receipt of a disability pension. Patients with seizures in remission were more likely to be employed and less likely to have experienced job problems, to feel limited by their epilepsy or to experience stigma. Job problems per se were experienced by 35% of the population. Of those with uncontrolled seizures, 50% experienced employment problems; while, 22% thought that their current employment situation had not been unduly influenced by epilepsy.

C) DRIVING

Because the automobile has become almost a necessity of life in most countries, restrictions on driving are among the most serious social consequences of epilepsy. Regulations with regard to driving licences for patients with epilepsy vary widely. The current regulations in Germany are based largely on an expert report titled "Illness and Driving," edited by a board of physicians and lawyers, and now in its third revision (Lewrenz & Fridel, 1985).

The important regulations are essentially as follows: - (a) in general, epileptics are not allowed to drive motor vehicles; (b) no exception is made for nocturnal seizures or for focal seizures without impairment of consciousness; (c) after a single seizure, the risk of recurrence has to be minimal to allow further driving; and (d) after several seizures, there is permanent suspension for professional drivers. The Epilepsy International Committee on Driving License Regulations (1982) recommends 1-2 years free of seizures before driving is permitted; only in exceptional cases are shorter periods considered acceptable (ibid).

D) INTERPERSONAL ADJUSTMENT

Interpersonal adjustment refers to a person's ability to relate to other people, i.e. having close personal friends, having sufficient number of social contracts, 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 society as a whole. It specifically assesses whether their epilepsy may have interfered with the forming or sustaining of interpersonal relationships. Thompson and Oxley (1988) point out that the ability to form and maintain friendships contributes to psychological stability and helps people cope with adverse life events. They 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 in 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 epileptics is common and may affect an individual's social presentation (Burden, 1981), and contribute to fewer fulfilments with respect to their family lives, friendships and marriages (Collings, 1990a).

Families also play a role in restricting the epileptics' 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 epileptics, who have led very restricted social lives from an early age, may not have had the opportunity to develop the necessary interpersonal skills to enable them to relate to others (Thompson & Oxley, 1988). Dependency is fostered and created by the perception that epileptics need a great deal of supervision and cannot be left on their own.

A supporting and caring 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 and Oxley (1988) found that only 8% of their epileptic respondents reported difficulties with relationships between them and family members.

Mimics, Bekes, Rozsa and Halasz (2001:1059-1311) investigated interrelationships between problems in psychosocial adjustment, coping and epilepsy variables. The Washington Psychosocial Seizure Inventory (WSPI), Ways of Coping Scale, Modified Version, as well as scales measuring depression and anxiety were administered to 310 outpatients with epilepsy.

When the relationships between adjustment and coping were modelled, coping was found to be a mediator between the effects of interpersonal and emotional adjustment and integration to the broader social context (vocational adjustment). Family background was found to be a significant predictor of the emotional well -being and interpersonal scores of the patients. Results support the central role of coping and well - being and emphasize the importance of family factors in adjustment to epilepsy.

Clear differences between epileptics and non-epileptics have been demonstrated in the way in which they relate to others. In Collings (1990a) study 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-situations, in having conversations and when interacting with strangers. In a different study in the United Kingdom, Thompson and Oxley (1988) found that as many as 68% of their sample of 92

patients admitted having no personal fiends and only 11% had a wide circle of friends. Almost 34% of the respondents never had an intimate relationship.

The findings on social adjustment of epileptic persons in Africa, in particular Nigeria, have been varied. 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 interactions; that is, they had many friends, interacted well with people, did not lose their spouses and did not have to change residence on account of their epilepsy.

Merely, 25% of the sample showed poor social interaction capability. Of this, approximately 17% had lost friends or spouses because of epilepsy and had felt rejected. The remaining 8% feared rejection and, thus, avoided making friends. Another 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 (Awaritefe, 1989; Nkwi & Ndonko, 1989; Whyte, 1991). This belief often leads to fear, dread and avoidance of epileptic persons; resulting in them being treated as social outcasts.

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).

In a small village of Maham in Cameroon where there is a 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 such as flies (Nkwi & Ndonko, 1989). These researchers report that the epileptic 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, physical contact is limited between the epileptic person and his or her family members. There is also the non-sharing of utensils, clothing and bed facilities between the epileptic and the rest of the family.

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

TWO MODELS FOR UNDERSTANDING PSYCHOSOCIAL PROBLEMS

Collings (1990a, 1990b) identifies two models in the research literature that account for psychosocial problems associated with epilepsy. The first, referred to as the 'medical' model, recognizes 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 model known as the sociopsychological model, proposes that the psychosocial effects of epilepsy are mediated by other individual and social factors. These social factors, according to a study by Ryan et al. (1980), include the degree to which the respondents feel debilitated by epilepsy, their perception of employment discrimination, and their level of education and, to a lesser extent, their age and sex. In addition, Griffin and 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 theoretically 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.

2.3 STUDIES ON EPILEPTICS' RECOMMENDATIONS

Previous studies on services for people with epilepsy have highlighted a number of deficiencies (Hopkins & Scambler, 1977:183-186; Lloyd, 1980:396-400; Goodridge & Shorvon, 1983:641-644; Report of the Working Group on Services for People with Epilepsy, 1986). One prominent deficiency identified, has been the amount of

information or counselling that patients with epilepsy receive, or at least retain (White & Buckley, 1981:82-88; Chappell, 1992:103-109).

The diagnosis of epilepsy carries with it important social, occupational and psychological consequences and it is important to provide care and attention to these areas as well as to seizure control. By identifying and describing the deficiencies and recommendations of epileptics, it may be possible to bring about changes in a larger arena.

The study of the epilepsies is already so diverse, and expanding so rapidly, that it cannot be easily encompassed by a single physician's competence, however skilled he or she may be. Epileptics believe it is only right, therefore, for epilepsy services to adopt a multiprofessional team approach. This means that equal emphasis must be given to the clinical and the social aspects of the epilepsies and their consequential impact on those around them, at school, at work, or in the wider community.

For people with established treated epilepsy, Bowman et al. (1984) have argued that the use of specialist nurses can reduce dependence on medical facilities while at the same time, increase opportunities for patient education, counselling and support; the needs for which often persist the stabilization of seizures. The individual doctor, nurse, social worker, psychologist, health educationalist, teacher or other professional worker needs to be aware of the matrix of expertise available and be able to exploit it with enthusiasm if all those affected by the epilepsies are to gain optimum benefit (Beintema, 1983:31-34; Betts, 1983:17-23; Parsonage, 1983:1-8). Expertise, enthusiasm and empathy are the key ingredients to the professional's ideal approach to the epileptic. It is an exhortation to the professional worker first to seek understanding of the personal impact of epilepsy. This can be used as a foundation on which to establish a partnership in which treatment can be initiated, pursued and modified as necessary to cope with the inevitable vicissitudes of living with epilepsy (Scambler and Hopkins, 1986:26-46; Buchanan, 1982:173; Mostofsky, 1978:46-61).

Lance (1977:907-908) has suggested that the attitudes of the doctor, in particular, may be reflected in the patient's self-perception and his or her understanding of the place of epilepsy in his or her life. The attitude displayed by the medical practitioner can either enhance or depress the quality of life of the epileptic. Reviewing recent Australian

experiences, Beran (1983:9-16) found that people with epilepsy generally had confidence in their doctors and looked to them for advice and support.

With regard to problems of professional attitudes in particular, suggestions have been made (Appolone et al., 1979:129-132 and Shapiro, 1983: 35-40) that all health workers concerned with epilepsy, be encouraged to acquire skills that will enable them to examine and, if necessary, correct their perceptions about epilepsy, enabling them to relate to epileptics in a more lucid and comfortable manner. Effective communication between doctor and patient is obviously central to an empathetic relationship. It is worrying, therefore, that a recent study (Maguire et al, 1986:1573-1578) highlighted serious weaknesses in young hospital doctors' skills in communication and a reluctance to explore psychosocial aspects of epileptics' conditions.

While the essential search for new techniques to gain control of established epilepsy, and to prevent the onset of new cases continues, the parallel search for techniques to stimulate and sustain positive attitudes in epileptics, the community and professional workers must receive greater attention (West, 1983:41-50). In the words of West (1983: 41):

> It is in this latter domain that the battle will ultimately be won or lost. The irony is that if no one with epilepsy had another seizure from tomorrow but retained the diagnosis, it would still constitute, for a considerable number, a real impediment in their lives. The best way to put expertise, enthusiasm and empathy to their optimum therapeutic use, is to strive towards the goal 'the degree of social adaptation in work, school and recreation is the final criterion for health care delivery to the patient with epilepsy.'

Early models of the doctor-patient relationship tended to portray the doctor's role as 'active' and the patient's as 'passive.' Haug (1976:23-42) puts it lucidly:

"The relationship with the physician is asymmetrical; the patient is in a dependent status and the physician a superordinate status. It is the 'competence gap' between doctor and patient that justifies the professional's authority and the client's trust, confidence, and norm of obedience. Although the objective of care is to return the patient to an active,

independent status, he/she is obligated in the model to become temporarily submissive and to accept the doctor's right to tell him/her what to do".

Friedson (1961) was perhaps the first to challenge this 'bias', insisting that while physicians may expect patients to accept their judgements and recommendations unquestioningly, patients generally 'seek services on their own terms.' He argues that there may well be a 'clash of perspectives', and therefore a potential for conflict. Patients may appear submissive during medical consultants but it does not follow that they are truly acquiescent or 'passive'. Behaviour that seems deferential is not necessarily indicative of agreement or satisfaction or even of a readiness to take medical advice (Stimson and Webb, 1975).

The importance of patients' perspectives is clearly demonstrated in relation to the 'problem of non-compliance.' There have been surprisingly few attempts to explore the epileptics' views on anticonvulsant medication. Schneider and Conrad's study (1983) in the US has shown that people with epilepsy frequently formulate their own strategies for drug -taking. They found that 'self-regulators' variously altered their prescribed dosages to test their lay theories of seizure control.

Scambler and Hopkins (1986) found that patients' sense of stigma led them to take umbrage at doctors' preoccupation with the diagnosis and treatment of disease. Most patients preferred treatment by their general practitioners. West (1979) has suggested that what doctors lack is a coherent 'stigma ideology' relating to epilepsy: in particular, they have no clear 'set of prescriptions, or 'practice theories', to enable the stigmatized themselves to manage their situation as effectively as possible. One result of this, he believes, is that 'the physician is in danger of legitimizing the stigma of epilepsy, not by talking about it, but by 'not' talking about it.'

Stigmatization and social functioning have been investigated among a largely untreated population of people with epilepsy in Kenya (Feksi, Kamugisha, Sander, Gatiti & Shorvon, 1991,a, b). Seizures were shown to constitute a considerable disruption in the lives of patients, as reflected in a questionnaire about knowledge, attitudes and practice.

Kenya now has a public education and support group for people with epilepsy- one of the first in Africa (International Epilepsy News, 1992). This program has considerably improved the social conditions of patients with epilepsy and has been encouraged in other countries.

The World Health Organization (WHO) (1990) proposes a community based treatment plan for epilepsy, where patients and families have some degree of control in the management of their illness. The primary goal is the control of their seizures. This is followed by the reintegration of patients into the mainstream of social life and the introduction of preventive measures in an attempt to lower prevalence rates of epilepsy. This requires a basic level of health-related knowledge. Education must be directed towards physicians and health workers and, most importantly, to the patients and the general community.

A new organization known as EPICADEC (Epilepsy Care in Developing Countries), based in Netherlands, has the goal of disseminating information about epilepsy and guiding people with epilepsy to their local health care facilities (Meinardi, 1994). Efforts such as these, which bring together the experiences of health care workers in developing countries, can add an extensive understanding of this illness and the strategies that can be used to reach higher levels of successful treatment.

It is suggested that education is necessary to inform epileptics of what precautions and restrictions to their lifestyle are required and what restrictions are in fact unfounded (Pefile, 1993). This should improve clinic attendance and compliance with medication. Further, epileptics may benefit from being informed of their rights, to a full education and employment so that they do not fall prey to self- discrimination or to discrimination by uninformed individuals. Tettenborn and Kramer (1992) believe that one of the primary goals of patient care for epileptics is to help them lead an independent life with as few restrictions as possible.

It needs to be borne in mind that a minority of people with epilepsy are unidentified and have no medical contact: for example, a recent estimate in the US puts the figure at 20-25% (Commission for the Control of Epilepsy and its Consequences, 1978:78-276).

One reason for not seeking medical help, of course, could be the perception of the medical label 'epileptic' as a social liability.

Schneider and Conrad (1983: 101) write:

> "When blackouts, headaches and spaciness become seizures, and when the cause is something called epilepsy or a seizure disorder certified by a medical expert, one moves to a set of meanings, prescribed courses of conduct, and interaction that alters experience, past, present, and future".

Some commentators have argued that the diagnosis of epilepsy should be used more sparingly. West (1979) has countered that this would almost certainly mean that only the 'worst' seizures would be labelled epileptic; and that this would merely serve to reinforce the negative image of epilepsy held by sections of the public. West, himself, suggests that more, rather than less use, should be made of the word epilepsy.

His argument is that exceeding the use of the term, by including febrile convulsions for example, should help diminish its associated stigma: the range of people with a history of epilepsy would be increased, and this might lead to a 'broadening of experience and commensurate modification of 'negative stereotypes.'

Scambler and Hopkins (1986) reject both these contradictory pieces of advice as unrealistic and defeatist. The advice is unrealistic in the assumption that both those who experience seizures and members of the public can be duped by an essentially artificial redefinition of epileptic phenomena. The advice is defeatist in its seeming acceptance of stigmatization against people with epilepsy as a given factor in the equations.

Whatever doubts there may be about the optimum criteria for diagnosing epilepsy, it remains the case that physicians need to address the likely effects of labelling on their patients. A precondition of doing so is taking patients' perspectives seriously, even, or especially, when they 'clash' with their own. It has already been implied that patients' perspectives are wide-ranging and touch upon all aspects of health care: the sense of epilepsy as stigma may be central but it does not monopolize patients' thoughts about their illness or its implications.

Oosterhuis (1994:1059-1311) examined the psycho-educational approach to epilepsy utilizing a symptomatic approach with emphasis on information, self-management, and interventions based on behaviour therapeutic principles, which have been adapted for the treatment of seizure disorders. Five patients with confirmed epilepsy who were referred for treatment of stress-induced seizures participated in the training.

Comparisons of pre- and post-training seizure frequency showed a decrease in seizures for the 4 of the 5 sessions. Seizure frequency was reduced by an average of 51%. Results offer some support for the psycho-educational approach to epilepsy. Advantages of this approach include the fact that it does not stigmatize the person with epilepsy by forcing him/her into psychotherapy. Instead, it offers an opportunity for education in the field of basic information, triggering mechanisms, and coping skills.

Epileptics believe that doctors do not take time to explore how they interpret their epilepsy and its impact on their lives. Evidence is plentiful across a whole range of illnesses that understanding patients' perspectives is an important ingredient of effective medical practice. Arguably, people with epilepsy have as much difficulty adjusting to the diagnostic label 'epilepsy', as they do to the recurring seizures.

Both the parents of children with epilepsy and adults with epilepsy need empathy, counsel and support in this process of adjustment. Responsibility for treatment and rehabilitation needs to be shared by doctor and patient. Clinical aspects of the management of epilepsy could clearly be improved, education on the management of epilepsy can be disseminated, and a need for counselling services can be provided.

Jain, Patterson and Morrow (1983:75-78) conducted a study entitled 'What people with epilepsy want from a hospital clinic.' A questionnaire was sent to 511 patients with epilepsy who were being reviewed at the clinics of two consultant neurologists. The questionnaire asked 19 questions about seizure type and how the diagnosis was given. It also asked how much information was given about the disease and advice about living with it. There were also questions about counselling and preference for hospital or community care. Over 96% returned the questionnaire. About one third said they were not told what epilepsy was, over 90% wanted more information about the disease, and about three quarters felt they had not been given enough information about the side-

effects of antiepileptic drugs. Over 60% wanted to talk about epilepsy to someone, other than a consultant, the most frequent person requested being a specialist nurse. Despite this, three quarters wanted to continue to attend the hospital clinic and 89% were generally satisfied with their hospital management.

Finally, as many researchers and epileptics illustrate in detail, there is room for improvement in the routine management of epilepsy. Hopkins and Scambler (1977:183-187) have described the current management of epilepsy in Britain as largely ritualistic. In their community study they report unnecessary referral to hospital, unnecessary electrocephalography, inadequate medication and follow-up supervision, which is not related to the patient's needs. Opinion on the potential of the kind of special centres and hospital-based epilepsy units advocated in a number of government-sponsored reports to improve routine management is divided.

The findings from the literature review suggests that there are unmet needs for personal and general information about epilepsy, which may include individual or group education and counselling. Information related to gaining control for people with epilepsy and targeted public education may contribute to the improved quality of life for people with epilepsy. Information that is individually relevant and delivered is in small groups or as part of an individual counselling service is required.

It is encouraging that there is an organization in South Africa such as SANEL (South African National Epilepsy League), which concerns itself with the welfare of people afflicted with epilepsy. SANEL provides therapeutic, educational, and social and employment services to sufferers of epilepsy to enable these individuals to overcome barriers so that they can enjoy fulfilled lives.

The aim of total care in epilepsy is to ensure the best possible management for each individual patient. Although pharmacotherapy for reduction or suppression of seizures is the basis of treatment in epilepsy, social and environmental problems are as likely to distress patients as are continuing seizures. One often-neglected aspect of management is the provision of adequate information for patients with regard to the various aspects of the seizure disorder. Improved education of society regarding

epilepsy is necessary to remove the many preconceptions and prejudices that still prevail.

It is important to encourage self-confidence in the patient and to avoid overprotection. Restrictions on lifestyle, including driving and employment, should be decided on a case-by-case basis, and only imposed if really necessary. Patients with epilepsy should have access to specialized referral centres and institutions. One of the major goals of total patient care should be to help the patient with a seizure disorder to lead a normal life, as this is not prevented by additional mental retardation or cognitive dysfunction.

2.4 FACTORS AFFECTING EPILEPTICS' PERCEPTION

Epilepsy in general has been considered as a frightening, dangerous and hopeless disease leading to severe mental deterioration. The stigma may be due to medieval prejudices and insufficient knowledge about epilepsy in the community. The effect, which major convulsions have on observers, is frequently reflected in their attitudes toward the patient. Patients recovering from major seizures are often subject to ridicule and expressions of horror by acknowledgeable and misinformed individuals, adding to the patient's already intense embarrassment and regret (Nursing Mirror, 198318-9).

The diagnosis of epilepsy has tremendous psychological and social repercussions. The initial reaction to the diagnosis often conjures up horrific images of the attacks and the stereotypes of people afflicted with the disorder. For many, a frightening mental collage emerges-uncertainty about the future, fear of the effects of medication on the body and mind, the unpredictability of seizures, progressive mental or physical disability, unwanted disclosure of their secret, loss of driving and other privileges, fear of losing control. This chapter focuses on the studies of the various factors (e.g. the stigma and label of epilepsy, erosion of an individual's self-esteem etc.) that influence the epileptics' perception of their disorder.

