THE EFFECTS OF EPILEPSY ON FAMILIES LIVING IN MAMELODI
WITH SPECIAL REFERENCE TO THE ROLE OF THE SOCIAL WORKER.

By

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Submitted in the fulfilment of the requirements for the Degree of

MASTER OF SOCIAL SCIENCE

in the subject

SOCIAL WORK

at the

UNIVERSITY OF SOUTH AFRICA

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NOVEMBER 1995
TO WHOM IT MAY CONCERN

I declare that "The effects of epilepsy on families living in Mamelodi with special reference to the role of the social worker" is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

P H RAMABOEA
I wish to express my sincere gratitude and appreciation for the support, guidance and motivation I received from my supervisor, Professor R van Biljon, as well as the assistance I received from my joint supervisor Dr A S du Toit.

It was through the permission received from the then Superintendent of Kalafong Hospital, Dr D J L van Rooy to interview epileptic respondents residing in Mamelodi which made this research possible. Hence my thanks to him. I would like also to express my appreciation to Mamelodi Clinic staff who made it possible for me to locate potential epileptic respondents who showed interest in participating in the research project.

For the typing and printing I want to thank Mrs Van Rensburg for her kind assistance. I am grateful to all those who have contributed towards making this study a success through their participation and valuable contribution especially South African National Epilepsy League - Durban and Coastal Areas and Mrs E J Pretorius who has done the editing for me.

My most sincere appreciation to my wife Mosibudi for her untiring motivation, support and interest in the pursuit of my career, and to my children Namedi, Mamohwela, Matlala, Sekgana, Mokokotlelo, Mokgadi and Pheeha whose encouragement and patience enabled me to proceed with my project.

P H RAMABOE
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A study of the relevant theoretical concepts and empirical research was undertaken to explore the role of the social worker pertaining to the problem of epilepsy in the black community of Mamelodi.

The sample comprised 40 families in which there was a person with epilepsy. Data were obtained through an interview schedule administered by the researcher.

The literature study highlighted the phenomenon of epilepsy, causes of epilepsy, psychosocial effects of epilepsy on the epileptic and his family and the treatment of the epileptic. However, it became quite clear that a multi-disciplinary team approach is of vital importance in the treatment of an epileptic. Furthermore, significant others like traditional healers, faith healers, priests, relatives and friends were identified as some of the important informal support systems.

Although the findings of the study cannot be generalised to the entire population they can be of great significance for further research.

KEY TERMS

Epilepsy; Causes of epilepsy; Black community of Mamelodi; Role of social worker; Psycho-social effects of epilepsy; Problem-solving approach; Exploratory study; Interview schedule; Self-help groups; Traditional healers; Ancestral spirits.
OPSOMMING

'n Studie van die relevante konsepte asook empiriese navorsing is gedoen om die rol van die maatskaplike werker met betrekking tot die probleem van epilepsie in die swart gemeenskap van Mamelodi te eksplorieer.

Die steekproef is saamgestel uit 'n groep van 40 gesinne met 'n epileptikus in hul midde. Inligting is verkry deur middel van 'n onderhoudskedule.

Die literatuurstudie beklemtoon die volgende: die verskynsel van epilepsie, oorsake van epilepsie, psigososiale gevolge van epilepsie op die persoon met epilepsie en sy gesin en die behandeling van die epileptikus. Dit het egter duidelik na vore gekom dat 'n multi-dissiplinêre spanbenadering van die uiterste belang is in die behandeling van die epilepsielyer. Dit het ook duidelik geword dat betekenisvolle ander persone soos tradisionele genesers, geloofsgenesers, priesters, familie en vriende van die mees belangrike steunstelsels is.

Alhoewel bevindinge van die studie nie veralgemeen kan word en van toepassing gemaak kan word op die bevolking as geheel nie, kan dit egter van groot belang vir verdere navorsing wees.
CHAPTER 1

INTRODUCTION AND ORIENTATION

1.1 PROBLEM FORMULATION

It is widely accepted that the family, as the basic unit in society, is the primary source of love and individual care for children, and that it provides the setting in which children's needs can best be met. The welfare of children depends on the stability and effectiveness of the family to which they belong (Maforah, 1987:262). Hence, within the family constellation, the exceptional member, for instance a child with epilepsy, should not be viewed as an isolated entity. Gargiulo (1985:42) states that such a child can only be seen and fully understood in the context of the family unit. Whatever affects the individual, affects the family and, conversely, whatever affects the family, also affects the individual family members.

In 1987 it was estimated that there were 1250 epileptics in Mamelodi alone out of a total population of 250 000 (Social Work, 1989:79). There was one epileptic for every 200 people.

There is little doubt that the presence of an epileptic child significantly affects the functioning and role fulfillment of the entire family. Gargiulo (1985:43) for instance, believes that families with handicapped children generally encounter many complex problems that can affect the parents of epileptic children, the epileptic children themselves and their siblings emotionally, socially and financially. The father, for instance, may wish to exercise discipline and control over all the children in the family but may en-
counter resistance from the mother that the epileptic child should be left alone because he is different from the other children. The presence of the epileptic child may also deprive the husband of his wife's attention and this in turn may lead to marital discord. Ritchie (1981:70) found that the epileptic child appears to withdraw from family interaction, which can make the siblings become suspicious and perhaps interpret the epileptic child's behaviour as attention-seeking from the rest of the family.

The changes brought about by the child's condition will definitely affect the epileptic child. For instance, if he is attending school at an ordinary school and his condition becomes such that he can no longer be accommodated at an ordinary school, it may mean the end of his school career if there is no special school to which he can be referred. This state of affairs will affect the entire family negatively.

Van Rensburg (1972:105) believes that since time immemorial it has been a conspicuous fact that all communities had, and still have, their handicapped persons - people who either congenitally or through some mishap acquired a physical or mental aberration which, in some way, characterise them as different from the accepted norm. Van Rensburg (1972:105) further points out that in bygone days the handicapped persons were not wanted by society and in cases where families still cared for them, they were hidden from the eyes of the community, almost as if they would bring shame on the family.

Every community is expected to cater for the needs of its members. In turn, the community members are also expected to contribute to the development of their community. However, due to his condition an epileptic may not be able to make any valuable contribution to the development of his community and may thus become a burden to the community.
According to the South African National Epilepsy League (1987:3), henceforth (SANEL) there are 315 000 South Africans with epilepsy. The country should be concerned about these exceptional people on local, regional and national level. For instance, there is a need to address the lack of facilities in the black community and the big classes in black schools which cannot cater for an exceptional child like an epileptic.

As can be seen from the discussion so far, it is obvious that the effects of epilepsy are far reaching. It was these reasons that prompted the researcher to explore them in detail and also to look at the role of the social worker as this professional person can help to alleviate the problem.

1.2 MOTIVATION FOR THE RESEARCH

The following factors motivated the researcher to undertake research into the problem of epilepsy in the black community in South Africa, namely:

1.2.1 the lack of information regarding epilepsy in the black community, as ascertained from personal observations, dearth of literature and published research and confirmed by the Human Sciences Research Council and SANEL (See Annexure II);

1.2.2 the serious psycho-social effects epilepsy could have for the child with epilepsy;

1.2.3 the economic and psychosocial consequences of epilepsy for the family of the epileptic child.
1.3 **AIM AND OBJECTIVES**

Goal: The goal of this study was to explore epilepsy in terms of the nature, causes and implications of epilepsy for the individual, the family and society, with special reference to black families in Mamelodi, and to make recommendations regarding a possible model of intervention by social workers.

Objectives:

1.3.1 To add to the body of knowledge regarding epilepsy, its nature, causes and implications for the individual, the family and society.

1.3.2 To add to the body of knowledge concerning the role of the social worker regarding work with the epileptic.

1.3.3 To conduct research into the experience of and the effects of epilepsy on black families in Mamelodi.

1.3.4 To make recommendations regarding a possible model for intervention by social workers.

1.4 **ASSUMPTIONS**

It is proposed that the following assumptions can be tested against the data obtained from the research.

1.4.1 The traditional beliefs of the black people have a significant influence on the causes and management of epilepsy.

1.4.2 The presence of the epileptic child in the family has a negative influence on the entire family.
1.4.3 A team approach in the treatment of the epileptics helps the social worker to render meaningful service to the epileptics.

1.5 METHOD OF INVESTIGATION

1.5.1 Research Design

The research is essentially an exploratory study as very little is known about epilepsy in the black community and/or the role of the social worker pertaining to the problem of epilepsy in the black community. Further description of the exploratory study is presented in Chapter 3.

It was decided to undertake an exploratory study with a view to identifying and developing areas for further research. Grinnel (1981:298) states that exploratory research represents the first stage of knowledge building.

1.5.2 Method of data collection

The researcher selected the interview schedule as the method of data collection. Further discussion on the method of data collection is provided in Chapter 3.