During a study of epilepsy in the United States, the Commission for the Control of Epilepsy and its Consequences (1980) conducted a series of public hearings. A universal complaint at these hearings was ignorance. The patients complained that they

were misunderstood by the public, that their relatives were confused, and that they, themselves, had never really been told what was wrong. Worst of all, they felt that many of the professionals they encountered were equally ignorant. It is customary to attribute the pathological attitudes of society toward epilepsy to age-long superstition.

A more immediate explanation is that it is frightening to observe a person lose control of him/herself. Being uneducated about epilepsy, the onlooker is seized with a feeling of abhorrence and helplessness. The result is a desire to avoid the situation. It is this avoidance that underlies the unwillingness of people to associate with epileptics. The solution for this is public education and public awareness programs.

The threat of stigmatization is often very real to the epilepsy sufferer. The 'hidden distress model' formulated by Scambler and Hopkins (1987, 1989) offers a useful framework for understanding the epileptics' perception of stigma. The model makes a distinction between 'enacted stigma' and 'felt stigma'. Enacted stigma refers to actual instances of discrimination experienced by epileptics. This occurs 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 his or her 'epileptic' status as socially undesirable.

Scambler and 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 maybe 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 (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 who has chosen to hide his or her illness from others.

Tandon (1989) conducted an Indian multicentre study of over 3,400 patients with epilepsy in Bangalore, Calcutta, Delhi, and Madras. The aim of the research was to examine the clinical and psychosocial aspects of illness. Over one third of patients belonged to joint families and two thirds to nuclear families, which were typical values for metropolitan areas. Patients with generalized epilepsy living in nuclear families sought medical attention sooner (within three years of onset) than those in joint families. No differences were found for other types of epilepsy.

Devlieger, Piachaud, Leung and George (1994) explored the experiences of persons with epilepsy in terms of coping in Zimbabwe and the Midwest, USA. Coping with epilepsy was explored with 37 adults (27 from Zimbabwe and 10 from the Midwest, USA) using open-ended questions in a written questionnaire. Questions aimed to elicit general feelings about epilepsy as well as experiences, strategies and skills in coping with epilepsy. The questionnaire covered such semantic domains as childhood, education, employment, friendships, relationships within the family, and the handling of seizures in public. Coping mechanisms were categorized into two modes, one being, adjustment to the disability (palliative) and the other adjustment to the environment (problem-solving). First, palliative skills during childhood in the Zimbabwean group are indicative of early development of personality characteristics and socialization as a result of the illness experience. A great variety in palliative mechanisms in handling seizures indicates better familiarity with seizures in the Midwestern group. Similarities between the two groups were found in the friendship domain and in problem-solving skills. Coping skills in the Zimbabwean group were related to the experience of 'being different', while in the Midwestern group 'not being able to do things' is a major experience. Two major cultural influences in Zimbabwe stand out as being different from the Midwest, the first being the belief in external control and cause of mental and physical health, and the second, cultural conflict.

A study was undertaken to determine what patients with epilepsy need to know about their condition, and to discern what differences exist between patients' perceptions of this need and the medical professions' perception of what patients should know (Choi-Kwon, Yoon, Choi, Kang & Lee, 2003: 785-789). About 75 consecutive patients with epilepsy and 56 medical personnel (residents and nurses) who were working in Neurology Units were studied using a structured questionnaire consisting of 3 subsets

with a total of 27 questions. Using a Likert scale, epilepsy patients gave high priority to their need for more information about "how epilepsy is diagnosed," "the structure of the brain ($p<0.05$, $p<0.01$, respectively), and "the diet that might prevent the attack" ($p<0.05$) than did medical personnel. The study concluded that an educational program for epilepsy patients should be developed on the basis of understanding that there are differences in perspectives among patients with different sociocultural contexts as well as between patients and medical personnel.

Collings (1990) conducted a survey questionnaire to examine the association between the social, psychological and physical well - being of a sample of 392 British and Irish people with epilepsy living in the community. The sample was drawn from urban and rural epilepsy support groups in various regions, and a hospital outpatients' population. Multiple regression analysis revealed that people's perceptions of themselves and of their epilepsy were the most powerful predictors of overall well-being. It also revealed that seizure frequency, time since diagnosis, a diagnosis of an absence of seizures, and employment was of some importance.

Implications for the care, counselling and management of people with epilepsy are discussed. It is emphasized that future research into the psychosocial aspects of epilepsy should examine the measures of people's subjective experience alongside neurobiological and sociodemographic indices.

Adjustment to seizures is an assessment of the epileptics' 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 is the most significant factor in adjustment.

Poor adjustment to epilepsy has been associated with increased scores on a scale of depression and emotional adjustment (Hermann and 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 and 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. Non-acceptance of the diagnostic label of epilepsy and the fear of disclosing their epileptic condition appear to be closely linked to the epileptics' perceptions that they will be subjected to stigmatisation and discrimination (see Levin et al. 1988).

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 though a doctor confirmed the diagnosis. 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).

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, which undoubtedly affect the way they feel about themselves. In a study exploring factors related to 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 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 and 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.

Accordingly, an overview of the studies provides evidence that negative attitudes, false beliefs and inadequate knowledge about epilepsy still prevail in varying degrees throughout the world. Hence, many people still hold irrational beliefs and negative attitudes towards those individuals afflicted with epilepsy.

According to McLin and de Boer (1995), although public perception about the disorder has improved and is continuing to improve, workers in the field of epilepsy have admitted that they are still far from fully demythologizing epilepsy and elucidating long-held prejudices about the condition.

Moreover, a review of the literature highlights, in general, a few aspects apart from those peculiarly inherent in each study. For example, most of the studies have been conducted using general populations, both rural and urban; a few of the studies have used epileptic patients themselves. Except for the research by Perfile (1997) and Newton and Gero (1984) which represent the only reported South African studies, most other studies have been conducted mainly in the rest of Africa and in other parts of the world.

Furthermore, the previous studies focused only on knowledge of and attitudes towards epilepsy while the present study attempts to investigate the self -perceptions and recommendations of epileptics, themselves, who form an important group of a population and who are likely to shape the future of other epileptics.

2.5 THEORY/MODELS ON EPILEPSY AND PERCEPTION

2.5.1. DEFINITION OF EPILEPSY

Epileptic seizures can be defined as manifestations of abnormal excessive neuronal activity in the gray matter of the cerebral cortex. The clinical features of seizures are determined by the normal functions of the region of the cortex in which neurons fire abnormally and include stereotyped alterations in consciousness, behaviour, emotion, motor function or sensation. Seizures can be caused by variety of pathologic conditions, include acquired brain injuries and genetic abnormalities.

Many physiologic disturbances of brain functions can provoke seizures (Dichter, 1997: S2-S6; Engel & Pedley, 1999; McNamara, 1999: A15-22). When unprovoked seizures occur recurrently, characterizing a diverse collection of brain disorders, the condition is called 'epilepsy[4]'

The World Health Organization has adopted a definition of epilepsy as "a chronic brain disorder of various etiologies due to excessive discharge of cerebral neurons" (WHO, 1990). 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; Shorvon, 1990). Rodin (1987) suggests 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 that occur in 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 manifest as disturbances of behaviour, emotion, motor functioning, and autonomic, or sensory functioning (Chadwick, 1990; Lishman, 1987).

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[4] (Commission on Epidemiology and Prognosis of the International League Against Epilepsy (ILAE), 1993:592-596).

A completely satisfactory definition of this syndrome has always been difficult and problematic to offer because of its complex nature. The terms seizure disorders, convulsive disorders, or fits are often used interchangeably to refer to this syndrome.

Rosenweig and Leiman (1989) define epilepsy as a brain disorder marked by sudden changes in the electrophysiological state of the brain referred to as seizures. Neppe and Tucker (1989), in addition to defining epilepsy in very similar terms, elucidate the association of epilepsy with alterations in consciousness, behaviour, cognition, affective and motoric functions.

Engel (1995) emphasizes that the modern views of epilepsy originated in the work of John Hughlings Jackson. Modern epileptologists defined and redefined the various forms of clinical epilepsy. Concepts of the basic mechanisms underlying epileptogenesis, epileptic seizures and epilepsy-related disturbances are being revised continually. The word "epilepsy" is presently used to refer to a class of epileptic disorders, defined as chronic neurological conditions characterized by recurrent epileptic seizures.

> "Epileptic seizures, in turn, can be defined as the clinical manifestations (symptoms and signs) of excessive and/or hypersynchronous, usually self-limited, abnormal activity of neurons, predominantly located in the cerebral cortex" (Engel, 1995, S23).

Moreover, the fact that the various concepts of epilepsy are by no means fixed nor are they noncontroversial, also confirms that a completely satisfactory definition of epilepsy is not easily forthcoming. At this juncture, it is important to note that the problem of arriving at a satisfactory definition of epilepsy makes the diagnosis of epilepsy problematic.

2.5.1.2 EPIDEMIOLOGY

The prevalence rate for epilepsy is 4-8 cases per 1 000 population (Hauser & Kurland, 1975:1-66; Goodridge & Shorvon, 1983:641-647) and the annual incidence rate including patients with recurrent unprovoked seizures typically varies between 30 and 50 per 100 000 population per year (Hauser & Kurland, 1975:1-66; Joensen, 1986:150-155). In Finland, Keranen (1988) reported an incidence rate of 24/100 000 and a prevalence of 6.3/1 000 in adult patients with epilepsy.

The estimates of lifetime prevalence, which is the measure of people in a population who have ever had epilepsy, vary from 2 to 6% of the population (WHO, 1957; Hauser & Kurland, 1975:1-66; Goodridge & Shorvon, 1983:641-647; Zielinski, 1988:21-48; Hauser et al., 1993). These statistics suggest that 1 in 20 persons will have suffered with epilepsy at some point in their lives and, conservatively, 1 in 200 will currently have epilepsy (Shorvon, 1996:S1-S3).

2.5.1.3 AETIOLOGY OF EPILEPSY

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 epileptics have no clear cause (Shorvon, 1990).

Certain postnatal insults such as brain trauma, central nervous system (CNS) infections, cerebrovascular disease, and brain tumours greatly increase the incidence of epilepsy. In a classical study in Rochester, Minnesota, (1935-1984) the presumed predisposing cause of epilepsy was vascular in 11% of all the incident cases of epilepsy, followed by congenital (8%), traumatic (5.5%), neoplastic (4.1%), degenerative (3.5%) and infective (2.5%) causes (Hauser et al., 1993).

More recently, a prospective cohort population-based study in the United Kingdom reported that the etiology of epilepsy was vascular disease in 15%, cerebral tumour in 6%, alcohol-related in 6% and post-traumatic in 3% of the patients (Sander, Hart & Shorvon, 1990:1267-1271). The etiology of epilepsy varies considerably in different age groups and maybe multifactorial. Notably, epidemiological studies have reported that in about 65% of cases the etiology of seizures was idiopathic/cryptogenic (Sander et al., 1990:1267-1271; Hauser et al., 1993).

It is evident that the more extensive the investigation, the more likely etiological factors are to be identified. Brain magnetic resonance imaging (MRI) identifies a high rate of positive causes in hospital-based surveys (Li, Fish, Sisodiya, Shorvon, Alsanjari & Stevens, 1995:384-387). However, no population-based epidemiological study with modern neuro-imaging has yet been reported. Therefore, it is likely that the true incidence of symptomatic epilepsies is higher than reported in previous studies, and that MRI will have an important impact on the diagnosis of previously undetectable structural abnormalities.

2.5.1.4 CLASSIFICATION OF EPILEPSY

Classification and terminology of the epilepsies have, not surprisingly, been problematic (Lishman, 1987). The International Against League 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 etiological data (Shorvon, 1990).

Kshirsagar and 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 or fixed origin. This proposed definition takes into account not only the ictal phenomena but also the interictal state of the patient (Rodin, 1987).

2.5.1.5 PROGNOSIS OF EPILEPSY

The issue of prognosis (possibilities of cure or complete control) of epileptic attacks can be addressed only in general terms. The fact that one is dealing with a symptom produced by a number of differing underlying causes imposes limitations on any generalizations. Patients have been cured spontaneously or even completely relieved from the total effects of epileptic attacks without treatment. Therefore, with treatment, the chances are undoubtedly much better for complete control (Penfield & Jasper, 1954).

According to Buchanan (1992), recent studies of patients with newly diagnosed epilepsy, according to Buchanan (1992), have shown a more favourable prognosis than studies of patients with chronic epilepsy. Only about 20 to 30% of newly diagnosed patients go on to develop chronic epilepsy.

Researchers have proposed several factors as being responsible for poor prognosis. These factors include partial or mixed seizure types, clinical or computerized tomography (CT) evidence of cerebral disease, intellectual handicap, psychiatric illness, personality change and social problems. The less certain indicators of a poor prognosis are older age, a family history of epilepsy or an abnormal electroencephalogram (Buchanan, 1992).

The number of seizures before treatment, according to Buchanan (1992), influences the longer-term prognosis. He points out that if seizures are not controlled within two years of commencing treatment, there is a higher chance of the condition becoming chronic.

The risk of secondary foci or multiple foci may be diminished by early surgery. However, a longer duration of seizure disorder and a younger age at onset are unfavourable factors. Also, the existence of dual pathology in a high proportion hampers prognosis. Seizure control by lesionectomy is obtained by 85% of patients. Therefore, in cases of failure to control seizures, a second operation may be considered for persistent intractability (Villemure & de Tribolet, 1997).

2.5.2 PERCEPTION

2.5.2.1 DEFINITION OF PERCEPTION

' Why do things look the way they do?' the gestalt psychologist Kurt Kofu asked many years ago (Morgan & King, 1975: 336). The question is simple, but the answer has turned out to be complex. Perception refers to the way the world looks, sounds, feels, tastes, and smells. In other words, perception refers to what is immediately experienced by a person.

First of all, it seems clear that any perception is an awareness that emerges as a result of a most complicated weighing process an individual goes through as his/ her mind takes into account a whole host of factors or cues. It must be emphasized at the very outset how tremendously complex even the simplest perception is. A whole host of indications are weighed and integrated to give us our final experience. Among these indications are those related to the environmental conditions just prior to and during the visual experience. This, together with all the past experiences individuals have had with similar stimuli have built up in us a sort of statistical average used as a frame of reference for our interpretation of the concrete stimulus of the moment. The integration of all these factors is accomplished in a fraction of a second and is, more frequently than not, entirely unconscious.

The study of perception is the attempt to understand those aspects of observations of the world of things and people that depend on the nature of the observer. Such understanding is obviously important to the physician, the physiologist, and, it was once thought, to the philosopher concerned with the question of how we can be sure about the truth of our ideas. Despite these different interests, perceptual study remains predominantly psychological. Research in perception requires the most sophisticated

controls of the motivational, judgmental, and learning processes, i.e. the use of the techniques of experimental psychology. More importantly, the touchstone of perceptual research is perceptual experience (Hochberg, 1962:255-330).

2.5.3 THEORIES OF PERCEPTION

2.5.3.1 THE STRUCTURALIST THEORY

The oldest and most complete theory of perception, now known as structuralism, held that simple elementary experiences, or sensations, recur in various combinations to compose the world as we perceive it. Sensations presumably result from the excitation of individual sensory cells, or receptor neurons, each contributing a characteristic signal, called a specific nerve energy, to the central nervous system.

Whether acting alone or with a host of others, any receptor would produce the same sensation, although the memories of past experiences evoked by each different context in which the sensation is embedded, would usually conceal from the untrained observer the fact that elementary sensation has occurred.

It is not only were the physical qualities of objects (their sizes, distances, shapes, etc.) that need to be explained in terms of these basic simple sensations but also our perceptions of people, their expressions, intentions and social relationships. This was much more than a theory of perception; it was central to a comprehensive program for understanding man's mind, since all ideas about the world must be composed of just these sensations, as well as memories of previous sensations, in various combinations.

Structuralism has had to be abandoned as far as any such unitary program is concerned, and a variety of competitive schools such as behaviourism, gestalt theory, and functionalism have attempted to replace it. Nevertheless, structuralism remains the most important. Most knowledge about perception has been gathered either within or against the structuralist program that has provided the framework of problems around which present research continues, and within which the researcher has to evaluate more recent approaches.

2.5.3.2 THE PSYCHOPHYSICAL APPROACH

The psychophysical approach to perception is concerned with studying the relationship stimuli from the environment, and people's perception of the stimuli. Modern ideas about the physiology of perception have evolved from a long line of speculation and research regarding the physiological workings of the mind, beginning with Aristotle and Galen in ancient times, and including 17th century philosopher Descartes and scientists such as Kepler.

Modern approaches began being developed by 18th and 19th century scientists. The psychophysical approach to perception deals with the stimulus question: How do we use information from the environment to create perceptions? The psychophysical approach provides tools that can be used to help answer this question.

2.5.3.3 THE COGNITIVE APPRAOCH

The cognitive approach to perception focuses on how perception is affected by the meaning of a stimulus, and by the subject's expectations. The development of cognitive psychology, beginning in the 1960s, gave impetus to considering the cognitive dimension of perception. One idea behind the cognitive approach is that the mind, like a computer, processes information.

CHAPTER THREE : RESEARCH METHODOLOGY

3.1 INTRODUCTION

Epilepsy is a stigmatizing disorder and available evidence suggests that its diagnosis can have important psychosocial consequences and can severely reduce the quality of an individual's everyday life. The social position of epileptics is often characterized by rejection, discrimination and even ostracism. The relationship between stigma and epilepsy has been addressed in other studies (Eidhin & McLeavey, 2001:213-222; Scambler & Hopkins, 1990:1187-1194; Jilek-Aal et al., 1997:783-795) but little is known about any association between noxious, negative self-perception and epilepsy.

The objective of this chapter is to present a discussion on the investigative techniques adopted for the purposes of this study, together with the research objectives and hypotheses. Furthermore, a complete description of the sample, the research instruments and techniques to be incorporated for analysis of the study will be presented. The chapter will conclude with a discussion on the statistical tests to be employed to analyse and interpret the data.

A review of the literature reveals that the only study investigating knowledge of, and attitudes towards epilepsy in South Africa was conducted by Newton and Gero (1984). This study was conducted on a sample of 158 rural African epileptic patients in the former homeland of Transkei. The findings of this study were based on the opinions or responses towards epilepsy expressed verbally by epileptic patients themselves. However, this study did not consider the influence of epileptics' perceptions, experiences, demographic, socioeconomic and sociocultural variables on subjects' knowledge of epilepsy.

Before any effort was made to construct a questionnaire, a literature survey undertaken, permitting the researcher to acquire an improved understanding of the subject under study. The literature review contributes to the theoretical groundwork upon which the empirical study is based. It acts as an integral step in the research process, and contributes to the other aspects of the complete research planning.

3.2 RESEARCH DESIGN

The selection of the research design or appropriate research strategy depends upon the research problems or questions (Edwards, 1990). A design is selected if it generates answers to the research problems/questions, or if it adequately tests the hypothesis (Herbert, 1990). The nature of the research questions for the present study will best be addressed using a descriptive research design, since previous studies had been able to employ this design successfully (Ramdas, 2001; Perfile, 1993, Anderman, 1995). This type of research is also referred to as ex post facto research.

An ex post facto study is a study in which the variable or variables of interest to the researcher are not subject to direct manipulation but must be chosen "after the fact". The researcher begins with two or more groups of subjects who already differ according to one variable (such as age, gender, etc) and then records their behaviour to determine whether they respond differently in a common situation.

Therefore, the descriptive approach is widely used and is of great importance. For example, we can observe the outcome of the descriptive approach whenever the results of Gallup polls or other surveys are reported (Gallup, 1976). Helmstadter (1970:65) has even gone so far as to say that the "descriptive approaches are the most widely used...research methods".

An example relevant to the present study with its emphasis on epilepsy, was a Gallup Poll survey of the opinions and attitudes towards epilepsy in the United States of America. Knowledge about epilepsy was noted in this study, in relation to demographical variables, such as age, socio-economic status and education.

The research aims for the present study are as follows:

- To investigate the nature of epileptic's self-perception
- To examine the psychosocial problems as reported by epileptics
- To find out what epileptics would like to recommend in this context
- To establish correlates of epileptics' perceptions, factors influencing perceptions

Descriptive studies are concerned with the following research issues:

- To ascertain the existence of an association between variables; to establish correlates of epileptics' perceptions and other aspects, for example, demographic variables.

- Experimentation is impossible with research problems involving the following variables: intelligence, socioeconomic status, etc. Here only descriptive research is feasible.

When initially investigating a new area, researchers use the descriptive method to identify existing factors and relationships among them. Such knowledge is used to formulate hypotheses to be subjected to experimental investigation. The descriptive method is also frequently used to describe the status of a situation once a solution, suggested by experimental analyses, has been put into effect (Christensen, 1994).

In summary, the present study involves:

(i) Finding a sample of epileptic patients in order to obtain their ideas, views and perceptions with regard to epilepsy (see Annexure A).
(ii) Constructing an attitude and perception scale.
(iii) Applying the scale to a representative group of epileptic patients with a view to testing the hypothesis.

3.3 THE METHOD OF SAMPLING

Sampling is the process of selecting members of a research sample from a defined population, usually with the intent that the sample accurately represents that population (Huysamen, 1994).

While a population refers to an entire collection of scores or individuals being investigated; a sample, refers to only a part of the total population under investigation. Harris (1995:436) defines a population as "All scores or members of a group that are of

interest to a researcher, the group to which the researcher wishes to generalise ". He goes on to define a sample as, "The group of scores that the researcher has or the people providing the scores, ordinarily, a subset of a population" (Harris, 1995: 436).

The manner in which the sample of subjects is selected depends on the goals of the research. If it is important that the results obtained from the sample mirror the results that would have been obtained if the total population had been included (Rosnow & Rosenthal, 1996). Since the research question for this present study requires an accurate depiction of the general population, a random sampling technique will be used. The advantage of this technique is that it provides a sample of subjects whose responses represent those of the general population. When a true random sample of subjects is obtained from the population, the results can be amazingly accurate.

Rosnow and Rosenthal, (1996) define a random sample as a group of research participants that is formed such that all members of the accessible target population have an equal and independent chance of being selected. Independent means that the selection of one individual for the sample has no effect on the selection of any other individual. The sample would be chosen by a process that will give each sampling unit in the population the same chance of being selected. In order for this to occur, the selection of one unit must have no influence on the selection of other units. In the case of simple random sampling, a further requirement is that the researcher has to have a list of the units in the population. The idea is to draw subjects one at a time until the researcher has the required number of sample. The actual method of subject selection will be effected by means of a table of random numbers (Huysamen, 1996).

The results obtained for the subjects can then be generalized to the entire population under investigation with limits of accuracy that can be stated (Harris, 1995:7). These individuals who comprise the sample can be termed sample units. One of the most important characteristics of quantitative research is the requirement that the sample reflects the attributes of the target population, and hence conclusions that are drawn are pertinent to the whole population.

3.4 RESEARCH PARTICIPANTS

A questionnaire was translated in Isizulu due to the demographic status in Kwa-Zulu Natal[5]. The sample size for this study comprised 100 epileptic patients aged between 18 to 50 was selected. The figure of 100 was dictated by considerations of time availability[6] and budgetary constraints. The number 100 is a round figure, more easier to compute and research was conducted on a one- to one basis. The participants were randomly. The study was conducted in the neurology clinics held once a week on Tuesday morning from 8h:00-13h:00 from Wentworth hospital. Patients selected were from both sexes and different racial groupings[7]. The sample included subjects' aged between 18 and 50 years of age at the time of investigations. Also, the sample was drawn from a population of newly diagnosed and chronic patients treated in the clinic in Wentworth hospital. In order to be eligible for the study, patients selected had to be exhibiting active seizures (i.e. at least one seizure in the past year) or which they were receiving treatment[8]. All subjects gave informed consent.

3.5 THE PILOT STUDY

The pilot study incorporated the use of a structured questionnaire consisting initially of thirty- six closed questions and five statements to be rated in order of importance. Closed questions provide respondents with a variety of alternative answers. The respondent is then asked to choose one answer from the alternatives that have been provided. Closed questions enable subjects to make a quick decision and this enhances the enthusiasm and commitment of the subjects (Rosnow & Rosenthal, 1996). Closed questions also facilitate the quick coding of information for analysis. These closed questions were formulated using a popular scaling format, the Likert scale. Questions were carefully designed to investigate the psychosocial perceptions and experiences of epileptics. A Likert scale consists of a collection of statements about the attitudinal object. In respect of each statement subjects have to indicate their degree of agreement or disagreement with its content, on a five-point scale. The pilot data was analysed using SPSS.

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[5] The inclusion of children in the present study would have required the development of a separate questionnaire to parents and is considered beyond the scope of the investigation.

[6] The sample were patients attending state hospitals, hence there were severe time constraints (in terms of long waiting hours, use of public transport etc).

[7] This information was ascertained from the patients' hospital folders. The data extracted from each folder consisted of age, gender, education, race, home language, occupation and place of residence.

[8] Patients with psychiatric illness, mental handicap or other chronic illness such as hypertension and diabetes were not accepted in the study.

The pilot study helped determine the following:

i. that questions were easy to understand.
ii. the adequacy of the questionnaire. This helped check for ambiguities and terminology that may not be easily understood.
iii. the efficiency of the instructions.

3.6 THE METHOD OF DATA COLLECTION

Data collection is concerned with how the researcher gathers information, i.e., which psychological instruments are used and the rationale for their use. In order to address the objectives of this present study a self-administered, structured 5 –point Likert questionnaire was devised (refer to Annexure C).

In this regard, in addition to consulting with identified experts in the fields of epilepsy as well as reviewing data collection instruments from relevant empirical studies (for example Eidhin & McLeavey, 2001; Hayden, Penna & Buchanan, 1992; Jacoby, 1992; Troster, 1998), the researcher conducted the following methodological tasks:

- Structured interviews with the Head of Department of Neurology at Wentworth Hospital and;
- A pilot runs with a sample of 10 epileptic patients attending Wentworth Hospital.

Furthermore, a review of the literature suggested that the following content areas would be important for the inclusion in the questionnaire:

- The subjective perception of epilepsy, for example, social impairment, constraints on daily life and the severity of seizures (Cramer & Mattson, 1993; Janz, 1989);

- Social and emotional consequences of epilepsy (Anderson & Bury, 1988); coping with the loss of control and unpredictability of seizures (Moos & Tsu, 1977);

- The relationship between stress, anxiety and seizure occurrence/ seizure provoking factors (Temkin & Davis, 1984; Hayden, Penna & Buchanan, 1992) willing/unwillingness to disclose epileptic status (Troster, 1998), and

- Knowledge, provision and accessibility of epilepsy counselling services, leagues and organizations (Perfile, 1993; Hoare & Kerley, 1992),

3.7 THE RESEARCH INSTRUMENT

A large number of statements relating to the object of enquiry were formulated in such a way that a Likert-type of scale was constructed. A number of statements were obtained from other diagnostic scales, for example, the Hopkins Symptom Checklist (Derogatis, Lipman, Rickels, Uhlenhuth & Covi, 1974), and the Diagnostic and Statistical Manual of Mental Disorders (DSM IV,1993), etc. A large item pool was complied and administered to the pilot sample.

The questionnaire had initially compromised 36 statements to be rated on a Likert scale, and 5 additional statements to be ranked in order of importance. Such a scale containing all the 36 items would have been unsuitable and laborious. When this happens, the consistency of accurate responding is frequently reduced as the amount of random error increases. The final questionnaire was prepared and reduced to comprise 14 statements.

The use of questionnaires allows researchers to quantify different attitudes, personality traits, opinions, and interests of the population under investigation (Babbie, 1990; Sudman & Bradburn, 1982). Furthermore, questionnaires enable researchers to uncover a variety of different biographical data (Harris, 1995: 45). A researcher is in a position to create and maintain rapport with his/her subjects by personally administering the questionnaire. Personally administering the questionnaire encourages a very high rate of response among individuals participating in the research (Sekaran, 1994: 220). The presence of the researcher is vital for solving any problems that might be encountered by the subjects while completing the questionnaire.

The type of language used in the questionnaire should be carefully matched against the subject's level of education and cultural background. It is imperative that the subject understands the questions immediately and provides answers that accurately reflect his/her attitudes, perceptions, and feelings (Sekaran, 1994: 203). In this study, every attempt was made to ensure that the questions were concise and easy to interpret. The fundamental objective of this research is to quantify the psychosocial perceptions of epileptics. This objective could only be achieved if subjects correctly interpreted the questionnaire.

The length of the questions and the entire questionnaire was kept to a minimum to ensure that the enthusiasm and concentration of subjects would not be adversely affected. In addition, shorter questions facilitate greater understanding among subjects. As a rule of thumb, Sekaran (1994: 206) suggests, "...a question or statement in the questionnaire should not exceed twenty words, or exceed one full line in print".

According to Martins, Loubser and Van Wyk (1996: 219) proper sequencing of questions will enable the researcher to improve the level of understanding achieved by the subject and also induces "...a harmonious flow of thought in the questionnaire ". In this research, the funnel approach was adopted for the sequencing of questions. This approach encourages "...easy and smooth progress of the respondent through the items in the questionnaire" (Sekaran, 1994: 207). An adequate amount of attention was also devoted to ensuring that positively worded questions relating to a particular concept, for example, anxiety, were placed consecutively. This was done to prevent any confusion and to promote overall consistency (Huysamen, 1994).

Findings from previous studies have strongly suggested the use of self-administered questionnaire. For example, a similar study conducted by Hayden, Penna and Buchanan (1997) focused on epilepsy and patient perceptions of their condition. A 47-item, anonymous questionnaire was devised and piloted on a number of patients attending an epilepsy clinic and was sent to members of Epilepsy Associations of South Australia. About 908 questionnaires were sent with a 45% response rate. The results

reinforce and extend previous observations that there is an ongoing need to educate individuals with epilepsy and their family members[9].

3.8 RELATION OF ITEMS TO THE AIMS OF THE STUDY

The questionnaire is specifically constructed to elicit optimum information based on the aims of the research study.

SECTION A: BIOGRAPHICAL INFORMATION

Questions 1 to 7: Biographical information

The researcher to ascertain pertinent information such as age, gender, racial group, socio-economic status, marital status, and educational levels constructs this section of the questionnaire. Demographic or biographical variables such as educational level, socio-economic status and marital status are frequently isolated for study purposes in research.

The names of the subjects were not required for the purpose of the study. According to Anastasi (1964:546), anonymity is a desirable condition in many types of attitude surveys because it encourages frankness and may even evoke private attitudes.

SECTION B: PSYCHOLOGICAL INLUENCE OF EPILEPSY

Aim 1: Perceptions of Epileptics' Condition

Descriptions follow of the focus of the 36 statements used in the piloting.

Questions 1-12: Relate to the Emotional aspect of epilepsy (A)

These questions deal with to the emotional behaviour of epileptics. They specifically relate to the depressive feelings of individuals which are formulated using the diagnostic criteria of the Diagnostic and statistical Manual of Mental Disorders-IV. (DSM- IV,1993).

[9] A similar study was conducted to determine the difference in perception on educational need in patients with epilepsy and medical personnel (Choi, Mi Ri, Kim, Yeon Hee, So, Yeon, Yun, Sun Moo, Lee, Guen Suk, Leem, Sang Sun, Kim, Geum Sun, Choi-Kwon & Mi, 1997).

Questions 13-21: Relate to the anxiety experienced by epileptics (B). This category was formulated with the help of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV,1993) and also selected items from the Hopkins Symptom Checklist (Derogatis, Lipman, Rickels, Uhlenhuth & Covi, 1974).

Previous research has indicated that patients' perception of the severity and emotional impact of their seizure disorder may be more important than seizure frequency in determining the psychological and social well-being of individuals whose epilepsy is poorly controlled (Arnston, Drodge, Norton & Murray, 1986).

Aim 2: Psychosocial Problems Encountered by Epileptics

Questions 22-27: Relate to the Social interaction and Self-Esteem of epileptics'(C).

This category attempted to analyse the social factors influencing epileptics' perceptions. To formulate these questions, the researcher used previous studies (Arangio, 1980; Arnston, Drodge, Norton & Murray, 1986; Danesi et al., 1984; Dodrill et al., 1980).

While the area of social support is addressed within the epilepsy literature (Scambler & Hopkins, 1986), an area that is as yet not investigated is perceived acceptance. Brock, Sarason, Sanghvi and Gurung (1998) propose that perceived acceptance may underlie perceived social support, which is defined as 'sense that one is loved, valued and unconditionally accepted' (Sarason, Pierce & Sarason, 1990).

The psychosocial impact of epilepsy is well- documented (Hills, 1983). The potential adverse effects of epilepsy include physical morbidity, social stigma, and impaired quality of life (Thapar, 1996). Epilepsy is associated with increased levels of depression (Jacoby, Buck, Baker & Ley, 1997; Robertson, Trimble & Townsend, 1997) and anxiety (Betts, 1992; Jacoby, Baker, Steen, Potts & Chadwick, 1996).

Questions 28-30: the questions for this section are based on the work of Bagley (1986), Danesi et al. (1981), and Ryan, Kempner & Emlen (1980). A central feature of epilepsy

is its stigmatizing nature, which results in social problems accompanied by a poor self-esteem (Levin, Banks & Berg 1988; Jacoby, 1994). Investigations of the psychosocial aspects of epilepsy have indicated that individuals with epilepsy tend to evaluate themselves somewhat negatively (Collings, 1990(a); Moore, Baker, McDade, Chadwick & Brown, 1994).

This association between negative self - perception and epilepsy has been related to the concept of stigma (Jacoby, 1994). There is considerable variance in the extent to which the individuals' self-perceptions are affected by a diagnosis of epilepsy. The aim of the current study is to ascertain if individuals who perceived their epilepsy to be more severe and stigmatizing, had lower levels of perceived acceptance than those who had no such perceptions.

Aim 3: Factors Influencing Epileptics' Perceptions of Their Condition

Questions 31-36: Relates to the Cognitive and behavioural aspects of epilepsy (D). This category endeavoured to establish some of the psychosocial problems encountered by epileptics. These questions are formulated from previous studies (Mittan, 1986; Strauss, Risser & Jones, 1982), which relate to the cognitive aspects of with having to deal epilepsy.

A study was conducted in Hong Kong to explore the psychosocial well - being of carers of people with epilepsy (Lee, Lee, Ng, Hung, Au & Wong, 2002: 147-157). Rating scales of mood, quality of life, and intensity of various epileptic and psychosocial variables were administeredd to sixty- five primary care - givers. About 22% of respondents were considered to have severe levels of anxiety, and 14% severe levels of depression. About ¾ of the carers' psychosocial adjustment was impaired.

Contrary to the findings of previous studies, caregivers of patients with additional illnesses or leaming disabilities were not more distressed than caregivers of patients with epilepsy only. Demographic characteristics and other medical and social factors associated with the psychosocial well-being of the carers of people with epilepsy were discussed. The findings of this study suggest the importance of including systematic measures of people's subjective experiences and perceptions in the study of social and psychological aspects of epilepsy.

Aim 4: **Epileptics' Recommendations**

Questions 37.1 – 37.5

This group of questions attempts to ascertain epileptics' recommendations, and ways of improving their lifestyle. Findings from other studies were adapted as questions (Dell, 1986). Results from previous studies extend previous observations that there is a need for improving the health care of persons with epilepsy (Hayden, Penna & Buchanan (1997).

3.9 METHOD OF SCORING

The final questionnaire (Annexure G) would consist of 14 items (the original scale had consisted of 36 items), which participants can rate on a Likert-type scale of one to five. Each respondent had to catergorize the response he or she made in relation to each statement, i.e., the respondent had to indicate by means of a cross (x) whether he/she strongly agreed, agreed, was unsure, disagreed or strongly disagreed with the statement at hand.

Assigning values of 1, 2, 3, 4, and 5, respectively, scored the categories. The total score for each person was obtained by summing up the values of individual items. This means that high total scores indicated positive perception and low total scores indicated negative perception.

The responses to the individual items of the scale are weighted. Weighting is deemed necessary because it allows the responses to be spread over a larger number of categories rather than be restricted. The wider spread from strongly agrees to strongly disagree allows effective variations, which are spread along the favourable - unfavourable continuum (Huysamen, 1994).

The mean score represents the assumed mid-point on the favourable-unfavourable continuum. The scores are not absolute and may not therefore be used for indicating specific trends of favourable or unfavourable perceptions. The total score however indicates whether epileptics' perception of their condition is favourable or unfavourable.

This type of attitude scale has been introduced by Likert (1903-1981) and is known as Likert scales. This scale is extensively used in the social sciences (Kidder & Judd, 1986). Its popularity stems from the fact that it is easier to compile than any of the other attitude scales, particularly, the Guttman and Thurstone scales. Furthermore, they may be used with multidimensional attitudes, which is not possible with other attitude scales (Huysamen, 1994).

3.10 METHOD OF DATA ANALYIS

According to Rosnow and Rosenthal, (1996) statistics are mathematical techniques for analysing numerical data to accomplish various purposes. These purposes are directly related to the research aims and the type of research design the researcher is choosing to accomplish the study. The research aims for this present study are as follows:

- To investigate the nature of epileptics' self-perception
- To examine the psychosocial problems as reported by epileptics
- To find out what epileptics would like to recommend in this context
- To establish correlates of epileptics' perceptions and factors influencing perceptions.

Empirical data would be analysed as follows:

- The Statistical Package for the Social Sciences (SPSS) (Norusis, 1993) would be utilized to analyse data. A coding template would be established in order to capture the key coding instructions for each variable, e.g. how responses relate to variables.

- Inferential and descriptive statistics

- The means and the standard deviations will be calculated.

- The t-test and f-test will also be used in the analysis of data on biographical variables (age, gender, etc).

- The chi-square test will be used to determine the significance of the differences among independent groups when frequencies in discreet categories (nominal or ordinal) constitute the data of the research (Siegel, 1956). Although the use of x^2 in research can be criticized, it continues to be widely used.

- One-way ANOVA and Tukey Test would also be used to analyse the scores on the 14-statement questionnaire in relation to the following variables: age, gender, ethnic grouping, home language, marital status, occupation and educational level.