1.5.3 Sample and sampling Procedure

The accidental or availability sampling method was used. The procedure is presented in more detail in chapter 3.
1.5.4 **Locality**

The Mamelodi Black Township is situated approximately 12 kilometres east of Pretoria, the executive capital of the Republic of South Africa. The township is divided into two big sections, namely, Mamelodi East and Mamelodi West. The Pienaars River divides the locality into two sections. The whole area is further divided into twelve (12) wards (Mamelodi Town Council, Mamelodi Newsletter, 1988).

1.6 **SHORTCOMINGS AND LIMITATIONS**

In the current study the following shortcomings and limitations can be identified:

- Because of the small size of the sample, it is not possible to generalise the findings to the total population.

- The researcher had to act as an interpreter. In the process of interpreting the exact information from the interview schedule the true meaning could have been lost. Since most respondents did not understand English during the interview at their homes it became necessary to interpret to them the content of the interview schedule from English to an African language used and understood by the respondents.

- A factor which may be regarded as a bias is the fact that the sample only consisted of blacks. However, since the aim of the study was specifically to focus on the effect of epilepsy on blacks, this factor is not seen as being problematic.

- The empirical work was done seven years ago (in 1988). This state of affairs can have an effect on the interpretation of the results and the recommendations made in view of all the changes in the macro environment
as well as attitudes and values which take place over a period of time.

- The parents/guardians and siblings of the epileptic respondents were emotionally involved and therefore may have shown unrealistic personal desire to assist epileptic children in the community because the family as a whole would benefit directly or indirectly.

- The researcher was compelled to interview all concerned in the family before he left to prevent contamination. The fact that all family members were present could have led to biased responses.

1.7 DEFINITIONS OF CONCEPTS

It is necessary to define some of the concepts which will be used frequently in this text to avoid any possible misinterpretation that may occur. Unless otherwise indicated in the text, the concepts indicated below shall be deemed to mean the following:

1.7.1 Epilepsy

1.7.1.1 The Encyclopedia Britannica (Vol. 12, 1982:1055) defines epilepsy as follows: "Epilepsy is a paroxysmal disorder of the nervous system recognised by recurring attacks of loss or impairment of consciousness with or without convulsive movements."

1.7.1.2 Webster's Third International Dictionary (1961), has the following definition of epilepsy: "A chronic nervous disorder of man and other animals that involves changes in the state of consciousness and of motion and that is due either to an inborn defect which produces convulsions of greater or lesser severity with clouding of consciousness or to an organic lesion of the brain produced by tumor, injury, toxic agents, or glandular disturbances."
1.7.1.3 The definition of epilepsy by Freed (1971:89) is more embracing: "Epilepsy is not, as is commonly supposed, a specific disease entity, but rather a syndrome or set of variegated concurrent symptoms projected by disease or injury of the brain. The disturbances of brain function thus produce many results in recurrent, short-lived seizures (with or without loss of consciousness) during which there may be involuntary movements, temporary paralysis, various sensations, impairment of intellectual functions, or combinations of these."

1.7.1.4 Gastaut & Broughton (1972:197) define the concept of epilepsy as: "... a chronic condition of various etiologies characterised by recurrent epileptic seizures, no matter what clinical or laboratory signs and symptoms are associated."

1.7.1.5 Terminology Committee for Social Work (1984:70) defines the epileptic as follows: "One who, because of a neurological disorder, is subject to spells of unconsciousness or semi-consciousness, whether accompanied by convulsions or not."

1.7.1.6 Shembe (1986:13) gives the following definition of epilepsy: "Epilepsy is not a form of mental disease or insanity; physical disease; feeblemindedness; or synonymous with nervous disease. It is a symptom of a disturbed cerebral function, and a seizure will occur when a group of cells becomes overactive and the well-ordered co-operation within the brain breaks down."

1.7.1.7 Dellatola (1981:42) defines epilepsy as follows: "Epilepsy is not the result nor the cause of mental disturbances; it is simply the building up of electricity in the brain cells. This results in a
discharge which causes short spells of unconsciousness, during which the sufferer feels no pain."

The definition of epilepsy by the Terminology Committee for Social Work (1984:70) appears to be the simplest and most concise. The definition does not refer to difficult medical terms - it is easy to understand that epilepsy is a neurological disorder and that the epileptic can experience spells of unconsciousness and semi-consciousness with or without convulsions.

However, from the definitions given above it is evident that the seat of epilepsy is the brain. An imbalance is experienced which culminates in the malfunctioning of the brain cells. If an equilibrium is not maintained, the end result may be loss of consciousness with or without convulsions. In contrast, the traditional medicinemen contacted by the investigator believe that the seat of "seebana", i.e. epilepsy, is the stomach and not the brain. Those parents who approached the traditional healers first before consulting the medical doctors caused negative effects in the treatment of their epileptic children because of the traditional healers' wrong conviction about the seat of epilepsy (see Chapter 4 for more details).

1.7.2 Family

The Terminology Committee for Social Work defines the nuclear family as follows: "Smallest social unit in society consisting of a man and his wife, a man and his wife and child, a woman and her child or a man and his child, usually under one roof" (Terminology Committee for Social Work, 1984:71).
The same Committee defines an extended family as: "Persons related by blood or marriage."

However, Tshabalala (1986:73) holds that for a better understanding of a typical African family, the extended family and not the nuclear family should be the major unit of analysis.

Martin & Martin (1978) cited by Tshabalala (1986:73) define a black extended family as a multi-generational, inter-dependent kinship system which is welded together by a sense of obligation to relatives, it is organised around a "family base" household; it is generally guided by a "dominant family figure"; it extends across geographical boundaries to connect family units to an extended family network; and it has a built-in mutual aid system for the welfare of its members and the maintenance of the family as a whole.

1.7.3 Parent/Guardian

For the purpose of this study any head of the household, male or female, will be called a parent/guardian. It will also mean a biological father or mother of the child.

1.7.4 Epileptic Child

For the purpose of this study an epileptic child is any person with epilepsy irrespective of age who is not yet married, but who lives with his parent or guardian in the same house.

1.7.5 Non-epileptic child

For the purpose of this study a non-epileptic child
means a normal person, whether an infant or not, who is under the age of eighteen years.

1.7.6 Sibling

For the purpose of this study a sibling is a brother or sister of the person with epilepsy.

1.7.7 Social worker

Klein (1984:18) defines a social worker as: "A professionally trained person registered as a social worker in terms of Chapter II of the Social and Associated Workers Act, No. 110 of 1978."


1.7.8 Social work

Boehm (1953) as cited by Compton & Galaway (1989:6) defines the functions of social work as follows: "Social work seeks to enhance the social functioning of individuals, singly and in groups, by activities focused upon their social relationships which constitute interaction between individuals and their environments. These activities can be grouped into three functions: restoration of impaired capacity, provision of individual and social resources, and prevention of social dysfunction."

Pincus and Minahan (1973) as cited by Skidmore and Thackeray (1982:9) give a vivid picture of the purpose of social work which fully agrees with the definition by Boehm above:
(i) enhance the problem-solving and coping capacities of people;

(ii) link people with systems that provide them with resources, services, and opportunities;

(iii) promote the effective and humane operation of these systems, and

(iv) contribute to the development and improvement of social policy.

1.7.9 Social case work

The Terminology Committee for Social Work (1984:60) defines case work as a "Social work method whereby a variety of skills, techniques and other aids are used to improve the social functioning of a client."

1.7.10 Social group work

Group work may be defined as a "Social work method whereby groups of individuals, through the handling of group processes and group relationships, are afforded the opportunity of improving their social functioning according to their capabilities" (Terminology Committee for Social Work, 1984:76).

1.7.11 Community work

According to the Terminology Committee for Social Work (1984:63) community work may be defined as a "Social work method or relating social needs to resources in the community or of developing new resources, and of promoting the integration, collaboration and co-ordination of welfare services both geographically and functionally". 
1.7.12 Traditional healer/witchdoctor

According to Lethlaka (1978:15) the traditional healer/witchdoctor is a person who is trained in the use of traditional medicines as opposed to the Western trained doctor. The traditional healer, Lethlaka (1978:15) explains further, is responsible for:

(i) diagnosis (divining)

(ii) healing

(iii) protection of individuals, family, cattle, property

(iv) supply of drugs or herbal medicines to avenge for any misfortune

(v) protection against lightning.

1.8 PRESENTATION OF CONTENTS

This dissertation is divided into five chapters as follows:

Chapter 1: contains the introduction and orientation.

Chapter 2: is devoted to the literature study, and forms the theoretical background of the literature study for epilepsy and family, epilepsy and school, and the treatment of epilepsy, and the role of the social worker.

Chapter 3: details the design of the empirical investigation.
Chapter 4: details the results of the research as a whole.

Chapter 5: contains the conclusions and recommendations.
CHAPTER 2

THEORETICAL AND LITERATURE STUDY

2.1 INTRODUCTION

In this chapter the global effects of epilepsy are reviewed in terms of both foreign and local literature. Specific attention is given to the role of the social worker who is equipped with knowledge to help the family understand the epileptic child in the different spheres of his life. It should also be noted that very little indigenous literature is available on this subject.