3.11 ITEM ANALYSIS

To establish the discriminatory merit of the items in this scale, items were subjected to an item analysis, using the correlational method. In this method, correlation coefficients for each statement with the total score are computed and those items with the highest correlations are retained (Openheim, 1972). Ferguson (1950) mentions several methods for item analysis and states that they are all open to question.

One objection against them is that all items in analysis contribute to the total scores. As a result values obtained are bound to be spuriously high. The internal consistency method of item analysis necessitates subtraction procedures, i.e., the score for the item in question is subtracted from the total score before the correlation coefficient is worked out.

The computing of such correlations is quite laborious. Because of a large pool of statements and a large sample, it was necessary to use a computer for solving statistical problems. The power of discrimination for each statement was determined. The original scale consists of 37 items. Items 37.1-37.5 were not subjected to the process of item analysis (see Annexure D). The final scale consists of 14 items whose correlation coefficients range between 0,33 and 0,90. These items survived the process of item analysis and were therefore retained in the final scale. Twenty-two items, whose correlation coefficients were below 0,33, were discarded.

Mouton and Marais (1990) mention that factor analysis is a widely used technique for determining construct validity. According to Cooper and Emory (1991), Cooper and

Schindler (1998), factor analysis looks for patterns among variables to discover if an underlying combination of the original variables (a factor) can summarize the original test.

4. VALIDITIY AND RELIABILITY OF THE QUESTIONNAIRE

Validity refers to the appropriateness, meaningfulness, and usefulness of specific inferences the researcher makes from test scores gathered from an instrument (Rosnow & Rosenthal, 1996:130-131). At a minimum, all instruments should undergo content validity. Content validity means that the questionnaire items represent the kinds of material (or content areas) they are supposed to represent, which is usually a basic consideration in the construction phase of any questionnaire.

Previous research conducted by Oostrom, Schouten, Kruitwagen & Peters (2003) emphasized the use of content validity of a questionnaire and the content analysis of data. This study focused on parents' perceptions of and reactions to the onset of epilepsy and the implications thereof. Content analysis was used to extract data on perceived (dis) continuity of parenting by means of questionnaires and interviews with parents of 69 schoolchildren with epilepsy. The methodology used for content analysis of the data was an adaptation of the open coding system described by Glaser and Strauss (Glaser and Strauss 1967) and included the following steps:

(i) Different important aspects of the experiences and reactions to epilepsy was identified in the data.
(ii) The core quality of the experiences and reactions were then identified and grouped.
(iii) Core examples of the respondents' behavioural or cognitive actions were identified.

Researchers need to invest a tremendous amount of effort in the design of a questionnaire to protect the reliability and validity of data (Sekaran, 1994). In designing an effective questionnaire which will provide acceptable content validity, attention needs to be focused on a number of key areas, namely, the wording, length and the sequence of the questions, and the style of the questionnaire (Neuman, 1997:244).

Content validity of the questionnaire was assured by having the instrument appraised by individuals identified as experts within the fields of epilepsy[10]. An expert statistician and research methodologist[11] also examined the questionnaire to assess its content validity. These individuals are proficient in the nature of this study and were able to provide valuable suggestions regarding the design and wording of the questionnaire. The questionnaire used in this present research study provides for an effective description of the nature of epileptics' perceptions of their condition, the psychosocial problems encountered by epileptics as well as epileptics' recommendations.

This validity testing served to:

- Assess the internal consistency of items constructed
- Extract new content areas that may have been overlooked; and
- Implement any changes in the questionnaire design that may have been necessary.

The psychometric properties of the measuring instrument using statistical techniques such as the Alpha value, descriptive statistics, One-Way Anova, the Pearson correlation, and the Chi-square were computed. In this study, factor analysis was used to determine validity and Cronbach's Coefficient Alpha was used to assess the reliability of the questionnaire.

The reliability of a test refers to the consistency of its scores over different administrations involving different occasions or, test forms or scorers (Huysamen, 1994). Therefore, reliability assumes that the attribute being measured remains stable during repeated administrations of the test and that the scores obtained on one administration are unaffected by the scores obtained on any previous administration of it (Huysaman, 1994).

The reliability of the measuring instrument is determined using Cronbach's coefficient alpha. Cronbach's alpha is a reliability coefficient that reflects how well the items in a set are positively correlated to one another. Cronbach's alpha is computed in terms of the

[10] The questionnaire for this thesis was examined by neurologists (Prof Bill and Prof Bhigjee) in the Department of Neurology at Wentworth Hospital, and the director of SANEL, Ms Gloria Andipatton

[11] Prof Evan Mantzaris (Lecturer of Research Methods, Dept of Sociology at University of Durban-Westville and Dr B Faulds at the University of Natal- PMB) scrutinised the questionnaire.

average interrelations among the items measuring the concept. The closer Cronbach's alpha is to 1, the higher the internal consistency (Sekaran, 1992). The Cronbach's coefficient was alpha = 0,8098. This value shows a high degree of internal consistency of items included in the questionnaire. The scale is taken as both valid and reliable because its reliability coefficient is 0,8098 and the coefficients for the 14 items range between 0,33 and 0,90 (see Annexure E). Overall, the statistical tests provide sufficient support for the administering of the scale in the final study.

5. CONCLUSION

The research design and methodology undertaken included an examination of the procedure in determining empirical data for the research. The questionnaire was validated on the basis of proper construction of the instrument, pretesting a pilot study, together with quantitative analysis by means of factor analysis and Cronbach's Coefficient Alpha.

CHAPTER FOUR : PRESENTATION AND ANALYSIS OF DATA

4.1 ADMINSTRATION OF ATTITUDE SCALE

Questionnaires were administered to 100 epileptic patients attending the out - patient epilepsy clinic at Wentworth Hospital. Subjects were reassured of their confidentiality and anonymity. The answering procedure was explained and illustrated[12]. The respondents were asked to individually fill in all the required data.

The forms were distributed and the respondents commenced with filling in the questionnaire. The respondents were not told that at the end of the attitude scale there were five statements that were to be numbered in order of importance, according to personal preference. The benefits of the study were explained to the subjects. They were informed that the data accumulated should be of value to doctors and other health care professionals in their association with epileptics. It was important to explain repetitively the nature of the study, as many Zulu respondents spoke volumes about their financial and medical problems.

All 100 questionnaires were examined for errors and completeness. The questions were complete and no inaccuracies, such as two responses to a question were found.

4.2 THE RELIABILITY AND VALIDITY OF THE ATTITUDE SCALE

The reliability of a measure, according to Sekaran (2000), indicates the extent to which the measure is without bias (error free) and hence, offers consistent measurement across time and across various items in the instrument. It indicates the stability and consistency with which the instrument measures the concept and helps to assess the "goodness" of a measure.

Cronbach's alpha is a reliability coefficient that indicates how well the items in a set are positively correlated to one another. The closer Cronbach's alpha is to 1, the higher the

[12] A Zulu speaking nursing sister was recruited to help administer the questionnaire to Zulu speaking patient.

internal consistency reliability (Sekaran, 2000:308). The reliability coefficient is scale-free in that its value cannot be less than zero or greater than 1,00. Cronbach's coefficient alpha was used to determine reliability amongst individual items. Cronbach's Alpha coefficient is 0.9120 (see Annexure I). Thus the research instrument has a high degree of reliability or inter-item consistency. Therefore, the questionnaire was valid and reliable.

4.3 ANALYSIS OF HYPOTHESES

A total score for each individual was obtained by summing all his/her scores to the 14 items. There were fourteen items altogether. It was explained in Chapter Three that a high total score indicates positive perception towards epilepsy and a low total score indicates negative perception towards epilepsy. A general mean score was obtained by adding the total scores for the respondents and dividing this sum by the number of cases, i.e., $\Sigma X = 4467$, and $n=100$, therefore the general mean score is 44,67 (see Annexure J). Both descriptive and inferential statistics were utilized to analyse the data in this study.

4.3.1 VALENCE OF PERCEPTION IN THE STUDY SAMPLE

Hypothesis 1: To ascertain if individuals who perceived their epilepsy to be more severe and stigmatizing, had lower levels of perceived acceptance than those who had no such perceptions.

To assess the hypothesis, the researcher analysed the scores by means of the x^2 one sample test. This test determines attitude, either positive or negative, this is well documented by Siegel (1956: 42).

Formula:

$$X^2 = \sum_{i=1}^{k} \frac{(oi-ei)^2}{Ei}$$

$df = k-1$

Let $\alpha = 0,05$

Total score of cases: 4467

Mean: 44,67

A: Above $\bar{x}$ 44,67 (above mean): positive attitude

B: Below $\bar{x}$ 44,67 (below mean): negative attitude

Table 4.1: AVERAGE LEVELS

	Observed N (oi)	Expected N (ei)	Residual
A (above $\bar{x}$)	46	50,0	-4,0
B (below $\bar{x}$)	54	50,0	4,0
Total	100		

Table 4.2: TEST STATISTICS

	Average levels
Chi-Square*	, 640
Df	1
Asymp.Sig	, 424

* 0 cells (, 0%) have expected frequencies less than 5. The minimum expected cell frequency is 50,0.

INTERPRETATION

An x^2 value of 0,640 was obtained. A x^2 of 0,640, at df = 1, can occur by chance between 70 and 80 times in a hundred. It is therefore not significant at our chosen level of significance which, is 0,05. Since the obtained x^2 is larger than the previously set level of significance, we uphold the null hypothesis and conclude that amongst epileptics there is evidence of unfavourable perception towards epilepsy.

Hypothesis number one has been confirmed. Fifty-four per cent of the epileptics were negatively disposed towards epilepsy, whereas 46% were positively disposed. Therefore we can ascertain that, individuals who perceived their epilepsy to be more stigmatizing, had lower levels of acceptance than those who had no acceptance. This finding is supported by the studies mentioned in Chapter One. Epileptics are characterized by markedly negative perceptions of their disorder. Significant changes have taken place towards epileptics' perceptions of their condition. There has been a gradual decrease in negative perception, moving progressively towards a positive, favourable attitude towards epilepsy.

4.3.2 THE PSYCHOSOCIAL PROBLEMS ENCOUNTERED BY EPILEPTICS

The following hypotheses were formulated:

There will be no relationship between the psychosocial factors of epilepsy (namely, emotional, anxiety, self-esteem and social interaction, and cognitive-behavioural) and each of the following demographic variables:

- Age of the respondent
- Ethnic group of the respondent
- Home language of the respondent
- Educational level of the respondent
- Occupational level of the respondent

In the present study there are four psychosocial factors of epileptics' perception that are derived from the attitude scale, namely,

Factor A - emotional factors
Factor B - anxiety factors
Factor C - self-esteem and social interaction factor
Factor D -cognitive-behavioural

An ANOVA test was used to find out if there was a significant difference among the means of the four factors and the demographic variables. In order to draw a hierarchy of means, a post hoc test was done. The Tukey Test is a post hoc test designed to perform a comparison of the means to see where the significance lies. One only performs Tukey tests if one rejects the null hypothesis.

1. AGE

TABLE 4.3 ANOVA FOR AGE AND THE FOUR FACTORS DERIVED FROM THE SCALE

ANOVA : Age Group

		Sum of Squares	df	Mean Square	F	Sig.
Factor A	Between Groups	456.312	4	114.078	2.051	.093
	Within Groups	5284.438	95	55.626		
	Total	5740.750	99			
Factor B	Between Groups	25.352	4	6.338	.992	.416
	Within Groups	607.238	95	6.392		
	Total	632.590	99			
Factor C	Between Groups	140.462	4	35.115	1.798	.136
	Within Groups	1855.648	95	19.533		
	Total	1996.110	99			
Factor D	Between Groups	4.703	4	1.176	1.284	.282
	Within Groups	87.007	95	.916		
	Total	91.710	99			

INTERPRETATION

Using a one-way ANOVA, there were no differences found among the 4 factors ($p > 0,05$); we therefore uphold the null hypothesis and conclude there are no differences among the scores on any of the four factors A, B, C and D, in relation to age.

2. ETHNIC GROUP

TABLE 4.4 ANOVA FOR ETHNIC GROUPS AND THE FOUR FACTORS DERIVED FROM THE SCALE

ANOVA : Ethnic group

		Sum of Squares	df	Mean Square	F	Sig.
Factor A	Between Groups	195.233	3	65.078	1.127	.342
	Within Groups	5545.517	96	57.766		
	Total	5740.750	99			
Factor B	Between Groups	79.098	3	26.366	4.573	.005
	Within Groups	553.492	96	5.766		
	Total	632.590	99			
Factor C	Between Groups	185.232	3	61.744	3.273	.024
	Within Groups	1810.878	96	18.863		
	Total	1996.110	99			
Factor D	Between Groups	8.998	3	2.999	3.481	.019
	Within Groups	82.712	96	.862		
	Total	91.710	99			

Factor B ($F = 4,573$, $p < 0,05$)

Factor C ($F = 3,273$, $p < 0,05$)

Factor D ($F = 3,481$, $p < 0,05$)

This significant value indicates that there are differences among the means, but it does not determine where these differences lie, i.e., one cannot ascertain which factors significantly differ from each other. In order to determine differences in data lie, a post-hoc comparison was conducted. There are several of these but for this analysis, The Tukey Test will be used.

TABLE: 4.5 POST HOC TESTS

Multiple Comparisons

Dependent Variable: Factor B

Tukey HSD

(I) Respondent Ethnic Grouping	(J) Respondent Ethnic Grouping	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
African	Coloured	.75	.809	.791	-1.37	2.87
	Indian	1.33	.574	.103	-.17	2.83
	White	2.44*	.701	.004	.61	4.28
Coloured	African	-.75	.809	.791	-2.87	1.37
	Indian	.58	.850	.905	-1.65	2.80
	White	1.69	.940	.280	-.77	4.15
Indian	African	-1.33	.574	.103	-2.83	.17
	Coloured	-.58	.850	.905	-2.80	1.65
	White	1.12	.748	.446	-.84	3.07
White	African	-2.44*	.701	.004	-4.28	-.61
	Coloured	-1.69	.940	.280	-4.15	.77
	Indian	-1.12	.748	.446	-3.07	.84

*. The mean difference is significant at the .05 level.

TABLE 4.6 HOMOGENEOUS SUBSETS

Factor B

Tukey HSD[a,b]

Respondent Ethnic Grouping	N	Subset for alpha = .05	
		1	2
White	16	13.13	
Indian	29	14.24	14.24
Coloured	11	14.82	14.82
African	44		15.57
Sig.		.138	.328

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 18.992.

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

INTERPRETATION

A one-way between- the- groups analysis of variance was conducted to explore the impact of ethnic grouping on the psychosocial factor B (emotional factors). Subjects were divided into four groups according to their ethnic group (Group 1: African; Group 2: Coloured; Group 3: Indian; Group 4: White).

There was a statistically significant difference at the p<0,05 level for the four ethnic groups (F= 4,573, p= 0,005). Despite reaching statistical significance, the actual difference in mean scores between the groups was quite small. The effect size, calculated using eta squared, was 0,12. Post-hoc comparisons using the Tukey HSD test indicated that the mean score for Group 1 African (MD= 2.44) was significantly different from Group 4 White (MD= -2,44). Group 2 (Coloured) and Group 3 (Indian) did not differ significantly from either Group 1 or 3. Thus, there is a difference between Factor B (emotional factors) and between African and White ethnic groups.

4.7 POST HOC TESTS

Multiple Comparisons

Dependent Variable: Factor C

Tukey HSD

(I) Respondent Ethnic Grouping	(J) Respondent Ethnic Grouping	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
African	Coloured	.34	1.464	.996	-3.49	4.17
	Indian	1.86	1.039	.285	-.86	4.57
	White	3.72*	1.268	.022	.40	7.03
Coloured	African	-.34	1.464	.996	-4.17	3.49
	Indian	1.52	1.538	.757	-2.50	5.54
	White	3.38	1.701	.201	-1.07	7.82
Indian	African	-1.86	1.039	.285	-4.57	.86
	Coloured	-1.52	1.538	.757	-5.54	2.50
	White	1.86	1.353	.519	-1.68	5.39
White	African	-3.72*	1.268	.022	-7.03	-.40
	Coloured	-3.38	1.701	.201	-7.82	1.07
	Indian	-1.86	1.353	.519	-5.39	1.68

*. The mean difference is significant at the .05 level.

TABLE 4.8 HOMOGENEOUS SUBSETS

Factor C

Tukey HSD[a,b]

Respondent Ethnic Grouping	N	Subset for alpha = .05	
		1	2
White	16	16.63	
Indian	29	18.48	18.48
Coloured	11	20.00	20.00
African	44		20.34
Sig.		.085	.554

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 18.992.

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

INTERPRETATION

A one-way between- the- groups analysis of variance was conducted to explore the impact of ethnic grouping on the psychosocial factor C (self-esteem and social interaction). Subjects were divided into four groups according to their ethnic group (Group 1: African; Group 2: Coloured; Group 3: Indian; Group 4: White). There was a statistically significant difference at the p<0,05 level for the four ethnic groups (F= 3,273, p= 0,024).

Despite reaching statistical significance, the actual difference in mean scores between the groups was medium (Cohen, 1988). The effect size, calculated using eta squared, was 0,09. Post-hoc comparisons using the Tukey HSD test indicated that the mean score for Group 1 African (MD= 3,72) was significantly different from Group 4 White (MD= -3,72). Group 2 (Coloured) and Group 3 (Indian) did not differ significantly from either Group 1 or 3. Thus, there is a difference between Factor C (anxiety and cognitive factors) and between African and White ethnic groups.

TABLE 4.9 POST HOC TESTS

Multiple Comparisons

Dependent Variable: Factor D

Tukey HSD

(I) Respondent Ethnic Grouping	(J) Respondent Ethnic Grouping	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
African	Coloured	.59	.313	.240	-.23	1.41
	Indian	.51	.222	.103	-.07	1.09
	White	-.22	.271	.856	-.92	.49
Coloured	African	-.59	.313	.240	-1.41	.23
	Indian	-.08	.329	.995	-.94	.78
	White	-.81	.364	.125	-1.76	.14
Indian	African	-.51	.222	.103	-1.09	.07
	Coloured	.08	.329	.995	-.78	.94
	White	-.73	.289	.063	-1.48	.03
White	African	.22	.271	.856	-.49	.92
	Coloured	.81	.364	.125	-.14	1.76
	Indian	.73	.289	.063	-.03	1.48

TABLE 4.10 HOMOGENEOUS SUBSETS

Factor D

Tukey HSD[a,b]

Respondent Ethnic Grouping	N	Subset for alpha = .05	
		1	2
Coloured	11	5.82	
Indian	29	5.90	5.90
African	44	6.41	6.41
White	16		6.63
Sig.		.210	.080

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 18.992.

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

INTERPRETATION

A one-way between- the- groups analysis of variance was conducted to explore the impact of ethnic grouping on the psychosocial factor D (cognitive-behavioural). Subjects were divided into four groups according to their ethnic group (Group 1: African; Group 2: Coloured; Group 3: Indian; Group 4: White). There was a statistically significant difference at the p<0,05 level for the four ethnic groups (F= 3,481, p= 0,019).

Despite reaching statistical significance, the actual difference in mean scores between the groups medium (Cohen, 1988). The effect size, calculated using eta squared, was 0,098. Post-hoc comparisons using the Tukey HSD test indicated that the mean score for Group 1 African (MD= -0,22) was significantly different from Group 4 White (MD= 0,22). Group 2 (Coloured) and Group 3 (Indian) did not differ significantly from either Group 1 or 3.

3. HOME LANGUAGE

TABLE 4.11 ANOVA FOR HOME LANGUAGE AND THE FOUR FACTORS

ANOVA : Home Language

		Sum of Squares	df	Mean Square	F	Sig.
Factor A	Between Groups	177.724	4	44.431	.759	.555
	Within Groups	5563.026	95	58.558		
	Total	5740.750	99			
Factor B	Between Groups	53.286	4	13.322	2.185	.077
	Within Groups	579.304	95	6.098		
	Total	632.590	99			
Factor C	Between Groups	129.510	4	32.377	1.648	.169
	Within Groups	1866.600	95	19.648		
	Total	1996.110	99			
Factor D	Between Groups	5.917	4	1.479	1.638	.171
	Within Groups	85.793	95	.903		
	Total	91.710	99			

Table 4.14 indicated that there was no significant difference between the psychosocial factors and home language of the respondent; therefore the null hypothesis was upheld. Hence, a Tukey Test could not be performed, since this test is only performed if the null hypothesis is rejected.

4. EDUCATION

TABLE 4.12 ANOVA FOR EDUCATIONAL LEVELS AND THE FOUR FACTORS

ANOVA : Educational Levels

		Sum of Squares	df	Mean Square	F	Sig.
Factor A	Between Groups	733.547	5	146.709	2.754	.023
	Within Groups	5007.203	94	53.268		
	Total	5740.750	99			
Factor B	Between Groups	59.141	5	11.828	1.939	.095
	Within Groups	573.449	94	6.101		
	Total	632.590	99			
Factor C	Between Groups	405.141	5	81.028	4.787	.001
	Within Groups	1590.969	94	16.925		
	Total	1996.110	99			
Factor D	Between Groups	6.346	5	1.269	1.398	.232
	Within Groups	85.364	94	.908		
	Total	91.710	99			

Table 4.15 indicates that there is a significant difference with the educational level and Factor A ($F = 2,754$, $p<0,05$), and C ($F = 4,787$, $p < 0,05$). Thus we reject the null hypothesis and perform the Tukey Test in order to determine where the variance in the data lies.

Multiple Comparisons

Dependent Variable: Factor A

Tukey HSD

(I) RespondentEducationalevels	(J) RespondentEducationalevels	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
No schooling	Primay Education	2.83	3.164	.947	-6.38	12.03
	Secondary Education	6.54	3.331	.371	-3.15	16.23
	High school education	9.23	3.466	.093	-.86	19.31
	Post Matric	5.67	5.959	.932	-11.67	23.00
	University education	5.92	4.711	.808	-7.79	19.62
Primay Education	No schooling	-2.83	3.164	.947	-12.03	6.38
	Secondary Education	3.72	1.831	.334	-1.61	9.04
	High school education	6.40*	2.066	.030	.39	12.41
	Post Matric	2.84	5.269	.994	-12.49	18.17
	University education	3.09	3.801	.964	-7.97	14.15
Secondary Education	No schooling	-6.54	3.331	.371	-16.23	3.15
	Primay Education	-3.72	1.831	.334	-9.04	1.61
	High school education	2.68	2.314	.854	-4.05	9.41
	Post Matric	-.88	5.372	1.000	-16.50	14.75
	University education	-.63	3.942	1.000	-12.09	10.84
High school education	No schooling	-9.23	3.466	.093	-19.31	.86
	Primay Education	-6.40*	2.066	.030	-12.41	-.39
	Secondary Education	-2.68	2.314	.854	-9.41	4.05
	Post Matric	-3.56	5.456	.987	-19.43	12.31
	University education	-3.31	4.056	.964	-15.11	8.49
Post Matric	No schooling	-5.67	5.959	.932	-23.00	11.67
	Primay Education	-2.84	5.269	.994	-18.17	12.49
	Secondary Education	.88	5.372	1.000	-14.75	16.50
	High school education	3.56	5.456	.987	-12.31	19.43
	University education	.25	6.321	1.000	-18.14	18.64
University education	No schooling	-5.92	4.711	.808	-19.62	7.79
	Primay Education	-3.09	3.801	.964	-14.15	7.97
	Secondary Education	.63	3.942	1.000	-10.84	12.09
	High school education	3.31	4.056	.964	-8.49	15.11
	Post Matric	-.25	6.321	1.000	-18.64	18.14

*. The mean difference is significant at the .05 level.

INTERPRETATION

A one-way between- the- groups analysis of variance was conducted to explore the impact of educational level on the psychosocial factor A (emotional aspects). Subjects were divided into six groups according to their educational group (Group 1: No Schooling; Group 2: Primary Education; Group 3: Secondary Education; Group 4: High School Education; Group 5: Post Matric; Group 6: University Education). There was a statistically significant difference at the p<0,05 level for the six educational levels (F= 2,754, p= 0,023).

Despite reaching statistical significance, the actual difference in mean scores between the groups was quite small. The effect size, calculated using eta squared, was 0,127. Post-hoc comparisons using the Tukey HSD test indicated that the mean score for Group 2 Primary Education (MD= 6,40) was significantly different from Group 4 High School Education (MD= -6,40). The other groups (Group 1,3,5 and 6) did not differ significantly from either Group 2 or 4.

TABLE 4.13 POST HOC TESTS

Multiple Comparisons

Dependent Variable: Factor C

Tukey HSD

(I) RespondentEducational levels	(J) RespondentEducational levels	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
No schooling	Primay Education	2.24	1.784	.809	-2.95	7.43
	Secondary Education	4.96	1.878	.098	-.50	10.42
	High school education	6.89*	1.954	.008	1.21	12.58
	Post Matric	2.33	3.359	.982	-7.44	12.11
	University education	5.08	2.656	.400	-2.64	12.81
Primay Education	No schooling	-2.24	1.784	.809	-7.43	2.95
	Secondary Education	2.72	1.032	.099	-.28	5.72
	High school education	4.65*	1.164	.002	1.27	8.04
	Post Matric	.10	2.970	1.000	-8.55	8.74
	University education	2.85	2.143	.769	-3.39	9.08
Secondary Education	No schooling	-4.96	1.878	.098	-10.42	.50
	Primay Education	-2.72	1.032	.099	-5.72	.28
	High school education	1.93	1.304	.676	-1.86	5.73
	Post Matric	-2.63	3.028	.953	-11.43	6.18
	University education	.13	2.222	1.000	-6.34	6.59
High school education	No schooling	-6.89*	1.954	.008	-12.58	-1.21
	Primay Education	-4.65*	1.164	.002	-8.04	-1.27
	Secondary Education	-1.93	1.304	.676	-5.73	1.86
	Post Matric	-4.56	3.075	.676	-13.51	4.39
	University education	-1.81	2.286	.968	-8.46	4.84
Post Matric	No schooling	-2.33	3.359	.982	-12.11	7.44
	Primay Education	-.10	2.970	1.000	-8.74	8.55
	Secondary Education	2.63	3.028	.953	-6.18	11.43
	High school education	4.56	3.075	.676	-4.39	13.51
	University education	2.75	3.563	.972	-7.62	13.12
University education	No schooling	-5.08	2.656	.400	-12.81	2.64
	Primay Education	-2.85	2.143	.769	-9.08	3.39
	Secondary Education	-.13	2.222	1.000	-6.59	6.34
	High school education	1.81	2.286	.968	-4.84	8.46
	Post Matric	-2.75	3.563	.972	-13.12	7.62

*. The mean difference is significant at the .05 level.

TABLE 4.14 HOMOGENEOUS SUBSETS

Factor C

Tukey HSD[a,b]

RespondentEducational levels	N	Subset for alpha = .05
		1
High school education	17	15.94
University education	4	17.75
Secondary Education	24	17.88
Post Matric	2	20.50
Primay Education	47	20.60
No schooling	6	22.83
Sig.		.059

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 5.778.

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

A one-way between- the- groups analysis of variance was conducted to explore the impact of educational level on the psychosocial factor C (self-esteem and social interaction). Subjects were divided into six groups according to their educational level (Group 1: No Schooling; Group 2: Primary Education; Group 3: Secondary Education; Group 4: High School Education; Group 5: Post Matric; Group 6: University Education).

There was a statistically significant difference at the p<0,05 level for the six educational levels (F= 4,787, p= 0,001). Despite reaching statistical significance, the actual difference in mean scores between the groups was quite small. The effect size, calculated using eta squared, was 0,202. Post-hoc comparisons using the Tukey HSD test indicated that the mean score for Group 1: No schooling (MD= 6,89) was significantly different from Group 4: High School Education (MD= -6,89). The mean score for Group 2: Primary Education (MD= 6,65) was statistically different from Group 4: High School Education (MD= -4,65). There were no further differences between the other groups.

5. OCCUPATIONAL LEVELS

TABLE 4.15 ANOVA FOR OCCUPATIONAL LEVELS AND THE FOUR FACTORS

ANOVA : Occupational levels

		Sum of Squares	df	Mean Square	F	Sig.
Factor A	Between Groups	1595.166	2	797.583	18.662	.000
	Within Groups	4145.584	97	42.738		
	Total	5740.750	99			
Factor B	Between Groups	42.965	2	21.483	3.534	.033
	Within Groups	589.625	97	6.079		
	Total	632.590	99			
Factor C	Between Groups	522.080	2	261.040	17.178	.000
	Within Groups	1474.030	97	15.196		
	Total	1996.110	99			
Factor D	Between Groups	.725	2	.362	.386	.681
	Within Groups	90.985	97	.938		
	Total	91.710	99			

Table 4.20 indicates that there is a significant difference between the occupational level of the respondent and Factor A (F = 18,662, p < 0,05); Factor B (F = 3,534, p < 0,05), and Factor C (F = 17,178, p < 0,05). We therefore reject the null hypothesis and conduct the Tukey Test in order to determine where the differences lie.

TABLE 4.16 POST HOC TESTS

Multiple Comparisons

Tukey HSD

Dependent Variabl	(I) RespondentOccupatior	(J) RespondentOccupatio	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
						Lower Bound	Upper Bound
Factor A	State employed	Unemployed	-8.06*	1.371	.000	-11.32	-4.79
		Self-Employed	.62	3.441	.982	-7.57	8.81
	Unemployed	State employed	8.06*	1.371	.000	4.79	11.32
		Self-Employed	8.68*	3.378	.031	.64	16.72
	Self-Employed	State employed	-.62	3.441	.982	-8.81	7.57
		Unemployed	-8.68*	3.378	.031	-16.72	-.64
Factor B	State employed	Unemployed	-1.00	.517	.136	-2.23	.23
		Self-Employed	1.69	1.298	.398	-1.40	4.78
	Unemployed	State employed	1.00	.517	.136	-.23	2.23
		Self-Employed	2.69	1.274	.093	-.35	5.72
	Self-Employed	State employed	-1.69	1.298	.398	-4.78	1.40
		Unemployed	-2.69	1.274	.093	-5.72	.35

*. The mean difference is significant at the .05 level.

TABLE 4.17 HOMOGENEOUS SUBSETS

Factor A

Tukey HSD[a,b]

RespondentOccupation	N	Subset for alpha = .05	
		1	2
Self-Employed	4	22.00	
State employed	37	22.62	
Unemployed	59		30.68
Sig.		.975	1.000

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 10.205.

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Factor B

Tukey HSD[a,b]

RespondentOccupation	N	Subset for alpha = .05	
		1	2
Self-Employed	4	12.50	
State employed	37	14.19	14.19
Unemployed	59		15.19
Sig.		.273	.633

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 10.205.

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

A one-way between- the- groups analysis of variance was conducted to explore the impact of occupation on the psychosocial Factors A and B. Subjects were divided into three groups according to their level of occupation (Group 1: State employed; Group 2: Unemployed, and Group 3: self-employed). There was a statistically significant difference at the p<0,05 level for the three occupational levels, Factor A: (F= 18,662, p= 0,00); Factor B: (F= 3,534, p= 0,033). Despite reaching statistical significance, the actual difference in mean scores between the groups was quite small. The effect size for Factor A, calculated using eta squared, was 0,277. The effect size for Factor B, was 0,067. Post-hoc comparisons using the Tukey HSD test indicated that the mean score for Group 1: State Employed (MD= -8,06) was significantly different from Group 2: Unemployed (MD= 8,06) and Group 3: self-employed (MD= -8,68).

TABLE 4.18 ONE WAY ANOVA WITH TUKEY

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
Factor C	Between Groups	522.080	2	261.040	17.178	.000
	Within Groups	1474.030	97	15.196		
	Total	1996.110	99			
Factor D	Between Groups	.725	2	.362	.386	.681
	Within Groups	90.985	97	.938		
	Total	91.710	99			

Multiple Comparisons

Tukey HSD

Dependent Var	(I) RespondentOccu	(J) RespondentOccu	Mean ifference (I-J)	td. Erro	Sig.	5% Confidence Interv ower Boun	pper Boun
Factor C	State employed	Unemployed	-4.40*	.817	.000	-6.35	-2.46
		Self-Employed	1.90	2.052	.626	-2.99	6.78
	Unemployed	State employed	4.40*	.817	.000	2.46	6.35
		Self-Employed	6.30*	2.014	.007	1.51	11.09
	Self-Employed	State employed	-1.90	2.052	.626	-6.78	2.99
		Unemployed	-6.30*	2.014	.007	-11.09	-1.51
Factor D	State employed	Unemployed	-.14	.203	.782	-.62	.35
		Self-Employed	-.36	.510	.755	-1.58	.85
	Unemployed	State employed	.14	.203	.782	-.35	.62
		Self-Employed	-.23	.500	.891	-1.42	.96
	Self-Employed	State employed	.36	.510	.755	-.85	1.58
		Unemployed	.23	.500	.891	-.96	1.42

*.The mean difference is significant at the .05 level.

TABLE 4.19 HOMOGENEOUS SUBSETS

Factor C

Tukey HSD[a,b]

RespondentOccupation	N	Subset for alpha = .05 1	2
Self-Employed	4	14.75	
State employed	37	16.65	
Unemployed	59		21.05
Sig.		.516	1.000

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 10.205.

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Factor D

Tukey HSD[a,b]

RespondentOccupation	N	Subset for alpha = .05
		1
State employed	37	6.14
Unemployed	59	6.27
Self-Employed	4	6.50
Sig.		.672

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 10.205.

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

A one-way between- the- groups analysis of variance was conducted to explore the impact of occupational levels on Factor C (self-esteem and social interaction). Subjects were divided into three groups according to their occupational group (Group 1: State employed; Group 2: Unemployed, and Group 3: self-employed). There was a statistically significant difference at the p<0,05 level for the three occupational levels, Factor C (F= 17,178, p=0,000) Despite reaching statistical significance, the actual difference in mean scores between the groups was quite small. The effect size for Factor C, calculated using eta squared, was 0,26. Post-hoc comparisons using the Tukey HSD test indicated that the mean score for Group 1: State Employed (MD= -4,40) was significantly different from Group 2: Unemployed (MD= 4,40). Group 3 (MD= -6,30) was significantly different from Group 2 (MD= 6,30).

CONCLUSION

A one-way between the groups analysis of variance was conducted to explore the impact of the various demographic variables (age, ethnic group, home language, educational level and occupation) on the different psychosocial factors. The Tukey Test was used and the results revealed that there was a statistically significant relationship between:

(i) Ethnic group and Factors B, C, D

(ii) Education and Factors A and C

(ii) Education and Factors A and C

(iv) Occupation and Factors A, B, C

4.3. SIGNIFICANCE OF AGREEMENT AMONG RANKS ASSIGNED TO EPILEPTICS' RECOMMENDATIONS

Hypothesis: 3

There will be no differences in the way epileptics' perceive, their various recommendations.

(i) I would be more content if I had people to provide me with information on epilepsy, e.g. Pastor, nurse, counsellor, etc.

(ii) I would be happier if I had easier access to my epilepsy medication.

(iii) There are not enough opportunities for work-training people with epilepsy.

(iv) There are not enough facilities for work training people with epilepsy.

(v) There are not enough training centres for work-training people with epilepsy.

Here the researcher wanted to find out whether there was any agreement among the five ranks assigned by 100 epileptics in accordance with their personal recommendations. In other words, the respondents act as judges. The questions were : Are the judges basing their judgement of the five types of personal recommendations on the same criterion? In other words, is there any correlation in the judgement of the 100 respondents?

At this juncture, the researcher dealt with ordinal data and subsequently used statistical tests of ordinal strength. The problem of determining the degree of correspondence among the ratings of the same five types of recommendation by 100 respondents requires the use of Kendall's Coefficient of Concordance W (Siegel, 1956:229). This test measures the association among several ranks.

Formula:

$$W = \frac{S}{1/12\ k^2\ (N^3-N)}$$

(See Table 4.8, page 154)

K= No of respondents: 100

N= No of columns: 5

Table 4.20: Calculation of Kendall W

Formula	Q.15.1	Q.15.2	Q.15.3	Q.15.4	Q.15.5
Rj	194	321	187	345	453
ΣRj / N	300	300	300	300	300
Rj – Rj/N	106	21	113	45	153
(Rj- Rj/N)²	11236	441	12769	2025	23409

ΣRj = 1500

$\Sigma (Rj - \frac{Rj}{N})^2 = S = \underline{49,880}$

$$W = \frac{S}{1/12\ k^2\ (N^3-N)}$$

$$W = \frac{49880}{1/12\ (100)^2\ [(5)^3 - 5)]}$$

$$= 0,4988$$

Conversion of W to x^2 (Siegel, 1956:236)

$x^2 = k\ (N-1)\ W$

$= 100\ (5-1)\ 0,498$

$= 400\ (0,498)$

$= \underline{199,5}$

$df = N-1$

$= 4$

and Let $\alpha = 0,05$

INTERPRETATION

A x^2 value of 1,96 at df = 4 is significant at the 0,05 level and conclude that epileptics ratings are related, i.e., there was agreement among the ranks assigned by the epileptics.

Hypothesis number 3 was confirmed. Epileptics' recommendations were the same. The agreement assigned to the five categories of recommendations illustrated that respondents have similar needs and preferences. This point is further explained under the heading "Discussion", to follow.

4.4.4. THE RELATIONSHIP BETWEEN DIFFERENT DEMOGRAPHIC VARIABLES AND PERCEPTION

Hypothesis: 4

There will be no significant relationship between the following variables and perception of epilepsy:

- Age of the respondent
- Gender of the respondent
- Ethnic group of the respondent
- Home language of the respondent
- Educational level of the respondent
- Occupational level of the respondent

4.4.4.1 The relationship between the variable of age and perception of epilepsy.

A test suitable for testing for the significance of differences among three or more unrelated groups is the x^2 test for k independent samples described by Siegel (1956:175).