2.2 EPILEPSY AS AN INVISIBLE HANDICAP

Eliot (1982:131) sees epilepsy as: "... the invisible wand of catalepsy ...". This statement draws to our attention the fact that epilepsy is an invisible handicap because it is quite difficult or even impossible to tell whether or not a person is an epileptic merely by looking at him, unlike the cripple, deaf-and-mute and the cerebral palsied, whose handicaps are noticeable. Jan Krielskool: Jaarblad (1971:113) acknowledges the invisibility of epilepsy as follows: "Epilepsie is nie op 'n epileptikus se gesig leesbaar nie."

2.3 TYPES OF EPILEPSY

In order to understand the family and/or individual's experiences of this illness, attention will be given to the various types of epilepsy.

There are two main types of epilepsy, namely, idiopathic epilepsy which is primary epilepsy where the cause is
unknown, and **symptomatic** epilepsy, which is secondary epilepsy in which the cause may be determined by, for example, brain injury (Hurst, 1963:208). The following sub-types of epilepsy may fall either under primary or idiopathic epilepsy or secondary or symptomatic epilepsy.

### 2.3.1 Grand mal

According to Kemp (1963:8), grand mal is the major form of epilepsy which starts with an aura (or warning), possibly a cry, then a fall, followed by a convulsion, and ends with a variable period of unconsciousness. Sussman (1971: 114-115) believes that this term is applied to a major convulsive seizure whatever its origin, and is classically divided into various phases.

(i) **Premonitory phase**
Vague changes, irritability, etc. may occur for many hours or days prior to an attack.

(ii) **The aura**
This is a sensation of immediate impending attack, and may manifest itself as a fullness or a queer sensation in the stomach.

(iii) **The tonic phase**
During this phase the expression may be blank or the eyes fixed and the patient falls down with stiffened limbs and body, and is unconscious. He sometimes utters a cry termed the "epileptic cry". This phase may last a half to one minute and is immediately followed by:

(iv) **The clonic phase**
The initial tonic muscular contraction is usually replaced by synchronised jerking movements of the body, wherein the tongue may be bitten if it happens to be protruding. The
arms are usually in a bent position and the legs in a straight position. The patient may wet or soil himself and there is usually some difficulty in breathing, as this phase also involves contractions in the diaphragm and chest muscles. The period of respiratory arrest is followed by deep laboured breathing and sometimes frothing at the mouth.

(v) The phase of recovery
The patient is usually quiet and stays unconscious, passing into deep sleep, eventually coming round with a feeling of bruised stiff muscles, often a headache, soiled undergarments, or a bitten tongue to tell him that he has had an attack. Sometimes a period of confusion and irresponsible behaviour follows, during which automatic acts may be performed. These attacks may occur at night, in bed, and the patient only knows of the attack from maybe his wife and relatives.

2.3.2 Petit mal (Typical absence)
Freeman (1979:23) holds that petit mal seizures usually consist of very brief periods of unconsciousness that often appear to be episodes of inattention or day-dreaming.

2.3.3 Partial fits
When a part of the brain has been damaged, even if only slightly, a fit may start in the damaged area. The disturbance may then spread to involve the whole brain. When this happens there will be loss of consciousness and a generalised convulsion (Laidlaw & Laidlaw, 1980:3).

2.3.4 Febrile convulsions
The brains of very small children are sensitive and they may have generalised convulsions when they are
stressed by a high fever. Although these febrile convulsions are very alarming to the family they are seldom dangerous and most children grow out of them as their brains mature and become more stable (Laidlaw & Laidlaw, 1980:6).

2.3.5 *Status epilepticus*
When a patient has one generalised convolution after another without recovering consciousness in between, he is said to be in status epilepticus. Epilepticus must be treated at once as it is dangerous (Laidlaw & Laidlaw, 1980:7).

2.3.6 *Psychomotor epilepsy (Temporal lobe)*
Attacks are not convulsions nor is there unconsciousness, but rather disturbances of thought or behaviour. The areas of the brain affected are those responsible for ideas, conduct, feeling, and other "higher" mental activities (Kemp, 1963:9, Boshes & Gibbs, 1972:157).

2.3.7 *Jacksonian epilepsy*
This type of epilepsy is named after the British neurologist, Dr Jackson. It is symptomatic epilepsy produced by injury to the brain. It is characterised by a muscular spasm usually localised in the beginning to a few muscles (of the hand, foot, mouth, etc) on one side of the body, but it may soon spread to the entire side (Freeman, 1979:22).

2.4 *CAUSES OF EPILEPSY*

When the types of epilepsy were discussed the two main categories were identified, viz. primary or idiopathic epilepsy and secondary or symptomatic epilepsy. Where the exact cause of epilepsy cannot be traced people think their beliefs in the supernatural cause epilepsy compared to the
real causes of epilepsy like the hereditary factors and the secondary factors.

2.4.1 Beliefs in the supernatural

Winterbach (1983:115-116) has found that the black people do not believe in the natural cause of events: "Niks gebeur toevallig nie. Die geloof van die Swarte dat siekte deur bonatuurlike magte veroorsaak kan word, gryp diep op die Swarte se bestaan in. Die Swarte glo dat 'n siekte veroorsaak kan word deurdat sy voorouergeeste dit meebring met die doel om hom aan 'n oortreding of 'n versuim met die oog op die regstelling daarvan, te herinner. Die Swarte glo dat siekte ook deur vergifting veroorsaak word. Towery speel 'n belangrike rol."

Babumba (1954:375) is of the opinion that superstitious fears play an important part in the explanation of illness among blacks. When an African falls ill he begins to wonder whether his disease is not due to one of the many taboos having been broken. For example, a condition such as Parkinson's disease is believed to be due to the sufferer having touched his mother-in-law, or a daughter of his maternal uncle.

Gelfand (1964:4) determined that in Central Africa the most important cause of sickness is believed to be the anger of one of the departed parents. Even amongst Western peoples burial of the dead is accompanied by religious services with prayers, not only for the consolation of the living but also for the souls of the deceased.

In a study undertaken by Levy & Auchterlonie (1977:401) in the Semokwe reserve, each patient or parent was asked what they believed was the cause of the disease in themselves or their children, and the
answers confirmed that widespread superstition and belief in witchcraft still existed among rural Africans. Of the 130 patients seventy-seven believed they were "bewitched" either by the spirits of their ancestors or by fairies, 17 of these attributed the bewitching to some living person who was jealous of them or who had some grudge against them (Levy & Auchterlonie, 1977:401).

Mbiti (1969:169) and several other authors (Le Roux, 1973:8; Karlsson & Moloantoa, 1984:43; Dube, 1975:1; Gelfand, 1974:879; Bopape, 1975:39) believe that medicinemen are concerned with sickness, disease and misfortune. In African societies these are generally believed to be caused by the ill-will or ill-action of one person against another, normally through the agency of witchcraft and magic. "In practical life, the action of a witch is not a haphazard affair. It is a matter involving two definite people, the result of a quarrel, disagreement, dislike or jealousy" (Gelfand, 1977:15).

In this discussion on belief in supernatural powers, Mechanic (1976) as cited by Bell (1981:460) is of the opinion that in some societies supernatural powers are attributed to the epileptic.

According to Mbiti (1969:201) nothing harmful happens by chance; everything is caused by someone directly or through the use of mystical power. If you pay attention, you will hear the names of people being blamed for misfortunes, sickness, accidents and other forms of suffering in every village. In support of this Shembe (1986:14) believes that Africans do not believe that disease, ill-health and physical suffering are natural. In her opinion, these things do not follow the laws of nature, but are caused by ances-
tral spirits or by man, through the agency of malevolent spirits or the "abathakathi", i.e. wizards and witches. "Therefore, if a person has epilepsy the witchdoctor, isangoma, divine healer or other elder would be consulted first before any steps are taken to consult a medical practitioner, clinic or hospital" (Shembe, 1986:14). However, this belief in the supernatural would have an effect on the way in which a doctor, nurse, social worker approaches such a case because it would be disastrous to ignore this belief (Mokhuane, 1986:5).

Acquina (1973:52) made a study of the spirit beliefs among the Karanga men and found that the Karanga believe that their ancestors like to be remembered and that when their descendants forget them, they punish them with sickness. Mankazana, 1979:1005; Mokhuane, 1986:4-5; Mutwa, 1965:507; Olivier, 1985:1; Nxosi, 1982:120; Osuntokun, 1977:372; Gelfand, 1977:15, all share the same opinion regarding the role that belief in the ancestors plays in African societies.

Sibisi (1972:71) also states the following: "The ancestors are said to be primarily concerned with the welfare of their descendants. When good things of life are realised it is said: 'The ancestors are with us' ("Abaphansi banathi"). When misfortunes happen it is said: 'The ancestors are facing away from us' ("Abaphansi basifulathele"), for the ancestors are believed to withdraw their protection and gifts of good fortune from the erring descendants."