Table 4.21

	PERCEPTION		
Age	Positive	Negative	Total
20 and under	10	3	13
21-30	8	13	21
31-40	8	12	20
41-50	11	18	29
50 and above	9	8	17
Total	46	54	100

INTERPRETATION

A x^2 value of 6,912 was obtained. A x^2 value of 6,912 at df = 4 can occur by chance between 10 and 20 times in a hundred. It is therefore not significant at the chosen level of significance, i.e., 0,05. Since p > 0,05, the researcher accepts the null hypothesis and concludes that there is no relationship between the age of the respondent and their perception of epilepsy.

Table 4.22

Chi-Square Tests

	Value	Df	Asymp.Sig. (2-sided)
Pearson Chi-Square	6,912*	4	,141

* 0 cells (,0%) have expected count less than 5. The minimum expected count is 5,98.

According to Siegel (1956: 198) Contingency Coefficient : C can be used to test for the degree of association (if any) between the age of the respondents and perception of epilepsy.

Formula:

$$C = \frac{\sqrt{x^2}}{\sqrt{N + x^2}}$$

$$= \frac{6,912}{100 + 6,912}$$

$$= 0,064$$

The correlation between age of the respondent and perception of epilepsy is expressed by a very low coefficient, i.e. 0,064. The x^2 value of 6,912 associated with a contingency coefficient of 0,064 at df = 4 appears on the level of significance higher than the chosen level of significance, which is 0,05. The null hypothesis is therefore accepted.

4.4.4.2 The relationship between the variable of gender and perception of epilepsy.

At this point, the researcher wanted to ascertain whether there was any connection between the gender of respondents and perception of epilepsy. The assumption was that the two groups, namely male and female epileptics, were drawn from a homogeneous population in which attitudinal tendencies towards epilepsy are distributed in accordance with the principles of the normal probability curve.

Table 4.23

	PERCEPTION		
Gender	Positive	Negative	Total
Males	15	19	34
Females	31	35	66
Total	46	54	100

Table 4.24 Chi-Square Test

	Value	Df	Asym.Sig (2-sided)
Pearson Chi-Square	,73*	1	,786

* 0 cells (,0%) have expected count less than 5. The minimum expected count is 15,64.

INTERPRETATION

A x^2 value of 0,73 at df = 1 can occur by chance between 70 and 80 times in a hundred. It is therefore not significant at the chosen level of significance, i.e., 0.05. The observed value of x^2 is thus an element of the acceptance region and consequently the null hypothesis of independence of gender and perception is accepted. Since p > 0,05, the researcher concluded that the variable of gender is not associated with epileptics' perception of epilepsy. Perception and gender are independent of each other. Male and female epileptics display a similar attitude towards epilepsy.

The degree of association (if any) between the variable of gender and perception may be tested by applying the following formula (Siegel, 1956: 198)

Formula:

$$C = \sqrt{\frac{x^2}{N + x^2}}$$

$$= \frac{\sqrt{,73}}{\sqrt{100 +, 73}}$$

$$= 0{,}0072$$

There is absolutely no evidence to conclude that there is any association between the two variables, viz., gender and perception, in the population from which our sample was drawn. There is no evidence of any correlation between gender and perception.

4.4.4.3 The relationship between the variable of ethnic grouping and perception of epilepsy.

In establishing whether a relationship existed between ethnicity and perception, the x^2 test for k independent samples described by Siegel (1956:176) was utilized.

Table 4.25

PERCEPTION

Ethnic group	Positive	Negative	Total
African	23	21	44
Indian	13	16	29
White	4	12	16
Coloured	6	5	11
Total	46	54	100

Table 4.26

Chi-Square Tests

	Value	Df	Asymp. Sig (2-sided)
Pearson Chi-Square	3,877*	3	,275

- 0 cells (,0%) have expected count less than 5. The minimum expected count is 5,06.

INTERPRETATION

A x^2 value of 3,877 was obtained. A x^2 of 3,877 at df = 3 is not significant at the 0,05 level. But, x^2 occurred by chance between 20 and 30 times in a hundred. Since p > 0,05, the null hypothesis was accepted. So, there is no relationship between an epileptics' ethnic group and perception of epilepsy, i.e., different ethnic groups do not influence an epileptics' perception of epilepsy. Again, the degree of association (if any) between ethnic group and perception of epilepsy can be tested by applying the following formula (Siegel, 1956: 198)

Formula:

$$C = \frac{\sqrt{x^2}}{\sqrt{N + x^2}}$$

$$C = \frac{\sqrt{3,877}}{\sqrt{100 + 3,877}}$$

$$= 0.037$$

4.4.4.4 The relationship between the variable home language and perception of epilepsy.

Table 4.27

PERCEPTION

Language	Positive	Negative	Total
European	24	33	57
African	22	21	43

Table 4.28

Chi-Square Tests

	Value	Df	Asymp. Sig
Pearson Chi-Square	2,427	1	,658

INTERPRETATION

A x^2 value of 2,427 was obtained. A x^2 value of 2,427 at df = 1 can occur by chance between 70 and 80 times in a hundred. Since p > 0,05, the null hypothesis is accepted. Therefore, there is no relationship between home language and perception of epilepsy. Chi-Square test is not significant, this test was suspect ("illegal") since cells had small Expected count.

$$C = \frac{\sqrt{x^2}}{\sqrt{N + x^2}}$$

$$= \frac{\sqrt{2,427}}{\sqrt{100 + 2,427}}$$

$$= 0,023$$

The obtained coefficient is very low. This indicates that the home language of the respondent does not influence his/her perception of epilepsy. The effect of home language on the perception of epilepsy is very weak. The finding indicates that there is no relationship between the variable home language and perception of epilepsy.

4.4.4.5 The relationship between the variable marital status and perception of epilepsy.

Table 4.29

	PERCEPTION		
Marital status	Positive	Negative	Total
Single	23	22	45
Married/cohab	5	20	25
Divorced	10	6	16
Widowed	8	6	14
Total	46	54	100

Table 4.30

Chi-Square Tests

	Value	Df	Asymp. Sig
Pearson Chi-Square	10,497*	3	0,33

INTERPRETATION

A x^2 value of 10,497 at df = 3 is less than the chosen level of significance, i.e., $p < 0,05$, the null hypothesis and conclude that there is a significant relation between the respondent's marital status and perception of epilepsy.

4.4.4.6 The relationship between the variable educational level and perception of epilepsy.

A test suitable for testing for the significance of differences among three or more unrelated groups is the x^2 test for k independent samples described by Siegel (1956: 175).

Table 4.31

	PERCEPTION		
Education	Positive	Negative	Total
No schooling	4	2	6
Primary	28	19	47
Secondary	8	16	24
High School*	3	14	17
Total	46	54	100

*includes high school and beyond

Table 4.32

Chi-Square Tests

	Value	Df	Asymp. Sig (2- sided)
Pearson Chi- Square	11,609*	4	,041

INTERPRETATION

An x^2 value of 11,609 was obtained. An x^2 value of 11,609 at df = 4 is less than the chosen level of significance, i.e., $\alpha = 0,05$. The null hypothesis was rejected the alternate hypothesis accepted. Therefore, there is an association between the respondent's level of education and perception of epilepsy. Contingency Coefficient: C was used (Siegel, 1956: 198). Three cells had to be combined (i.e. high school, post matric and university education) since 6 cells had an expected count less than 5.

Formula:

$$C = \frac{\sqrt{x^2}}{\sqrt{N + x^2}}$$

$$= \frac{11,609}{100 + 11,606}$$

$$= 0,104$$

The correlation between educational level and perception of epilepsy is expressed by a very low coefficient, i.e., 0,10. The x^2 value of 11,609 associated with a contingency coefficient of 0,104 at df = 5 appears on the level of significance, which is lower than the chosen level of significance, which is 0,05. The null hypothesis is rejected.

Studies reveal that an increase in the number of years of education of the test subject is accompanied by an increase in negative attitudes towards members of a minority group (Strabo, 1970; Thorson, 1975). Thorson (1975) found that the attitude of a combined group of practitioners, university students, and high school students was influenced by the number of years of education. So, this research shows that there is a relationship between one's level of education and rejection of stereotypes towards epilepsy.

4.4.4.7 The relationship between the variable occupation and perception of epilepsy.

Table 4.33

	PERCEPTION		
Occupation	Positive	Negative	Total
Employed	6	35	41
Unemployed	40	19	59
Total	46	44	100

Table 4.34 Chi-square tests

	Value	Df	Asymp. Sig (2- sided)
Pearson Chi- Square	27,715*	1	,34

* 2 cells (33,3%) have expected count less than 5. The minimum expected count is 1,84.

INTERPRETATION

A x^2 value of 27,715 at df = 1 is less than the chosen level of significance, i.e. $p < 0,05$, the null hypothesis is accepted. Accordingly, there is no association between the respondent's occupation and perception of epilepsy. The above statistical analysis reveals that the respondent's educational level and marital status are significantly related to perception of epilepsy

4.5 DISCUSSION OF FINDINGS

The aim of this study was to identify how epileptics perceive their condition. Three basic problem areas emerged from the data that the individual has to deal with in relation to living with epilepsy. These are:

(i) Dealing with the psychosocial symptoms of epilepsy

(ii) Dealing with their personal reactions to epilepsy

(iii) Dealing with the reactions of the surroundings.

These perceptions involve how an individual interprets the situation with seizures and their consequences. It is clear from the data that perception is dependent on educational qualifications, i.e. the more educated the respondent was, the more negative they viewed their status. It has also been argued in the literature that there were many patients who had little or no social support network. Another interesting finding was that the patients with a higher educational level were more likely to conceal their status. Surprisingly the analysis of the data revealed that there are still negative stereotypes around epilepsy. Therefore it would appear that patients would benefit greatly from being aware a variety of coping strategies, and how to benefit from them.

This study also proposed to find answers to the following questions:

(i) The nature of epileptics' self-perception.

(ii) The relationship between the perception of epileptics and their psychosocial problems.

(iii) The attributes of epileptics' recommendations

(iv) The relationship between perception of epileptics and the following variables in respect of the respondent:

(a) Age

(b) Gender

(c) Ethnic grouping

(d) Home language

(e) Marital status

(f) Educational level

(g) Occupation

In response to the above questions, the study revealed the following:

Epileptics are unfavourably disposed towards their condition. Hence hypothesis number one has been confirmed. What accounts for these negative perceptions? Studies in Chapter One revealed that the social position of epileptics is often characterized by rejection, discrimination, and even ostracism (Hopkins, 1984; Collings, 1990; Jillek-Aall et al., 1997). Such negative and judgemental perceptions towards epileptics are rooted in erroneous beliefs about the causes and nature of convulsive disorders.

If the above assertion is true, then it stands to reason that a decrease in prejudice and stigma towards epileptics will increase an individual's self-esteem and self-efficacy. Epilepsy is a stigmatizing disorder, in which many patients develop what Scambler and Hopkins (1986) describe as a deep sense of 'ontological inferiority.' In the present study, it is clear that many respondents view epilepsy as stigmatizing, therefore they are negatively inclined towards the disorder. This finding corresponds with that of Blaxter (1976), who believed that the burden of the diagnosis of epilepsy and its uncertainty would always prevail.

In response to question two, hypothesis number 2 has been confirmed. Results indicated that there was a significant relationship among the various psychosocial factors and the demographic variables of the study. The psychosocial factors were divided into the four categories i.e.,

(i) Factor A -emotional factors
(ii) Factor B -anxiety factors
(iii) Factor C -self-esteem and social interaction
(iv) Factor D -cognitive-behavioural

No significant differences existed among the variables age and home language, and the four psychosocial factors. However differences existed between ethnic group, education and occupation with the psychosocial factors.

Thus, the null hypothesis was rejected since significant differences between the various factors were obtained. These findings were further analysed using the post-hoc Tukey test and it was found that significant differences between the means of the following factors existed:

- Ethnic group and Factors B, C and D
- Education and Factors A and C
- Occupation and Factors A, B, and C

These results suggest that epileptics endure endless psychological and emotional trauma as well as stigmatization. Similar findings were obtained by Lai et al. (1990) in a study of psychosocial attitudes amongst epileptics in China. Support for this argument has been provided by Kemp et al. (1999), who argue that the diagnosis of epilepsy has a high risk for psychological disorder. Similar findings were obtained by Anderson and Bury (1988) who argued that, for many people, it is the psychological problems encountered by epileptics that are its most distressing aspects. Arnston et al. (1986) concluded that psychosocial indices such as stigma, helplessness, self-esteem and life satisfaction were more closely related to individuals' perceptions of how severely their seizures affected their lives, than actual seizure frequency.

These findings are consistent with recent studies undertaken by Britten at al. (1986) and Thompson and Oxley (1989). Their findings demonstrated that a majority of individuals experienced distress in a number of areas. The extent to which such individuals worried about their epilepsy was related their self-esteem, social interaction, emotional distress and feelings of stigmatization.

To suffer from epilepsy in Africa often means to also suffer from a very specific psychological and social trauma (Billington, 1968; Dada & Odeku, 1966; Jilek-Aal & Jilek, 1989; Orley, 1970). The label 'epileptic,' drastically changes the way a person perceives life, and his or her position within the family unit.

The hypothesis that epileptics perceive various recommendations in the same way, did not receive confirmation. There was no agreement among ranks assigned by epileptics to their recommendations. The above finding shows that individuals

perceive their epileptic condition differently. This accounts for variation in ranks assigned to different types of epileptics' recommendations in this study. Hypothesis number 4 did receive a positive confirmation. Although an association was found between the educational level and perception of epilepsy; this relationship is very weak. This association is expressed by a correlation coefficient of 0,104, which is a very low correlation coefficient. However, it should be pointed out that coefficients of correlation are erratic.

A correlation coefficient increases with sample size (Morgan, King and Robinson, 1979). If the sample size increases the correlation coefficient will be higher than the obtained coefficient. Studies in psychology illustrate that there is a relationship between educational level and rejection of stereotypes (Strabo, 1970; Thorson, 1975).

The findings, according to educational levels, were discrepant with those of other studies. Educational levels and vocation have previously reported to be strongly related to knowledge of epilepsy (Tekle-Haimanpot, Aebe, Forsgren, Gebre-Mariam, Heijbel, Holgren & Ekstedt, 1991; Jensen & Dam, 1992). In the Tekele-Haimanot et al., (1991) study in Ethiopia, 1,4% of the sample was reported to have a secondary school level of education. These researchers further reported that 98% of the respondents had stated that epilepsy was a contagious disease and that contact with an epileptic patient during a seizure would result in the transfer of the condition.

In a community-based study amongst teachers' perception in Nigeria, Ojinnaka (2002: 386-91) made the following findings. The social problems encountered by schoolchildren with epilepsy as a result of negative attitudes and beliefs are enormous. Varying reports on teachers' perception of epilepsy abound. Furthermore previous research has shown that urbanization and differences in socio-cultural environments could also influence teachers' perception of epilepsy. A few studies have explored the knowledge, attitude and beliefs of schoolteachers towards epilepsy in urban schools in Nigeria. This study was undertaken to examine teachers' perception of epilepsy in the rural communities with regards to knowledge, attitude and beliefs. A cross-sectional survey, using a self-administered questionnaire, was carried out among rural community primary and secondary schoolteachers in schools randomly selected from three local government areas in Enugu. One hundred and twenty five teachers correctly completed their questionnaires. Despite a

fairly high level of education of the teachers, the mean overall score for correct response for knowledge was 59.2%. A majority of the teachers had negative attitudes and beliefs. None had received any form of health education on epilepsy. The level of education significantly affected various aspects of knowledge, attitudes and beliefs. This study concluded that paucity of good knowledge of epilepsy probably resulted in negative attitude and beliefs despite the teachers' high level of education.

In the study by Jensen and Dam (1992) among the Danish public, it was reported that there was a significant correlation between the educational level of the respondent and the acquaintance with epilepsy ($p<0,01$), which they used as an index of knowledge of their condition. The researchers argued that education of the respondents allowed them to read and acquire systematic information about the condition. In the context of the Western – dominated educational model in Denmark, epilepsy was depicted as a disease and therefore was treatable.

In the study by Gambhir, Kumar, Singhi and Goel (1995), urban and rural subjects' responses to a questionnaire assessing attitudes towards epilepsy were investigated. When groups' responses were analysed together, lower education and a lower level of occupation showed significant correlation with negative attitude towards epilepsy ($p<0,01$)

In the present study no relationship was found between age and perception of epilepsy. The majority of the study sample (30%) was found to be in the 41-50 year age range, with the minority (14%) being in the age group of 20 and below. In a study by Mason, Fenton and Jamieson (1990), in which they investigated the teaching of medical students about epilepsy, the age range of their sample was found to be 18 to 26 years. Many of the findings in this study are generic to all groups with epilepsy regardless of ethnicity or gender.

In contrast, Rwiza, Matuja, Kilonzo, Haule, Mbena, Mwang'ombolo and Jilek-Aall (1993) included respondents between the ages of 15 and 90 years in their study. Similarly, Chung, Chang, Lai and Lai (1995) included subjects ranging in age between 15 and 91 years in their study. Thus, there appears to be a strong basis for comparability of findings obtained in the present study with those reported in the studies above. It may

be then that such similarity in findings may be attributable to the age range of the sample in the present study and their status as epileptics.

This study reveals that there is no relationship between gender and perception of epilepsy. Perception of epilepsy is independent of one's sex. In the present study there were 68% of female respondents and 32% of male respondents. This statistic is an indication that female respondents are keen to seek assistance and support rather than their male counterparts. The findings according to gender distribution were discrepant with some studies and yet similar in other studies. In the Mason et al., (1990) study there was a relatively equal gender representation with 58% reported to be male and 42% reported to be male. However, in the study by Mielke, Adamolekun, Ball and Mundana (1997), the majority of their sample was represented by females (64,2%), while in the study by Kankirawatana (1999), there was also a preponderance of females in the study sample, with 94% constituted by this gender. What accounts for the lack of differences between genders? The researcher is of the opinion that biological differences cannot be potent factors in determining attitudes and perceptions. Attitudes are acquired; they are not innate. The foundations of attitudes may be traced to developmental trends of early childhood training. Factors such as education, geographical area, socio-economic status serves to modify attitudes and perceptions that were inculcated in early childhood.

This study reveals that there is no relationship between ethnic group and perception of epilepsy. A majority of respondents (46%) were African, 29% of respondents were Indian, 14% of respondents were White, and a minority (11%), of the respondents were Colored. The findings of the study with regard to ethnicity are consistent with the findings from previous studies conducted in South Africa (Ramdas, 2001; Perflie, 1997; Ratele, 1996). As indicated by Ramdas (2001), in his study on the knowledge, attitudes and perceptions of epilepsy, a majority of his sample comprised of African university students (43%), followed by Indian students (39%).

These findings probably reflect the socialization process that is presently occurring in South Africa, whereas previously disadvantaged groups (Africans) were denied access to health care facilities. The high proportion of African respondents could also be due to

the geographical region of the hospital. It is situated south of Kwa Zulu Natal, where the majority of the population comprises of African.

The relationship between language and perception of epilepsy was found to be non-existent. With respect to language, English was the language spoken by the majority (54%) of the respondents' 31% of respondents home language was Isizulu, 10% of respondents' home language was Xhosa, and 3% of the respondents' home language was Vernacular.

The current study revealed that there was a relationship between marital status and perception of epilepsy. A majority of the sample were single (46%), 23% of the respondents were married, 14% were divorced and widowed, and 3% of the respondents were living with their partner.

Results from the present study indicate the status of the respondents- they are either divorced or single. Previous research has indicated that there is sufficient evidence to conclude that individuals afflicted with epilepsy are less likely to marry and have children (Jacoby, 1992: 658-663). This evidence is further supported by an exploratory study on psychosocial problems experienced by epileptics in Cape Town (Perfile, 1994). In the study Perfile (1994), found an overwhelming 85% of participants were unmarried.

There are many possible reasons for being divorced or unmarried. Low levels of confidence and self-esteem amongst respondents; overprotection on the part of the respondents' family, and social isolation which restricts an individual's socialization are the primary factors which could have contributed to the high level of epileptics being unmarried or divorced. (Lectenberg, 1984; Dansky, Andermann. E, and Andermann, F., 1980). Baker, Buck and Jacob (1999) identified a similar high level of unmarried individuals in their study. The reasons they postulated for this high rate is that epileptics restrict social support network to family, neighbours, and health-care givers, and rely less on friends and work associates. As a result, rejection by loved ones, may be the contributing factor to an epileptic sufferer being either divorced or unmarried (Hills & Baker, 1992).

The overall rate of marriage amongst respondents in the current study was similar to that found among a group of individuals with severe epilepsy, where it was 42% (Collings, 1990: 418-426), but somewhat lower among disabled people in the Office for Population, Census and Statistics (OPCS) survey (53%).

The study reveals that there is no relationship between the occupation of the respondent and perception of epilepsy. According to the present study, 57% of respondents were unemployed, 40% of respondents were state-employed, and 3% of the respondents were self-employed.

The findings in the present study reflect a high rate of unemployment of individuals with epilepsy. This finding corresponds with a study conducted by Perfile (1994). Findings indicated that a staggering 90% of the epileptic respondents were unemployed. 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 (40%) 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 related to the findings cited in two other Cape Town hospitals. The unemployment figure in a sample of mainly so-called Coloured (65% of the sample) and Black (20,6% of the sample) epileptic out-patients attending Groote Schuur Hospital was found to be 41,3% (Fist & James, 1992). The percentage in a sample of Coloured epileptic patients attending Heideveld Day Hospital was 61,3% (Le Roux & Rutherford, 1992).

Previous research (Jacoby, 1992: 658) indicated that there is evidence that individuals with epilepsy experience both under- employment and unemployment. As pointed out by Hayden, Penna and Buchanan, 46% of respondents were unemployed, and perceived employment as one of their major problems. This is always a vexed issue, since whilst there is evidence of some discrimination, especially in difficult economic times, it is not surprising that employers are not keen about taking on staff with a medical problem (Chandra, 1988; Masland, 1985; Sands & Zalkind, 1972). A countrywide survey of 1660 Blacks conducted by the Human Science 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 is congruent with the proposed rate of unemployment amongst South African Blacks in general. Previous research has shown a relationship between disability and working status: in the OPCS survey of disability (Martin & White, 1988), only 33% of disabled men and 29% of disabled women under pensionable age were working, compared with 78% and 60% in the population as a whole. The results of the present study reveal that the condition epilepsy, has a significant effect on an individual's occupation.

Several researchers such as Caramer & Mattson, 1993; Janz, 1989; Ryan et al. 1980 have pointed out that the subjective perception of disease in patients (perceived social impairment, severity of seizures, constraints on daily life through seizures) bears little relation to the clinical categories of seizure symptoms.

CHAPTER FIVE

5. SUMMARY, RECOMMENDATIONS AND LIMITATIONS

The present study was undertaken to investigate and explore patients' perceptions towards epilepsy. Epilepsy is a condition with recurring unprovoked seizures often resulting in a temporary impairment of consciousness, which may be associated with physiological, behavioural or cognitive reactions. Between the seizures most individuals are neurologically unaffected but may be affected by the psychological and social consequences of having epilepsy. It is well recognised that the medical manifestations of epilepsy are only part of the individual experience of epilepsy. This study shows that epilepsy is also associated with a broad range of psychosocial problems, which are related both to factual limitations and to perceived stigmatisation.

The following hypotheses was formulated:

Hypothesis: 1

To find out whether individuals who perceived their epilepsy to be more severe and stigmatizing, had lower levels of perceived acceptance than those who had no such perceptions.

Hypothesis: 2

There will be no relationship between the psychosocial factors of epilepsy (namely, emotional, anxiety, self-esteem and social interaction, and cognitive-behavioural) and each of the following demographic variables:

- Age of the respondent
- Ethnic group of the respondent
- Home language of the respondent
- Educational level of the respondent
- Occupational level of the respondent

Hypothesis: 3

There will be no differences in the way epileptics' perceive, their various recommendations.

Hypothesis: 4

There will be no significant relationship between the each of the following demographic variables and perception of epilepsy:

- Age of the respondent
- Gender of the respondent
- Ethnic group of the respondent
- Home language of the respondent
- Educational level of the respondent
- Occupational level of the respondent

SUMMARY OF FINDINGS

Some major themes were evident from the data and are presented below. Attitudes to epilepsy were marked by a distinct unfavourableness. In some cases dominated by a marked non-acceptance, but in other cases the diagnosis appeared to be a fairly well-integrated part of life especially among the semi literate. The study showed explicitly that the medical symptoms and circumstances of epilepsy were domains that seemed to be more accepting with semi literate respondents than the more educated patients.

Though there were expressions of a negative self-image and even of self-destructive tendencies, there were also abundant examples of confidence and acceptance. The feeling of insecurity and social isolation was however often present. Perceptions of the reactions of other people to epilepsy emerged as another problem area. Several respondents demonstrated some difficulties in dealing with the reactions of other people especially in accessing employment. Almost all declared that they had sometimes met a negative attitude or lack of understanding from other people.

Major Themes From the Study

(i) Perception of medical symptoms.

Respondents descriptions of having to deal with the seizure itself and with the cognitive limitations related to the condition.

(ii) Perception of one's own reactions to epilepsy.

Respondents' descriptions of having to deal with their own reactions to having epilepsy, their loss of self-esteem and belief in themselves.

(iii) Perceptions of others' reactions to epilepsy.

Respondents' descriptions of having to deal with reactions and limitations from their surroundings, including both other people (family, friends and strangers) and the social and working environment (e.g. employment and driving regulations).

Finally, there was consensus with reference to their recommendations[13].

RECOMMENDATIONS

The findings of the present study need further investigation particularly in a comparative context. Future research could investigate if the current findings pertain to the disabled, disadvantaged or other stigmatised groups such as those who are HIV/AIDS positive. Secondly in the developing world there is a great need for the expansion and evaluation of educational programmes aimed at maximizing the psychological adjustment of individuals who have epilepsy. More, importantly, these programmes should be culturally sensitive whilst demystifying the myths. Additionally, information resource packs should be distributed at the time of diagnosis containing audio and videotapes, clearly written information on all aspects of epilepsy including treatment and side effects, and outlining further sources of support, information and advice. Also, information on epilepsy should take into account different official languages, religions, cultures and lifestyles. Epilepsy needs more attention from the mainstream media. The top three priority audiences for health communication campaigns to counter epilepsy-related stigma are:

- School personnel
- Persons with epilepsy and their parents or caregivers
- Health care gatekeepers, including nurse practitioners.

Health communication strategies must be based on the following prioritised criteria:

[13] For example, this included easier access for medication, dissemination of information and work opportunities for epileptics.

- **Impact:** whether the change with each target audience is likely to have a sufficient impact on the problem to justify the effort required
- **Relevance:** how the audience is relevant to persons with epilepsy, public health, and the problem
- **Feasibility:** whether the change within the audience is achievable; and whether it can be attained through health communication strategies
- **Leverages:** whether the audience can facilitate change in larger communities and populations (e.g., opinion leaders, stakeholders)
- **Connection:** whether the audience can be reached easily by at least some partners engaged in the effort.

Support groups for people with epilepsy and their carers should be set up taking into account language, gender, location and age. Establishing an Epilepsy Register would equip local health providers with a valuable tool for monitoring access and equity of services for patients. Thirdly, the present study has shown that there is a need for attention to be given to the relationship between stress and seizure occurrence as well as between seizure provoking factors and the occurrence.

There are also implications that supporting the patient, encouraging him/her to participate in social activities will be interventions of great importance. Stigma and the factors should be addressed as the top priority in epilepsy self-management and advocacy. Factors include:

- Lack of awareness
- Lack of timely, complete, and accurate information
- Misperceptions
- Learned helplessness
- Social tolerance for stigma and discrimination
- Insufficient research on stigma and psychosocial aspects of epilepsy
- Fear

LIMITATIONS

The present study is unique, particularly within the South African context. Thus, given the innovative nature of the present study, there some limitations. Perhaps, the most significant and obvious limitation concerns the lack of a control group. The researcher deliberately omitted a control group, as it would have been nearly impossible to constitute a control group with the same constellation as the sample (i.e. age, occupation, gender, education, attendance, at the clinic). Secondly, it is extremely difficult to measure perception, as respondents can easily falsify information. Perhaps, there should be a scientific instrument to measure perceptions. A third limitation concerns the lack of an interview accompanying the questionnaire. This would have allowed for more spontaneous, and unstructured responses. Perhaps, future research combining the two methods of data collection needs to be undertaken. Also, the questions on drug therapy was clearly absent, for this reason, forthcoming research should include questions on pharmacology and its impact thereof.

CONCLUDING REMARKS

The present study was undertaken to investigate the epileptics' perception of their condition. Respondents' concerns about the impact of epilepsy on their lifestyle were directly linked to whether epilepsy was a barrier for them in completing their education, in seeking employment, in finding a marriage partner, and in having a 'normal' social life. The answers were affirmative. It is hoped that this study has provided some insight into the stigma and debilitating effects of labels on epileptics. Patients with special needs include those with developmental disabilities such as epilepsy, cerebral palsy, and autism. However, each patient is an individual who requires unique attention. Apart from the medical labels, each epileptic is a human being, first and foremost. Hopefully, the greater community will shed these identity markers and treat them as humans.

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ANNEXURE A: Copy of letter sent to Wentworth Hospital

THE CHIEF EXECUTIVE DIRECTOR

WENTWORTH HOSPITAL
PRIVATE BAG
JACOBS
4026

Dear Sir or Madam:

I am currently registered for a Master of Arts degree in Psychology at the University of Zululand. The title of my thesis is, "EPILEPTICS' PERCEPTIONS OF THEMSELVES". The chief aim of my study is to explore the psychosocial perceptions of individuals with epilepsy. It is in this regard that I am writing to you to seek permission to obtain this sample at Wentworth Hospital. I have had a discussion with Prof. Bill, the head of the department of neurology, and Prof. Bhigjee, the deputy head, who have supported my initiative, but suggested that I write to you to obtain formal consent.

The study will take the form of a biographical questionnaire, which is essentially very uncomplicated. I am also presently a voluntary counsellor at the Department of neurology, epilepsy clinic, at IALCH, therefore the sample of patients will be comfortable and completely at ease. The patients would be requested to participate voluntarily and will b e free to withdraw from the study at any stage without prejudice. The questionnaire will take approximately 10-15 minutes to be completed and will be conducted when the patient is available at the out- patient epilepsy clinic. A sample of 100 epileptics, aged between 18-50 years is required.

This type of study has not been undertaken in South Africa previously, hence it would shed some light on the psychosocial perceptions of epileptics. The findings of the study would be made available for perusal to your institution via the dissertation. I am willing to abide by any ethical or other requirements that govern research by your institution.
I thank you anticipating a favourable response.
Sincerely,

Ms Sonia Roopnarain
18 March 2003

ANNEXURE B

Letter of consent from Wentworth Hospital

PROVINCE KWAZULU NATAL
HEALTH SERVICES

ISIFUNDAZWE SAKWAZULU-NATALI
EZEMPILO

Cohsasa

PROVINSIEKWAZULU-NATAL
GESONDHEIDSDIENSTE

100% ACCREDITATION, BY COHSASA

DEPARTMENT OF HEALTH
WENTWORTH HOSPITAL
Private Bag, Jacobs 4026
TEL: (031) 460 5063 FAX: (031) 468 9654 E-mail: mthembutn@dohwent.kzntl.gov.za

Thursday, 02 October 2003

Ms Sonia Roopnarain
University of Zululand: Psychology Department
Empangeni
3880

Dear Ms Roopnarain

RE: REQUEST TO CONDUCT STUDY AT OUR INSTITUTION

Your request regarding the above request has reference.

Please note that permission regarding the above request has been granted. Kindly liase with the relevant department(s), including all other relevant stakeholders, to ensure that proper logistics are put in place, to facilitate your research.

We take this opportunity to wish you well in your quest.

Thank you

Yours sincerely

Mr. TN Mthembu
PUBLIC RELATIONS OFFICER

MR. T.N. MTHEMBU
PUBLIC RELATIONS OFFICER
WENTWORTH HOSPITAL

SERVICE EXCELLENCE
BRONZE WINNER
2002
PREMIER'S GOOD
GOVERNANCE
AWARDS

BATHO PELE

ANNEXURE C

The scale used in the pilot study.

RESEARCH QUESTIONNAIRE

INSTRUCTIONS: Please complete the following questionnaire as fully as possible by choosing the answers which apply to you and make a cross (**X**) in the space provided. All information provided to the researcher will be treated in **STRICT CONFIDENCE**.

SECTION A: BIOGRAPHICAL INFORMATION

1. Age

20 and under	
21-30	
31-40	
41-50	
50+	

2. Gender

MALE	
FEMALE	

3. Ethnic Grouping

AFRICAN	
COLOURED	
INDIAN	
WHITE	

4. Home Language

ENGLISH	
AFRIKAANS	
ISIZULU	
XHOSA	
VERNACULAR	
OTHER	

5. **Marital status**

SINGLE	
MARRIED	
DIVORCED	
WIDOWED	
LIVING WITH PARTNER	

6. **Educational Level** (tick one)

NO SCHOOLING	
PRIMARY EDUCATION	
SECONDARY EDUCATION	
HIGH SCHOOL EDUCATION	
POST MATRIC (technical/college certificate/diploma)	
UNIVERSITY EDUCATION	

7. **Occupation**

STATE EMPLOYED	
UNEMPLOYED	
SELF-EMPLOYED	

SECTION B: PERCEPTIONS OF EPILEPTICS

In this section it is expected of you to indicate the influence of epilepsy in your daily life.

Indicate to which extent you agree or disagree with each of the following statements. There are 5 possible answers to each of the questions. For your answer, place a cross (**x**) in a box next to each statement. Please answer all questions.

The meaning of abbreviations:

SA = Strongly agree

A = Agree

U = Unsure

D = Disagree

SD = Strongly disagree

Example:

I usually take my medication every day:

SA	A	U	D	SD
1 X	2	3	4	5

1. I feel depressed everyday because of my epilepsy.

SA	A	U	D	SD
1	2	3	4	5

2. I feel sad everyday because of my epilepsy.

SA	A	U	D	SD
1	2	3	4	5

3. I feel down because of my epilepsy.

SA	A	U	D	SD
1	2	3	4	5

4. I have lost interest in all usual activities and pastimes.

SA	A	U	D	SD
1	2	3	4	5

5. I have lost pleasure in all usual activities and pastimes.

SA	A	U	D	SD
1	2	3	4	5

6. I often feel tired and without energy to go on because of my epilepsy.

SA	A	U	D	SD
1	2	3	4	5

7. I often feel like crying without any reason.

SA	A	U	D	SD
1	2	3	4	5

8. Because of my epilepsy I have trouble with my sleeping pattern (example, difficulty in falling asleep, wake up every now and then during the night, wake up in the morning).

SA	A	U	D	SD
1	2	3	4	5

9. Because of my epilepsy I have a poor appetite and have lost weight.

SA	A	U	D	SD
1	2	3	4	5

10. In spite of epilepsy my appetite is better than usual and I have gained weight.

SA	A	U	D	SD
1	2	3	4	5

11. Because of epilepsy I feel hopeless about the future and feel that life is not worthwhile.

SA	A	U	D	SD
1	2	3	4	5

12. Because of epilepsy I sometimes wish I was dead and I am bothered by suicidal thoughts.

SA	A	U	D	SD
1	2	3	4	

13. I feel nervous, tense and irritated because of my epilepsy.

SA	A	U	D	SD
1	2	3	4	5

14. Because of my epilepsy I often awake suddenly during the night and due to my worry I find it difficult to go back to bed.

SA	A	U	D	SD
1	2	3	4	5

15. Because of epilepsy I become very tense and upset when I think about the day's events.

SA	A	U	D	SD
1	2	3	4	5

16. Because of epilepsy small things tend to upset and worry me although I know it is not necessary.

SA	A	U	D	SD
1	2	3	4	5

17. I am startled very easily because of my epileptic condition.

SA	A	U	D	SD
1	2	3	4	5

18. I am often restless due to my epileptic condition.

SA	A	U	D	SD
1	2	3	4	5

19. Due to my epileptic condition I tremble and perspire when I have to make difficult decisions.

SA	A	U	D	SD
1	2	3	4	5

20. I often have headaches as a result of my epilepsy.

SA	A	U	D	SD
1	2	3	4	5

21. I have tightness and tension in my back, neck and muscles and feel miserable because of my epilepsy.

SA	A	U	D	SD
1	2	3	4	5

22. Because of my epilepsy I feel uneasy and self-conscious amongst people.

SA	A	U	D	SD
1	2	3	4	5

23. I have lost friends because I have epilepsy.

SA	A	U	D	SD
1	2	3	4	5

24. I wish that people would be more interested in me regardless of my epileptic condition.

SA	A	U	D	SD
1	2	3	4	5

25. I feel that I have no control over my epilepsy.

SA	A	U	D	SD
1	2	3	4	5

26. Because of my epilepsy I would rather stay at home than go out.

SA	A	U	D	SD
1	2	3	4	5

27. Because of my epilepsy my friends and family consider me a burden.

SA	A	U	D	SD
1	2	3	4	5

28. I feel inferior and worthless because of my epilepsy.

SA	A	U	D	SD
1	2	3	4	5

29. Because of my epilepsy I have little confidence.

SA	A	U	D	SD
1	2	3	4	5

30. Because of my epilepsy I feel that other people reject me.

SA	A	U	D	SD
1	2	3	4	5

31. I am continually afraid that I might die with the next epileptic seizure (for example, drown, suffocate, involved in an accident).

SA	A	U	D	SD
1	2	3	4	5

32. I am continually afraid that I might get another epileptic seizure.

SA	A	U	D	SD
1	2	3	4	5

33. Because of my epilepsy I am afraid of being alone.

SA	A	U	D	SD
1	2	3	4	5

34. Because of my epilepsy I nowadays have more trouble to think clearly.

SA	A	U	D	SD
1	2	3	4	5

35.I am afraid that one day my child/children will also have epilepsy.