2.4.2 The Hereditary factor

Kemp (1963:28-31) holds that it is common, particularly in America, to refer to true (i.e. primary)
epilepsy as genetic epilepsy. This name and this view - not universally accepted - are particularly disadvantageous to the patient for several reasons:

- that epilepsy in the individual is such a terrible menace that it would have been better that he hadn't been born;

- this view suggests that the family stock carries a "taint" like haemophilia or a tendency to insanity or cancer; and

- some European countries and quite a few American states have enacted drastic and repressive laws aimed at preventing epileptic patients from marrying and/or having children.

In answer to the question "Is epilepsy inherited?" Lagos (1974:149) framed an answer in the following manner: "In more than one way, yes, but so many factors appear to be involved for the condition to be passed on from one generation to another that all practical purposes, nobody needs to worry too much about it".

Hopkins (1981:28) discloses that until about 30 years ago most doctors believed that inheritance was a major factor in causing epilepsy. This belief is still strong amongst the population at large. It is true that genetic factors do play a part in epilepsy, but not an overwhelming part.

2.4.3 The Secondary factors

According to Laidlaw & Laidlaw (1980:7) everybody is liable to have fits but only about one person in every 200 actually does. There are two causes which combine to produce fits.
(i) **A tendency to have attacks**
People are born with brains with widely differing sensitivities. Some have very stable brains and are most unlikely to have fits. At the other extreme there are those whose brains are so sensitive that they may have attacks for no obvious reasons. Brain sensitivity also varies throughout life, being high in very small children and rising again at adolescence. As patients get older, their brains become less sensitive and so fits usually decrease with increasing age.

(ii) **Damage to the brain**
If a part of the brain is damaged, that part will not work properly and may trigger off partial fits which may spread, giving rise to secondary generalised convulsions. There are many ways in which the brain may be damaged:

- Injuries from traffic accidents
- Injuries during war time
- Injuries before, during or after a particularly difficult birth
- Infections on the brain (encephalitis) or on the membranes which cover the brain (meningitis).

(iii) **Precipitating factors**
Livingston (1963:42-57) and Hopkins (1981:43-46) agree that the factors which
precipitate epileptic seizures are the following:

- Emotional disturbances
- Sleep
- Menstruation
- Withdrawal of anti-epileptic drugs
- Fever
- Environment
- Drugs and chemicals
- Alcohol

2.5 THE INCIDENCE OF EPILEPSY

Bird, Heinz & Klintworth (1966:175-187) investigated the incidence of epilepsy among mine workers in and around Johannesburg and found that epilepsy is common among Africans. The survey suggests that the incidence of epilepsy in the African is considerably higher than in white races. The age distribution indicates that the incidence of epilepsy is higher in the age group 20-24 years and lower in the age group 55-59 years. However, Barnard (1966:1022-1023) revealed that the Interdepartmental Committee on Deviate Children estimated the white epileptic population of South Africa, between the ages of 7 and 18+ years, to be 1,200 in 1945, 400 of whom were considered candidates for special education.

Freed (1971:91) is of the opinion that the incidence of epilepsy in South Africa is not precisely known, but it is
estimated that there were at that stage (at a minimum) 85000 epileptics in the Republic. Furthermore, Freed (1971:91) believes that the differential age and sex incidence is of interest. The incidence is higher in the first year of life, almost 20 per 1000. It then drops to 3,4 per 1000 in the age group 20-29 years, and rises again to 16,8 per 1000 in the over 60 age group. The condition is only slightly higher among males. Grand mal attacks are slightly more common in males than in females.

Behr (1972:30) points out that in South Africa no real survey of the incidence of epilepsy among school children has been made to date. The author maintains that in 1968 there were some 250 children with epilepsy at the Jan Kriel and the W.K. Du Plessis special schools, and some 700 pupils at ordinary schools for white pupils, i.e. ± 1,2 per 1000 of the total white school population. SANEL (1982:2) published an article in which it was stated that a special school for black children with epilepsy would be built in Bloemfontein and would be named after its founder, Sister Eileen Ntuka. When completed the school would accommodate ± 3000 pupils with epilepsy (Sunday Times Extra, October 3, 1982). Unfortunately this did not materialise because of lack of funds.

A decade ago SANEL (1981:114-115) found that about 125000 South Africans of all races suffer from epilepsy - about 500 for every 100 000 people, i.e. about 0,5% of the population. From 1981 until 1987 South Africans with epilepsy numbered ± 315 000 (SANEL, 1987:3).

In other countries like the United Kingdom and the United States, there has been an increase in the incidence of epilepsy, as in South Africa. Burden & Schurr (1980:50) state that approximately five percent of the population (or one person in twenty) in the United Kingdom will have an epileptic fit at some time in their lives, and there are
about 3000 new sufferers each year. However, Hopkins (1981:9) maintains that it can be calculated that about 5.9 percent of the total population of the community may be expected to have one or more febrile seizures at some stage of their lives.

2.6 EPILEPSY AND FAMILY LIFE

2.6.1 Family type

During a seminar on Family Preparedness (Gesinsweerbaarheid) in 1985, one of the speakers gave a lecture on South African family life in the eighty's. Because there is a diversity of family lives and family types, she posed the question: "Which family?" She made it clear that families have characteristics of their own and that African family life is mainly influenced by religion. For the purpose of this study the African family life and epilepsy will be considered. (Criminology Department: 1985 Seminar).

2.6.2 Behaviour towards epileptic

Barnard (1966:1023) believes that even in the immediate family circle, the young epileptic child soon finds that he is considered "different". He may be treated as sick or delicate, he may be pampered and spoiled, and be given preferences over his healthy siblings, to the detriment of his relationship with them. Often in this setting he develops his own particular brand of tyranny and parasitism, exploiting the concern lavished on him. Alternatively, he may be considered a burden and a tribulation, an undeserved misfortune, and he may become the cause of bickering between parents who feel guilty or blame each other for the child's condition. Furthermore,
the constant care he demands imposes restrictions on home and family life.

In their practice social workers have found that some people with epilepsy use epilepsy as a shield or defense mechanism in order to manipulate others because they have been spoiled and overprotected by their parents.

2.6.3 Reactions of family members after diagnosis of epilepsy

After the diagnosis of epilepsy has been determined by the physician, the family goes through a number of reactions ranging from ambivalence to denial. The denial sometimes culminates in complete rejection. The reactions may also include deep sorrow or anxiety, which may culminate in acceptance (Olshansky, cited by Chinkanda, 1986:6). Chinkanda (1986:6) further maintains that at times the feelings of the individual family members may be at extreme opposites, and this may lead to a great deal of tension and friction, especially between the parents. In most cases, one finds the parents either blaming themselves or each other for having brought such a child into the world.

Erasmus (1971:124) writes that the first reaction of parents with epileptic children is fear and the second reaction is guilt-feelings. However, these have not been found with African families (Hurst, et al. 1961). The following authors share this former opinion: Mosovich (1972:112); Hardy & Cull (1974:29); McCormack (1978:106); Wishner & O'Brien (1978:850); Svoboda (1979:173); Hill & Hynes (1980:576).
Barrow & Fabing (1966:26) conclude that upon learning that their child has epilepsy, parents are usually horrified and frightened and are aware of the stigma attached to the condition. The natural reaction is to conceal the condition for as long as possible. This negative approach in most cases is more harmful than epilepsy itself. On the other hand, it is important to note that in their study of neuropsychiatric disorders in the Africans living in Meadowlands, Hurst et al (1961:758) found that no relatives were ashamed of having epilepsy in their family and as a result they did not conceal the disorder. Another important factor in the development of the child with epilepsy is the way in which siblings react to the presence of a handicapped child in the family - they can become overprotective or jealous (Smith, 1969:20).

2.6.4 Treatment of an epileptic child

Livingston (1971:694) discloses that all parents of epileptic children should be instructed to allow their children to play and conduct themselves, whenever physically feasible, in the same manner as their normal associates. Social workers working with epileptics in black families are of the opinion that many families discourage their children from playing games for fear that the games may precipitate seizures.

If we consider the idea of a family as a system that operates through transactional patterns, it is significant to note that the presence of a person with epilepsy in the family will have an influence on the members of the family and the members of the family in turn will have an influence on the person with epilepsy. As Minuchin (1974:51) puts it:
"Repeated transactions establish patterns of how, when and to whom to relate, and these patterns underpin the system. When a mother tells her child to drink his juice and he obeys, this interaction defines who she is in relation to him and who he is in relation to her, in that context and at that time. Repeated operations in these terms constitute a transactional pattern."

2.6.5 Fears regarding the epileptic child

Burden & Schurr (1980:52) are convinced that a condition such as epilepsy, which may well be life-long and carry all sorts of emotional overtones, makes an indelible mark on the family history. Some parents spend a great deal of time worrying about their personal responsibilities for this misfortune, the "blemish" in the family. Hopkins (1981:116) supports Burden & Schurr by stating that many relatives of people with epilepsy are naturally concerned as to what may happen during a seizure if they are not present to assist: "I have known this anxiety carried to extremes. One of my patients, an epileptic woman of 30, was still sharing her parents' bedroom, as they were concerned that she might come to harm during a nocturnal seizure, even though she had had none for 15 years!" (Hopkins, 1981:116).