SA	A	U	D	SD
1	2	3	4	5

36. I feel resentful and angry toward life because I have epilepsy.

SA	A	U	D	SD
1	2	3	4	5

PART TWO

Rank-order the following statements in order of importance/ preference to you. Assign rank order number one to the most preferred/important to you. Assign the last rank order to the least applicable item:

Statements	**Rank order**
(I) I would be more content if I had people to provide me with information on epilepsy, e.g. Pastor, nurse, counsellor, etc.	( )
(II) I would be happier if I had easier access to my epilepsy medication.	( )
(III) There are not enough opportunities for work training people with epilepsy.	( )
(iv) There are not enough facilities for work training people with epilepsy.	( )
(v) There are not enough training centres for work training people with epilepsy.	( )

----------**Thank You for Your Co-operation**----------

ANNEXURE D

The validity of the scale was obtained through the use of the internal-consistency method of item – analysis (Oppenheim, 1972: 133-142

Internal Consistency

Reliability or Internal Consistency

****** Method 1 (space saver) will be used for this analysis ******

R E L I A B I L I T Y A N A L Y S I S - S C A L E (A L P H A)

		Mean	Std Dev	Cases
1.	PEQ1	2.0000	.8660	9.0
2.	PEQ2	2.1111	.7817	9.0
3.	PEQ3	2.1111	.7817	9.0
4.	PEQ4	2.0000	.8660	9.0
5.	PEQ5	2.1111	.7817	9.0
6.	PEQ6	2.0000	.0000	9.0
7.	PEQ7	2.2222	.8333	9.0
8.	PEQ8	2.0000	.0000	9.0
9.	PEQ9	2.3333	.7071	9.0
10.	PEQ10	3.5556	1.0138	9.0
11.	PEQ11	2.7778	1.2019	9.0
12.	PEQ12	3.3333	1.1180	9.0
13.	PEQ13	2.1111	.7817	9.0
14.	PEQ14	2.0000	.0000	9.0
15.	PEQ15	2.0000	.0000	9.0
16.	PEQ16	2.4444	.8819	9.0
17.	PEQ17	3.0000	1.0000	9.0
18.	PEQ18	1.8889	.3333	9.0
19.	PEQ19	2.0000	.0000	9.0
20.	PEQ20	1.6667	.5000	9.0
21.	PEQ21	1.7778	.4410	9.0
22.	PEQ22	1.8889	.3333	9.0
23.	PEQ23	1.8889	.3333	9.0
24.	PEQ24	1.8889	.3333	9.0
25.	PEQ25	2.0000	.0000	9.0
26.	PEQ26	2.0000	.0000	9.0
27.	PEQ27	2.2222	.6667	9.0
28.	PEQ28	2.4444	.8819	9.0
29.	PEQ29	1.7778	.4410	9.0
30.	PEQ30	2.1111	.7817	9.0
31.	PEQ31	2.6667	.8660	9.0
32.	PEQ32	2.0000	.0000	9.0
33.	PEQ33	1.8889	.3333	9.0
34.	PEQ34	2.3333	1.0000	9.0
35.	PEQ35	2.1111	.3333	9.0
36.	PEQ36	1.8889	.3333	9.0

Alpha Value :

****** Method 1 (space saver) will be used for this analysis ******

R E L I A B I L I T Y A N A L Y S I S - S C A L E (A L P H A)

Reliability Coefficients

N of Cases = 9.0 N of Items = 36

Alpha = .8098

Statistics for	Mean	Variance	Std Dev	N of Variables
SCALE	78.5556	73.5278	8.5748	36

R E L I A B I L I T Y A N A L Y S I S - S C A L E (A L P H A)

Item-total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Alpha if Item Deleted
PEQ1	76.5556	67.5278	.3689	.8024
PEQ2	76.4444	67.2778	.4397	.7995
PEQ3	76.4444	67.2778	.4397	.7995
PEQ4	76.5556	63.5278	.6700	.7882
PEQ5	76.4444	62.5278	.8403	.7820
PEQ6	76.5556	73.5278	.0000	.8105
PEQ7	76.3333	62.7500	.7637	.7842
PEQ8	76.5556	73.5278	.0000	.8105
PEQ9	76.2222	72.9444	.0069	.8158
PEQ10	75.0000	62.2500	.6407	.7878
PEQ11	75.7778	64.4444	.3959	.8027
PEQ12	75.2222	60.1944	.6965	.7833
PEQ13	76.4444	72.2778	.0481	.8154
PEQ14	76.5556	73.5278	.0000	.8105
PEQ15	76.5556	73.5278	.0000	.8105
PEQ16	76.1111	72.3611	.0259	.8180
PEQ17	75.5556	62.2778	.6494	.7874
PEQ18	76.6667	74.5000	-.1883	.8149
PEQ19	76.5556	73.5278	.0000	.8105
PEQ20	76.8889	71.6111	.1970	.8082
PEQ21	76.7778	72.4444	.1184	.8100
PEQ22	76.6667	73.5000	-.0146	.8119
PEQ23	76.6667	69.7500	.6586	.8002
PEQ24	76.6667	74.5000	-.1883	.8149
PEQ25	76.5556	73.5278	.0000	.8105
PEQ26	76.5556	73.5278	.0000	.8105
PEQ27	76.3333	70.2500	.2535	.8068
PEQ28	76.1111	68.8611	.2657	.8073
PEQ29	76.7778	69.9444	.4595	.8021
PEQ30	76.4444	72.5278	.0292	.8161
PEQ31	75.8889	68.6111	.2904	.8060
PEQ32	76.5556	73.5278	.0000	.8105
PEQ33	76.6667	74.5000	-.1883	.8149
PEQ34	76.2222	65.1944	.4541	.7983
PEQ35	76.4444	73.7778	-.0631	.8128
PEQ36	76.6667	69.7500	.6586	.8002

Descriptive stats :

Age Group

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	21-30	1	10.0	10.0	10.0
	31-40	3	30.0	30.0	40.0
	41-50	2	20.0	20.0	60.0
	50 and above	4	40.0	40.0	100.0
	Total	10	100.0	100.0	

Gender

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	4	40.0	40.0	40.0
	Female	6	60.0	60.0	100.0
	Total	10	100.0	100.0	

Ethnic Grouping

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	African	4	40.0	40.0	40.0
	Coloured	1	10.0	10.0	50.0
	Indian	3	30.0	30.0	80.0
	White	2	20.0	20.0	100.0
	Total	10	100.0	100.0	

Home Language

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	English	7	70.0	70.0	70.0
	Isizulu	3	30.0	30.0	100.0
	Total	10	100.0	100.0	

Marital status

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Single	5	50.0	50.0	50.0
	Married	2	20.0	20.0	70.0
	Divorced	2	20.0	20.0	90.0
	Living with Partner	1	10.0	10.0	100.0
	Total	10	100.0	100.0	

Educational levels

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Primay Education	2	20.0	20.0	20.0
	Secondary Education	1	10.0	10.0	30.0
	High school education	4	40.0	40.0	70.0
	Post Matric	3	30.0	30.0	100.0
	Total	10	100.0	100.0	

Occupation

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	State employed	4	40.0	40.0	40.0
	Unemployed	6	60.0	60.0	100.0
	Total	10	100.0	100.0	

ANNEXURE G

RESEARCH QUESTIONNAIRE

INSTRUCTIONS: Please complete the following questionnaire as fully as possible by choosing the answers, which apply to you and make a cross (x) in the space provided. All information provided to the researcher will be treated in **STRICT CONFIDENCE.**

SECTION A: BIOGRAPHICAL INFORMATION

1. Age

20 and under	
21-30	
31-40	
41-50	
50+	

2. Gender

MALE	
FEMALE	

3. Ethnic Grouping

AFRICAN	
COLOURED	
INDIAN	
WHITE	

4. Home Language

ENGLISH	
AFRIKAANS	
ISIZULU	
XHOSA	
VERNACULAR	
OTHER	

5. Marital status

SINGLE	
MARRIED	
DIVORCED	
WIDOWED	
LIVING WITH PARTNER	

6. **Educational Level** (tick one)

NO SCHOOLING	
PRIMARY EDUCATION	
SECONDARY EDUCATION	
HIGH SCHOOL EDUCATION	
POST MATRIC (technical/college certificate/diploma)	
UNIVERSITY EDUCATION	

7. **Occupation**

STATE EMPLOYED	
UNEMPLOYED	
SELF-EMPLOYED	

SECTION B: PERCEPTIONS OF EPILEPTICS'

In this section it is expected of you to indicate the influence of epilepsy in your daily life.

Indicate to which extent you agree or disagree with each of the following statements. There are 5 possible answers to each of the questions. For your answer, place a cross (**x**) in a box next to each statement. Please answer all questions.

The meaning of abbreviations:

SA = Strongly agree

A = Agree

U = Unsure

D = Disagree

SD = Strongly disagree

Example:

I usually take my medication every day:

SA	A	U	D	SD
1 X	2	3	4	5

1. I feel depressed everyday because of my epilepsy.

SA	A	U	D	SD
1	2	3	4	5

2. I feel sad everyday because of my epilepsy.

SA	A	U	D	SD
1	2	3	4	5

3. I feel down because of my epilepsy.

SA	A	U	D	SD
1	2	3	4	5

4. I have lost interest in all usual activities and pastimes.

SA	A	U	D	SD
1	2	3	4	5

5. I have lost pleasure in all usual activities and pastimes.

SA	A	U	D	SD
1	2	3	4	5

6. I often feel like crying without any reason.

SA	A	U	D	SD
1	2	3	4	5

7. In spite of epilepsy my appetite is better than usual and I have gained weight.

SA	A	U	D	SD
1	2	3	4	5

8. Because of epilepsy I feel hopeless about the future and feel that life is not worthwhile.

SA	A	U	D	SD
1	2	3	4	5

9. Because of epilepsy sometimes I wish I was dead and I am bothered by suicidal thoughts.

SA	A	U	D	SD
1	2	3	4	

10. I am startled very easily because of my epileptic condition.

SA	A	U	D	SD
1	2	3	4	5

11. I have lost friends because I have epilepsy.

SA	A	U	D	SD
1	2	3	4	5

12. Because of my epilepsy I have little confidence.

SA	A	U	D	SD
1	2	3	4	5

13. Because of my epilepsy I nowadays have more trouble to think clearly.

SA	A	U	D	SD
1	2	3	4	5

14. I feel resentful and angry toward life because I have epilepsy.

SA	A	U	D	SD
1	2	3	4	5

15. Rank-order the following statements in order of importance/ preference to you. Assign rank order number one to the most preferred/important to you. Assign the last rank order to the least applicable item:

(l) I would be more content if I had people to provide me with information on epilepsy, e.g. Pastor, nurse, counsellor, etc. ( )

(II) I would be happier if I had easier access to my epilepsy medication. ( )

(III) There are not enough opportunities for work training people with epilepsy. ( )

(iv) There are not enough facilities for work training people with epilepsy. ( )

(v) There are not enough training centres for work training people with epilepsy. ( )

----------**Thank You for Your Co-operation**----------

Demographic Stats:

Respondent Age Group

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	20 and Under	13	13.0	13.0	13.0
	21-30	21	21.0	21.0	34.0
	31-40	20	20.0	20.0	54.0
	41-50	29	29.0	29.0	83.0
	50 and above	17	17.0	17.0	100.0
	Total	100	100.0	100.0	

Respondent Gender

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	34	34.0	34.0	34.0
	Female	66	66.0	66.0	100.0
	Total	100	100.0	100.0	

Respondent Ethnic Grouping

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	African	44	44.0	44.0	44.0
	Coloured	11	11.0	11.0	55.0
	Indian	29	29.0	29.0	84.0
	White	16	16.0	16.0	100.0
	Total	100	100.0	100.0	

Respondent Home Language

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	English	54	54.0	54.0	54.0
	Afrikaans	3	3.0	3.0	57.0
	Isizulu	30	30.0	30.0	87.0
	Xhosa	10	10.0	10.0	97.0
	Vernacular	3	3.0	3.0	100.0
	Total	100	100.0	100.0	

Respondent marital status

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Single	45	45.0	45.0	45.0
	Married	21	21.0	21.0	66.0
	Divorced	16	16.0	16.0	82.0
	Widowed	14	14.0	14.0	96.0
	Living with Partner	4	4.0	4.0	100.0
	Total	100	100.0	100.0	

RespondentEducational levels

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No schooling	6	6.0	6.0	6.0
	Primay Education	47	47.0	47.0	53.0
	Secondary Education	24	24.0	24.0	77.0
	High school education	17	17.0	17.0	94.0
	Post Matric	2	2.0	2.0	96.0
	University education	4	4.0	4.0	100.0
	Total	100	100.0	100.0	

RespondentOccupation

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	State employed	37	37.0	37.0	37.0
	Unemployed	59	59.0	59.0	96.0
	Self-Employed	4	4.0	4.0	100.0
	Total	100	100.0	100.0	

	agegroup	gender	ethinic	language	marital	educatio	occupati	totascor	average
1	31-40	Female	Indian	English	Single	University educatio	State employed	35	B
2	41-50	Female	Indian	English	Married	Primay Education	Unemployed	39	B
3	20 and Und	Male	Indian	English	Single	Primay Education	Unemployed	56	A
4	50 and abo	Female	Indian	English	Single	Primay Education	Unemployed	38	B
5	41-50	Male	Indian	English	Married	Secondary Educati	Self-Employed	33	B
6	21-30	Female	Indian	English	Single	University educatio	Unemployed	53	A
7	41-50	Female	Indian	English	Divorced	High school educat	State employed	36	B
8	31-40	Female	Indian	English	Married	Secondary Educati	State employed	42	B
9	41-50	Male	Indian	English	Married	Secondary Educati	State employed	30	B
10	50 and abo	Female	Indian	English	Single	No schooling	Unemployed	32	B
11	50 and abo	Female	Indian	English	Single	Primay Education	Unemployed	34	B
12	21-30	Female	Indian	English	Single	High school educat	State employed	42	B
13	21-30	Female	Indian	English	Single	Secondary Educati	State employed	42	B
14	41-50	Female	Indian	English	Widowed	Secondary Educati	State employed	40	B
15	50 and abo	Male	Indian	English	Divorced	Primay Education	Unemployed	46	A
16	31-40	Female	Indian	English	Married	Primay Education	Unemployed	46	A
17	41-50	Female	Indian	English	Divorced	High school educat	State employed	42	B
18	20 and Und	Male	Indian	English	Single	Secondary Educati	Unemployed	48	A
19	21-30	Female	Indian	English	Married	Post Matric	Unemployed	38	B
20	20 and Und	Female	Indian	English	Single	Primay Education	Unemployed	61	A
21	20 and Und	Male	Indian	English	Single	Primay Education	Unemployed	54	A
22	50 and abo	Male	Indian	English	Widowed	High school educat	Unemployed	47	A
23	21-30	Female	Indian	English	Single	University educatio	State employed	51	A
24	31-40	Male	Indian	English	Married	Secondary Educati	State employed	40	B
25	41-50	Female	Indian	English	Divorced	Post Matric	Unemployed	51	A

	agegroup	gender	ethinic	language	marital	educatio	occupati	totascor	average
26	50 and abo	Female	Indian	English	Single	Primay Education	Unemployed	55	A
27	20 and Und	Female	Coloured	English	Single	Primay Education	Unemployed	42	B
28	31-40	Male	Coloured	English	Married	Primay Education	Self-Employed	32	B
29	31-40	Female	Coloured	English	Single	No schooling	Unemployed	56	A
30	41-50	Male	Coloured	Afrikaans	Married	Primay Education	Unemployed	55	A
31	21-30	Female	White	English	Divorced	Secondary Educati	State employed	44	B
32	20 and Und	Female	Coloured	Afrikaans	Single	Primay Education	Unemployed	54	A
33	21-30	Female	Coloured	English	Married	Primay Education	Unemployed	50	A
34	31-40	Male	Coloured	Afrikaans	Married	High school educat	State employed	32	B
35	50 and abo	Female	Coloured	English	Divorced	No schooling	Unemployed	57	A
36	20 and Und	Female	Coloured	English	Single	High school educat	Unemployed	33	B
37	50 and abo	Male	Coloured	English	Widowed	Primay Education	Unemployed	48	A
38	41-50	Female	Coloured	English	Married	Primay Education	State employed	40	B
39	50 and abo	Female	Indian	English	Single	Primay Education	Unemployed	32	B
40	41-50	Female	Indian	English	Widowed	Primay Education	Unemployed	53	A
41	41-50	Female	African	English	Divorced	Secondary Educati	Unemployed	49	A
42	31-40	Female	African	English	Single	Primay Education	Unemployed	53	A
43	20 and Und	Male	African	Isizulu	Single	Primay Education	Unemployed	58	A
44	21-30	Female	African	Isizulu	Single	Primay Education	Unemployed	54	A
45	41-50	Male	African	Isizulu	Married	Primay Education	State employed	31	B
46	41-50	Female	African	Isizulu	Widowed	Primay Education	Unemployed	58	A
47	31-40	Female	African	Isizulu	Married	Primay Education	Unemployed	58	A
48	50 and abo	Female	African	Isizulu	Widowed	No schooling	Unemployed	57	A
49	41-50	Male	African	Isizulu	Single	No schooling	State employed	55	A
50	20 and Und	Male	African	Isizulu	Single	Primay Education	Unemployed	34	B

	agegroup	gender	ethinic	language	marital	educatio	occupati	totascor	average
51	41-50	Female	African	Isizulu	Divorced	High school educat	Unemployed	54	A
52	41-50	Female	African	Isizulu	Married	Primay Education	State employed	34	B
53	21-30	Male	African	Isizulu	Single	High school educat	State employed	36	B
54	50 and abo	Male	African	Xhosa	Widowed	Primay Education	State employed	36	B
55	41-50	Female	African	Xhosa	Married	Primay Education	State employed	37	B
56	31-40	Female	African	Isizulu	Single	Primay Education	Unemployed	57	A
57	31-40	Female	African	Vernacular	Divorced	Secondary Educati	State employed	54	A
58	20 and Und	Female	African	Isizulu	Single	Primay Education	Unemployed	56	A
59	41-50	Female	African	Xhosa	Married	Primay Education	Unemployed	57	A
60	41-50	Male	African	Xhosa	Widowed	Secondary Educati	State employed	36	B
61	20 and Und	Female	African	Isizulu	Single	Secondary Educati	Unemployed	60	A
62	21-30	Female	African	Vernacular	Married	Primay Education	State employed	40	B
63	41-50	Female	African	Xhosa	Single	Primay Education	State employed	56	A
64	41-50	Male	African	Xhosa	Single	Primay Education	State employed	42	B
65	31-40	Female	African	Isizulu	Married	Primay Education	State employed	41	B
66	21-30	Male	African	Xhosa	Widowed	Secondary Educati	State employed	51	A
67	41-50	Female	African	Xhosa	Single	Secondary Educati	State employed	38	B
68	31-40	Female	African	Xhosa	Married	Primay Education	Unemployed	39	B
69	41-50	Female	African	Isizulu	Widowed	High school educat	State employed	34	B
70	21-30	Male	African	Xhosa	Single	Primay Education	Unemployed	50	A
71	21-30	Male	African	Isizulu	Single	High school educat	State employed	40	B
72	41-50	Female	African	Isizulu	Single	Primay Education	Unemployed	55	A
73	31-40	Female	African	Isizulu	Divorced	High school educat	State employed	41	B
74	21-30	Female	African	Isizulu	Single	Primay Education	Unemployed	54	A
75	31-40	Female	African	Isizulu	Widowed	Primay Education	Unemployed	54	A