Ballard (1982:75-76) explains that the discovery of a child with a handicapping disorder represents a crisis event in the life of any family. Most families make some sort of an adaptation to what has happened, and learn to live with the consequences and to find fulfilment in bringing up a disabled member of society. Others, however, may not be able to make such an adjustment. Where one person will cope, another will not.
2.7 **EPILEPSY AND SCHOOL**

Unlike a normal child who on reaching school-going age then attends an ordinary school, a handicapped child may attend a special school suited for his type of handicap, if such facilities are available in the vicinity or affordable. The absence of such facilities may be a cause of concern for the parents of an epileptic child.

A normal child starts to attend school at the age of six or seven years. A child with epilepsy also starts attending school at about the same age, depending on his condition and the advice from physicians. According to Nkosi (1982:122) black schools have about 50 or more pupils per class. The situation is such that no teacher can pay attention to any individual pupil. Even if he recognises that particular pupils need attention he cannot immediately attend to them due to pressure of work on him. It is therefore not an easy task for him to pay special attention to a child with epilepsy even if he is aware of the child's illness. Hence the epileptic child may show poor performance at school which can disturb the family atmosphere.

Barnard (1968:539-540) differentiates between ordinary and special schools. Both schools present difficulties for epileptics. For instance, Barnard mentions that a special school represents an artificial milieu where very limited opportunities for training are prevalent. On the other hand, he points out that in an ordinary school the available personnel have very little or lack knowledge of epilepsy. However, Pryse-Phillips (1969:77) holds that there is no reason to segregate children who have epilepsy from others unless one of two conditions holds. Firstly, if the seizures are so frequent or the behaviour disorder so marked that it would be unfair to the patient and his school fellows to put him in their class, and secondly, if due to mental defect, the patient cannot learn at the usual rate.
Barnard (1970:1022) also supports Pryse-Phillips in this regard. Since there is no special school for epileptics in Mamelodi such a child may be forced to leave school and this move may affect the family negatively.

Bagley (1971:214) puts forward the idea that an emotionally disturbing situation, such as rejection by schoolmates and in some cases by teachers, could make both the behaviour of the epileptic and the epilepsy itself worse. Smith (1969:39) points out that when the child goes to school the parent then has to face the fact for the first time that epilepsy can no longer be hidden. The parents who cannot cope are empowered by social workers to cope in these situations.

Authors such as Erasmus (1971:124); Behr (1972:29) and Du Toit (1972:12) prefer to see children with epilepsy in ordinary schools than in special schools. Livingston (1972:137) believes that the teacher should definitely tell the other students that the illness is not contagious: "This may appear to be ridiculous, but we have on numerous occasions been told by some intelligent parents that they were afraid to allow their children to play with an epileptic for fear that their own children would 'catch' the disease".

McCormack (1978:124) cites a remark by one of her clients who is not in favour of the segregation of handicapped people: "One of my pet theories is that there should not be segregation of handicapped people, particularly in schools. If classes for handicapped children were attached to normal schools, you would have people growing up who were not frightened to death if they didn't know how to go about helping a handicapped person."

Hopkins (1981:125-126) is convinced that the vast majority of children with epilepsy should be educated at
normal schools alongside their brothers and sisters. Even if seizures are rare, the head of the school and the form teacher should be informed that a seizure might occur in class. The teachers will know what to expect and what to do, and they may usefully involve other children in the care of the affected child during the seizure. There is no school activity which a child with epilepsy should not do on account of his seizures, with the exception of climbing ropes in the gym. If the child has frequent seizures at school, which do not respond to anticonvulsant drugs, then there is a case for considering placement at one of the few special schools for children with epilepsy.

2.8 PSYCHOSOCIAL EFFECTS OF EPILEPSY ON THE EPILEPTIC

An epileptic who shot himself in the head left a note telling his family they would no longer have to be ashamed of his illness. The note read: "I am sorry it had to happen like this. You will be better off without me, my problem and the scandal at the SATS. Now you do not have to be ashamed because I suffer from epilepsy. Farewell..." (Pretoria News, September 25, 1985). Had the social worker known the plight of the deceased in time his family would have been sensitized on how they should behave towards the epileptic with the aim of any possible attitude change for purposes of prevention.

To explain why, as in the above named case, a person with epilepsy decides to take his own life, Hines (1981:43) is convinced that it is because there is a difference between an external situation, or fact, and an internal one, or feeling. It is a fact that the person suffered from epilepsy but it was not known how he felt about his family's attitude toward him until the family read the suicide note. Hines believes that this happens because in life each situation sets up a reaction.
Op't Hof (1985:15.1-15.11) discusses the psychosocial aspects of the handicapped child's experience of his handicap under the following headings:

- The handicapped child's experience that takes place within his own relationship with himself;

- Experience within his relationship with other people, especially his family;

- Experience within his relationship with things;

- Experience within his relationship with God.

These aspects will now be discussed in turn.

2.8.1 The epileptic and his relationship with himself

The National Occupational Safety Association (NOSA) has laid down statements concerning the child, for example, "a child who lives in criticism learns to condemn". A person with epilepsy who is ridiculed by his peers may easily learn to be shy. This means that the person with epilepsy may develop a negative self-concept (Encyclopedia Britannica, Vol. 16 1982; Pearlman & Scott, 1981:147).

Hopkins (1981:122) states that the ability to cope with epilepsy depends primarily upon the strength of personality of the epileptic. Depression and inability to cope with the life situation caused by epilepsy may be so severe as to cause the unfortunate sufferer to take his own life. Middleton, Attwell & Walsh (1981:37) hold that self-induced seizures are not uncommon. Some people do it deliberately. Others, usually children, have been able to cause a seizure by using a particular reflex stimulus
(e.g. a flashing light) that they know precipitates an attack.

Barrow & Fabing (1966:22) disclose that it is commonly thought that epileptics range lower on the intelligence scale than non-epileptics. Of course, an unintelligent child, may suffer more trauma than a child of normal intelligence and this may cause seizures. However, it does not appear that the level of intelligence, as such, is a factor in epilepsy. Many of our most intelligent, creative people have achieved greatness notwithstanding the handicap of seizures. Among the great rulers of history who have had epilepsy may be mentioned Julius Ceasar, Napoleon Bonaparte, Peter the Great of Russia, Louis XIII of France, the Roman Emperor Caligula - to mention only a few.

Livingston (1977:6) believes that the most serious hazard of epilepsy is frequently not the seizures per se, but the associated behavioural and emotional aberrations that are prone to develop in patients with this disorder. Epileptics frequently develop antisocial tendencies, feelings of inferiority and of being "different". In support of Livingston, Laidlaw & Richens (1976:10) express it in the following way: "It is small wonder therefore that such a patient may come to look upon himself as a secondhand citizen, prevented from living a normal life through no fault of his own."

Mittan (1992:5) is of the opinion that for the person with epilepsy to feel good about himself he must accept his situation, he must get the best treatment possible and that when self help does not work and his doctor has checked out the medical aspects, a professional counsellor must be sought. According to
Mittan (1992:6) social workers and psychologists are there because people need help once in a while. Mittan (1992:6) concludes that it is a wise person who knows what is needed and goes and gets it, rather than sitting back and hoping that somehow things will correct themselves.

2.8.2 The epileptic and his relationship with other people, especially his family

According to Ritchie (1981:68), the epileptic child has been found to withdraw from family interaction. However, Hopkins (1981:119-120) who is convinced that epilepsy is an invisible handicap, holds that a major problem that someone with epilepsy has to resolve, is how much to tell, and to whom. For example, no mother wants to tell everyone that her son has epilepsy, but if the boy is staying the night at the house of a friend, it is only sensible to let his friend's parents know that he might have a seizure, and to tell them how to cope.

Middleton, Attwell & Walsh (1981:37) are of the opinion that children, and occasionally some adults, may use seizures as an escape mechanism or means to gain attention. They may find that there are advantages to having seizures, such as getting increased attention from persons important to them, being cared for, or avoiding responsibilities expected of them that they do not feel capable of handling. For these individuals, the benefits of seizures outweigh all the negative consequences.

Laidlaw & Laidlaw (1980:44) argue that it must be accepted that there is still considerable fear of and prejudice against a person with epilepsy. Acquaintances, school fellows, workmates and the general
public with whom the patient comes into contact are likely to reflect to an important degree the attitudes of family and close friends to the patient and his epilepsy. Sullivan (1979:123) shares the same opinion. Appolone (1978:141) describes the fantasies and fears of parents of epileptics by stating that some authors have suggested that parents unconsciously feel hostile or rejecting towards the epileptic children and the children can sense it. Lerman (1977) as cited by Appolone (1978:145) extends the idea further by identifying overprotection as the main problem in causing maladjustment in epileptic persons. Further, Livingston (1977) as cited by Appolone (1978:145) reports that parents may regard the epileptic child as a pitiful, unfortunate person and feel, therefore, that they should make no demands on the child.

Tavriger (1966) as cited by Appolone (1978:141) states that the parent of an epileptic child may have the notion that his child has blood clot in the brain and this might lodge itself in another part of the brain and cause him to "go crazy" or might lodge in his heart and cause him to die. Appolone (1978:141) points out that these fantasies and fears seem to emerge from the parents' emotional needs and are seldom the least scientific. Families, according to this author, frequently do not reveal these beliefs to the doctor and will do so to the social worker rather sheepishly. They seem afraid of appearing ridiculous. Only when such ideas are openly discussed can they be disarmed. These fantasies not only feed the parents' anxiety but may interfere with treatment (Appolone, 1978:145). However, death seems to be the most prevalent fear.

Authors such as Gunn (1977:91) and Mulder &
Suurmeijer (1977:17) agree that from the interviews with parents and children it appears that the child with epilepsy functions in social isolation. "I am looked upon as the black sheep of the family. The trouble is I can't get a proper job - they won't have me at home anymore..." (Gunn 1977:91).

Mbiti (1973:178-179) argues that the whole family, including other children and relatives, as well as friends and visitors, should avoid making the disabled child feel too conscious of his disability. This could make him despair and become discouraged, which would worsen the situation by creating a permanent sense of inferiority in him. Love for the disabled child will do for him more than what anything else will. It will give him a feeling of being wanted, accepted, and respected as an individual in spite of his disability.

2.8.3 The epileptic and his relationship with things

Before it is established that the seizures in a specific person are controlled the person may not be allowed to drive a car. The person with epilepsy may feel unhappy about it and this in turn may affect the entire family because their supportive role will be threatened.

Livingston & Berman (1973:237) cited an example of a student who was restricted from playing soccer at college because his doctor insisted that he had brain-injury. In response to this restriction he withdrew from college and became emotionally ill. He became depressed and full of anxiety. When Livingston & Berman (1973:237) recommended that he be allowed to play football again his emotional aberrations disappeared. He then graduated with good
grades. Authors such as Pryse-Phillips (1969:80) and Smith (1969:38) agree that the person with epilepsy must not go swimming alone but must be accompanied by a good swimmer to help him at the time of emergency. Commonsense decisions must be made in each case but we can be fairly certain that the boredom and frustration of not being allowed to do the same things as his peers is likely to cause more trouble as far as his epilepsy is concerned than the risk he would be taking in most cases if he is allowed to do these things.

Mittan (1992:5) explains that a person with epilepsy has got to do something that will satisfy him, will give him a sense of accomplishment, a sense of meaning as an individual. If he does not have a regular job he must have a regular hobby. He further mentions that the person with epilepsy must do one or two of the following things:

- Volunteer for work at a hospital
- Grow a garden
- Keep a pet and take it to shows
- Join an art or pottery class (Mittan, 1992:5).

2.8.4 The epileptic and his relationship with God or a Supreme Being

Riga (1983:1) believes that the problem of people who believe in the supernatural with regard to epilepsy is common to all the racial groups. The magnitude of the problem, however, is by far the greatest amongst our African people. This is due to their strong cultural and traditional beliefs. A person who
cherishes the belief that sickness, pain, bodily suffering and well-being are all perceived to be the net result of a fine balance between the living, the dead and his relationship to God or a Supreme Being may to a great extent be influenced by his belief.

Riga (1983:1) further states that the African people's general lifestyle is designed on a firm conviction of the existence of the spirits of their departed forefathers. Their departed ones, 'Abaphansi', can influence their lives for better or for worse, in health and diseases, as well as in prosperity. In times of crises the African turns to those very spirits for help.

A person with epilepsy may believe in the existence of God but may also believe that his relationship with God may be effected through his relationship with ancestral spirits (badimo). The African prays by spitting water on the ground while saying what he wishes to say to his forefathers. After communicating with them by spitting water on the ground, snuff is then sprinkled on the ground.

The parents' relationship with God will have a bearing on the epileptic child's relationship with God. If the parents uphold Christian principles and beliefs the child may have a different relationship with God than his counterpart whose parents believe in ancestral spirits. In times of crises the parents who believe in Christian teachings may turn to the medical practitioner or priest while the parents who believe in their departed ones may turn to the traditional healers.

However, Nkosi (1982:116-117) believes that the religious tradition of the black people was ancestor-
worship (worship of the spirits of deceased members of the family). Mkosi (1982:116-117) further maintains that this religion has been to a great extent replaced by Christianity. The black people are mostly members of numerous Christian denominations and sects. Embracing christianity has effected a change in the family. Hence, the parents of the epileptic child are likely to adhere to christianity particularly in an urban area where this research took place.

2.9 THE TREATMENT OF THE EPILEPTIC

The person with epilepsy has a choice of being helped by professionally trained people like the social worker, the nurse, the doctor, the occupational therapist and many others. Furthermore, the epileptic and/or his family may seek help from the unprofessionally trained people such as the traditional healer, friends and relatives. Therefore, it is important to look into the treatment of the epileptic focusing more attention on the above mentioned scenarios.

2.9.1 Epilepsy and multi-disciplinary approach

Social workers who are attached to any agency cannot on their own do much in helping people with epilepsy. The community nurse or physician at the clinic or hospital cannot do much on their own. The teacher or priest cannot do much on their own. The traditional healer or medicineman cannot do much without the help of the other professionals in their own fields. Furthermore, all the professionals mentioned above need the help of the handicapped person, that person's family, other professionals and the community for them to succeed in their service provision.

According to Compton & Galaway (1989:610) teamwork is
defined as follows: "cooperative effort of an organized group to achieve a common goal".

In his paper on the "Social Problems of Black people who suffer from epilepsy" Nkosi views a complete team who work together as follows: "The handicapped person, the family, the physician, the teacher, the social worker and the community" (Nkosi 1982:133).

The purpose of coming together as a team is not to win one's way or prove one's rightness but use the different capacities brought by the different members of the team to expand their knowledge and their range of skills so that they can offer the client the best service in the direction that the client wishes to go (Compton & Galaway, 1989:610). The essential aim of treatment is to enable clients to lead as near normal lives as possible; that is to say, they should be capable of earning their living and of enjoying their leisure in a reasonably normal manner (Reynolds & Trimble, 1981:363).

2.9.1.1 Membership of the multi-disciplinary team
Reynolds & Trimble (1981:363) hold that, broadly speaking, the members of the multi-disciplinary team are those whose disciplines fall within the province of neuropsychiatry. In the most ideal circumstances, it would consist of the following members:

(i) The neurophysician. The role of the neurophysician can generally be regarded as primary in the sense that he begins the work of the team by investigating the epilepsy as such. He must search for causes that can be removed or modified and should be the initiator and controller of drug therapy, keeping a careful watch for adverse effects of all kinds. In
many respects he is probably best equipped to be the leader of the team but this need not necessarily always be the case (Reynolds & Trimble, 1981:365).

(ii) The clinical neurophysiologist
Stores as cited by Reynolds & Trimble (1981:-366) is of the opinion that the clinical neurophysiologist is primarily concerned with determining the type of epilepsy coupled with observations on the extent and distribution of seizure discharge.

(iii) The psychiatrist
With a special interest in epilepsy the psychiatrist has acquired an increasingly important role in the work of a multi-disciplinary team. This is because of the high incidence of associated psychiatric disorders in patients, especially those referred to special centres, and he therefore often has an important part to play in day-to-day management (Reynolds & Trimble, 1981:366).

(iv) The clinical psychologist
A clinical psychological assessment of all patients with chronic epilepsy is essential in defining suspected or unsuspected areas of cerebral dysfunction, in determining levels of intellectual functioning, in assessing progress and in providing educational and vocational guidance. Furthermore, the clinical psychologist has an important role to play in the development of new methods of seizure control other than by drug therapy (Reynolds & Trimble, 1981:366).
The Social Worker

The services of a social worker, whether medically or psychiatrically trained or both, are almost invariably required in all cases of chronic intractable epilepsy since associated social problems are to be expected in virtually every case. These range from the very mild, which can be easily disposed of, to the severe which can only be partially resolved, if at all. The social worker with the right kind of interest and training must make a thorough inquiry into the patient's socio-domestic situation, supplementing this with interviews with relatives, employers, teachers, and with home visits. Liaison with all relevant social services is essential, particularly when after-care is being arranged (Reynolds & Trimble, 1981:366).

Van Staden (1988:269) explains the role of the social worker when a person apparently shows symptoms of depression by being passive as a result of insufficient self-confidence. The same situation can be experienced by an epileptic, and then according to van Staden (1988:269) insufficient self-confidence can be dealt with by means of guidelines for the practising of self-asserting behaviour.

By acquiring self-asserting behaviour in situations with specific problems, symptoms are relieved, the causes eliminated and the self-image of the person strengthened. Self-asserting behaviour can be acquired in groups or individually. Adequate exploration is, however, important for making the most acceptable diagnosis (van Staden, 1988:269).
It is most appropriate for the social worker to engage an epileptic in family therapy as the focus is directed to the interaction of the family which includes the total manner in which the family members get on together as well as the effect they have on each other. (Van Staden, 1988:269).

(vi) The nursing staff
Reynolds & Trimble (1981:366) are convinced that much of the success of a multi-disciplinary team depends upon the contributions made by specially trained nursing staff. In many ways their role is the most difficult of all since they are responsible for the daily care of patients who are often resentful and bitter about their lot. Truculence, aggressiveness, passivity, apathy, personal inadequacies and uncooperativeness are frequently the features of behaviour with which they have to cope; however, those who undertake such work should appreciate how vital are their contributions in terms of the daily observations they make on the general behaviour of their patients in addition to more specific direct observations on the nature, features and incidence of their attacks (Reynolds & Trimble, 1981:366).

(vii) The occupational therapist
An occupational therapist is able to give invaluable assistance in the day-to-day management of medium or long stay inpatients. Occupational therapy is needed not merely as a diversion but as a means of developing overt
or latent skills which can often do much to raise morale and build up self-confidence. At the same time patients' attitudes and handicaps related to visual-spatial and motor skills can be assessed in a practical manner. Usually patients begin with simple handicrafts and thereafter progress in stages to work in an industrial therapy unit. Furthermore, it is helpful if the latter requires short-distance travel by public transport at regular hours in order to re-establish the habit of regular time-keeping lost during long periods of unemployment (Reynolds & Trimble, 1981:366-367).

(viii) **The physiotherapist**
There are more general ways in which the physiotherapist can help. For example, the organization of ball games, swimming, can do much to improve impaired motor co-ordination and provide pleasant recreation for patients needing a boost to their morale and self-esteem (Reynolds & Trimble, 1981:367).

(ix) **Technicians and secretaries**
They are important contributors to the work of the multi-disciplinary team which would virtually be impossible without their assistance. Furthermore, their interest in the care of patients is to be encouraged as a valuable aid to the successful functioning of the team as a whole (Reynolds & Trimble, 1981:367).

The technicians are knowledgable about various technological equipments like blood level
testers and EEG testers. They, therefore feed the relevant information to the team members or to the panel discussions. It goes without saying that the secretaries are equally important because they render supportive service to the production worker by having reports and memorandums typed and ready for submission to the panel discussions or case conferences. The management cannot exist without the secretaries because the latter are the link between management and the external environment and they are valuable internal resources for any agency.

(x) **Significant others**
The multi-disciplinary team may from time to time need the assistance of the traditional healer in order to understand the beliefs of the person with epilepsy better. Hence the traditional healer may become a potential team member depending on the policy of the agency concerned. Parents, relatives, friends, teachers, priests and many more significant others can make valuable contributions to the team if approached to do so by the social worker, for instance, who is a bona fide member of the multi-disciplinary team.

2.9.1.2 **Mode of operation of the multi-disciplinary team**
According to Reynolds & Trimble (1981:367-368) for a multi-disciplinary team to operate successful inpatient or out-patient service there are a number of basic prerequisites.
- Each member must adapt his discipline and apply his resources to the problem in hand.

- In the approach to a new case, the leader of the team would normally invite the appropriate individual members to undertake whatever investigation is necessary when the case is first presented for discussion.

- Thereafter it is essential that the multi-disciplinary team should hold regular conferences so that management can be co-ordinated and progress assessed.

- The main role of the leader of the team is to integrate the information and advice submitted by the members of the team, to resolve all differences of opinion as far as possible and to act as the final arbitrator when reconciliation of views is not possible.

- Individual members of the team should be prepared to make reasonable concessions whenever this is in the best interests of the patient.

- At all times the leader should exercise tact and understanding in the interests of a smoothly working team and ensure that every contributor has a fair hearing.

According to Van Staden (1988:268) the social worker as a member of a multi-professional team contributes from the three acknowledged methods, viz case work, group work and community work. The focus of the social worker is directed mainly on the family
system, mutual influencing and symptom maintenance as well as on the degree in which the family system and sub-systems can satisfy the needs of the person with epilepsy (Van Staden, 1988:268).

Taylor (1987) as cited by Van Staden (1988:269) states that the best program of treatment can be formulated after the social worker has explored the patient's:

- home and ecological environment;
- academic knowledge;
- social cognitive abilities;
- level of current and past social skills functioning;
- quality and quantity of social support systems; and
- degree of medical chronicity.

However, Compton & Galaway (1989:612-613) acknowledge the fact that teamwork has some distinct advantages of bringing a shared expertise to the client and providing a mechanism for the coordination of services. They also concur that there are also some disadvantages that need to be weighed and considered before making a decision regarding the use of teams.

One clear disadvantage is the cost. In a black developing or poor community this would certainly be a problem. Team meetings requiring the time of several professionals can be a costly use of resources. A second disadvantage is that often clients are
excluded from the process. This is perceived as very inconsistent with social work practice because one of the functions of a social worker should be to ensure that, preferably, the client is present at the team meeting (or at least has the opportunity to be present) and if this is not possible, that the client is fully informed and advised of the team meeting and a systematic way is developed to ensure input of client views into the team decision making (Compton & Galaway, 1989:613).

Epilepsy is beyond doubt a medical problem which needs to be addressed by the medical personnel first. Barnard (1970:17) believes that the seizures of practically all epileptics can be lessened considerably if the right medicine(s) and the correct dosages are administered. Parents should therefore be advised by the community nurse or social worker to have the child thoroughly examined, preferably at a neurological clinic where the necessary special methods of investigation will be employed to make a full diagnosis of the child's type or degree of epilepsy. It is considered essential today at least to examine all epileptics with an instrument measuring electric brain waves, called the Electro-encephalo-graph or E.E.G. With this electronic device the specific nature of the child's seizures can be determined (Barnard 1970:17).

The doctors and nurses should co-operate with the social workers because epilepsy as a medical problem can bring about psychosocial difficulties in families of epileptic children. With his knowledge of counselling the social worker can educate the parents of an epileptic child who fallaciously believe that an increase in the dosage of medication will cure the child sooner. The fact that an epileptic child may
need to take medication for the rest of his life may also cause the family distress. It is, therefore, the task of the social worker to interpret to the family the essence of epilepsy and medication in order to alleviate distress. For instance, parents who blame themselves for the mishap in the family may develop feelings of resentment and a poor self-image which can be destructive to the entire family if social work intervention is not sought in time.

Bodibe (1988:36) investigated the possibility of including traditional healers in a mental health team. According to her the mental health team specialists, most of the time, communicate with the patient through an interpreter. This poses a problem for the therapist when one considers strategies of probing, reflections, in trying to reach the core of the patient's problems (Bodibe 1988:36). This author believes that the traditional healers are knowledgeable about the culture and belief system of their patients. If the therapist is not of the same culture as the patient, or the therapist is not well versed in the culture of the patient, he/she is bound to make erroneous assumptions or conclusions about the patient's problem. For example, the patient might tell the therapist that his ancestors are talking to him and in Western culture that could be interpreted as having hallucinations. The patient may want to slaughter a fowl, sheep or goat and thereafter "feel okay" because he has propitiated the gods (ancestors). The social worker dealing with epileptics therefore, need to acquire this knowledge in order to be able to interpret correctly the behaviour of the person with epilepsy.
2.9.2 Medical attention and treatment

SANEL (1987:6) believes that any investigator who wishes to determine the effects of epilepsy on a group of people should ascertain whether the epileptics take medication regularly and correctly. Social workers rendering service to people with epilepsy agree that the medical problems of such people should be attended to first. The social workers hold that people with epilepsy wish to know the following: "Why am I sick? Why should I take medication? Why am I not cured?" However, the argument of Mulder & Suurmeijer (1977:22) that patients with epilepsy do not only need medical help but also help for psycho-social problems, is well recognised.

Voeller and Rothenberg (1973) as cited by Appolone (1978:144) point out that the most common cause for lapses in seizure control is failure by parents to comply with medication. Mare (1986:10) supports the abovementioned statement by saying that if children become troublesome, mothers tend to increase the dosage of medicine in the hope that such incorrect medication will make the affected child better.

Van Rooyen (1990:5) is of the opinion that to effectively suppress the abnormal electrical discharge in the brain, the right amount of the anti-epileptic drug must be present in the brain. She maintains that too little of the drug might result in seizures and too much can affect the brain and result in all sorts of unwanted effects, such as inco-ordination or an inability to walk properly.

The amount of anti-epileptic drug that reaches the brain will depend on the amount which is present in
the blood. Once the patient's blood concentrations reach a "steady state" (usually after taking medication regularly for about a week) therapeutic drug monitoring can be done to determine whether the patient's blood level is within the therapeutic range or therapeutic window. The therapeutic window refers to the blood concentrations between the minimum effective concentration and the maximum safe concentration (Van Rooyen, 1990:5).

Van Rooyen (1990:5) further states that when treating a patient the aim is to achieve and maintain blood levels within the therapeutic window. The doctor or neurologist will have some blood samples taken from the patient, from time to time, to measure the blood levels of the anti-epileptic drugs, not only to select the correct dosage, but also to determine the right interval at which the drug is to be taken by the patient.

2.9.3 The role of the traditional healer

Dube (1975:1) postulates that whenever there is misfortune in the daily activities of the village, or when the villagers want to ensure success and protection, they resort to medicine. Medicinemen provide help in times of need. There are, however, some who use medicine for evil ends. Medicine has two functions, the one therapeutic and the other magical. Dube (1975:1) further holds that when anything goes wrong in a village, especially if a person falls ill or animals sicken, the head of the village consults a diviner who usually indicates the cause of disturbance and refers the village head to a herbalist.
Temkin (1979:103) found that the remedies which were used in medieval times to fight epilepsy were both rational and superstitious on the one hand, magic and religious on the other. Temkin furnishes examples of "sacred medicines", as he calls such superstitious prescriptions: giving a frog's liver, smearing the patient's mouth with blood, to killing a dog and letting the patient have its bile, advising the person who first saw the epileptic fall to urinate into his own shoe, stir the urine, and give it as a drink to the patient (Temkin 1979:103).

Schweitzer (1980:28) holds that the iggira (traditional healer) does not choose this role but is called to the profession by the ancestors: "My subjective impression of the efficacy of treatment has generally been very favourable. I have interviewed patients on a number of occasions who were treated unsuccessfully by Western trained doctors. They then visited an iggira as a last resort and found satisfaction". He further points out that a well recognised fact in psychotherapy is that the person who is most knowledgeable about the patients' value system is best able to be of help. There can be little doubt that the indigenous healer is, in the majority of cases, best able to understand his or her client's difficulties, needs, beliefs, goals, alternatives and expectations, and therefore the one most likely to be of meaningful assistance. However, Schweitzer (1980:28) also acknowledges the fact that there are organically based conditions such as epilepsy and post-traumatic psychoses that require medical care. In this regard Western medicine has an important role to play.

Janzen (1978) as cited by Edgerton (1980:167) indicates that depending on preference, the recourse
is either to a nganga (traditional healer) or to a practitioner of Western medicine. If healing takes place, it may be concluded that the affliction was natural ("of God") and concern may end there. But if the illness persists, as epilepsy does, then it is thought that the cause is either "human" due to misconduct on the part of the sufferer, or "supernatural", due to witchcraft or sorcery.

According to Winterbach (1983:118) symbol and association play a very important role in the use of medicine. For example, green medicine is associated with growth and it is usually given to children. Hanekom (1972) as cited by Winterbach (1983:118) puts it as follows: "...beskrywe watter bestanddele almal met 'n simboliese betekenis, vir medisyne vir 'n epileptikus gebruik word. Onder andere word die kop van 'n sekere duif gebruik aangesien die duif geneig is om soms deur die lug te tuimel, soos wat epileptikus geneig is om te val. Hierdie duif keer nie na sy nes terug nadat hy uitgebroei is nie en daarom sal die epileptikus nie weer die siekte opdoen nie."

Olivier (1985:1) has disclosed that Dr Elliot, director of the Division of Education and Science at Medunsa, found that even black medical students at Medunsa still believe that some illnesses can only be cured, and natural phenomena (such as lightning) only controlled, by the witchdoctor, who has much more status than is generally realised. During a TV series on Aids on 86/12/11 Dr Sher remarked that traditional healers are health-care witnesses and have contact with 80% of black patients.
2.9.4 **The role of the social worker guided by the treatment approach based on contracting in problem solving**

There are a good number of theoretical approaches utilized in social work practice such as problem solving; behaviour modification, crisis intervention, but for illustration, the main focus will be put on Smit's (1983) and Hines' (1981) approaches namely treatment approach based on contracting and thresholds: taking control by learning to make decisions respectively.

Contracting in problem solving in social work implies the entering into a working relationship (agreement) between the worker and the client, where both of them have some basic understanding as to the major goals to be pursued and the procedures to be used in the helping process so that they both own the same thing (Egan, 1990:80-81). He further explains that the client has the basic right to know about the purpose and nature of helping and must have the freedom of choice about his participation.

Cormier and Cormier (1975) as cited by Egan (1982:25) have noted that a helping contract designed to help a client change some behaviour has the following basic features:

- The contract should be negotiated, not proclaimed by the parties involved i.e. helper and client;

- The contract should be clear to all parties involved. They should know what helping is about;

- Some kind of oral or written commitment to the contract should be obtained;
- The contract should be reviewed as the parties progress, and revised if necessary.

2.9.4.1 The use of the contract in problem solving

(Individual client)

Any welfare agency follows a specific procedure in determining whether or not an applicant has come to the correct place. Usually, this task is allocated to the intake worker. Social work administration plays an important role here because the policy of the organisation should be well known to avoid any inconvenience to the person with epilepsy, for instance.

The social worker during intake can use all the resources at his disposal to help in the identification of the problem, which is then discussed with the epileptic client and the necessary adjustments are then made. In other words, both the worker and the epileptic must agree on the problem as identified.

For instance, there is a lack of understanding and acceptance of epilepsy on the part of the person with epilepsy and his family which results in poor seizure control (Jackson, 1991:1). According to Jackson (1991:1) the possible psychosocial problems experienced by people with epilepsy are the following:

(1) Ignorance re condition of epilepsy;

(2) Ignorance re role of medication;

(3) Poor seizure control;

(4) Ostracism/prejudice by primary and secondary groups;

(5) Interpersonal relations problems;
(6) Learning difficulties;

(8) Employment difficulties;

(9) Financial problems;

(10) Accommodation problems.

The identified problem, according to Smit (1983:2) becomes the point of departure (starting point) of treatment and has the following advantages:

- The client has a share in the problem identification.

- He becomes aware of his responsibility in the treatment programme.

- Insight is already being developed and he gains perception into his own behaviour.

- He is acquainted with the demands of his involvement in social work.

Smit (1983:2-3) believes that after the identification of the problem, both the worker and the client get involved in the determination of the expected change. This then becomes the aim (target) of treatment and has the following advantages:

- The worker is enabled to determine how realistic the client is concerning himself and possible change;

- Both the worker and the client can realize what is to be achieved and it offers security to both of them;
- The client can visualize the worker's role and get an idea of what his involvement with the worker entails;

- The client can effectively look at himself and his problem and attend to it (Smit, 1983:1-2).

If earlier identified problems are poor seizure control, poor interpersonal relationships and employment difficulties, the target (aim) is then set for each problem situation. The next step will then be to determine with the epileptic, the method to be used for treatment, that is, through case - or group work. This has the following advantages:

- The epileptic develops a more direct interest into how his problem is to be attended to;

- The epileptic's own choice and responsibility is emphasized here;

- The epileptic's motivation is improved and he also gains knowledge of how the group can be of benefit to him as an individual.

The last but one step will be role-expectations. The role expectations of both the worker and the epileptic are then clarified. The epileptic knows what demands the worker will place upon him. He also knows the worker's limitations and what he expects from him. Attention is then given to the time aspect which is the last step in the contract. The epileptic's responsibility, involvement with himself, individuality and free choice are therefore really emphasized and cultivated. The epileptic can therefore realistically think in terms of which problem is the most critical and should therefore be attended to first (see Figure 2.1).
## FIGURE 2.1: INDIVIDUAL CONTRACT

<table>
<thead>
<tr>
<th>PROBLEM IDENTIFICATION (Point of departure)</th>
<th>EXPECTED CHANGE (Target)</th>
<th>METHOD (TREATMENT)</th>
<th>ROLE EXPECTATIONS (TREATMENT)</th>
<th>TIME</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Ignorance of epilepsy</td>
<td>Gain more knowledge on epilepsy</td>
<td>Group-work</td>
<td>Co-operation - Honesty - Honour appointments - Involvement</td>
<td>Sept 1992</td>
</tr>
<tr>
<td>2. Poor seizure control</td>
<td>Better seizure control</td>
<td>Case and group work</td>
<td>Honour appointments - Give directions - Prepared to listen</td>
<td></td>
</tr>
<tr>
<td>3. Poor self image</td>
<td>Better self image, self determination. Decision-making</td>
<td>Casework</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Interpersonal relationships: Shallow; maintain self agression</td>
<td>Maintain meaningful interpersonal relationships</td>
<td>Case and group work</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**SOURCE:** ADAPTED FROM SIGNED: SMIT (1983:4)

**ADAPTED FROM:** SOCIAL WORKER .......... EPILEPTIC ............
The epileptic can be taught how to take an appropriate decision through the following approach by Hines:

**Five-step approach:**

Hines (1981:42-44) has formulated a five-step decision-making approach which can be adopted for the treatment of persons with epilepsy. The approach is taught in one-to-one and group sessions, usually over a period of six (6) to twelve (12) weeks. A variety of techniques are employed, including a particular emphasis on visual symbols and mental images to help clients keep the concepts in mind. This also allows for participation by those with minimal reading and writing skill. The approach is called Thresholds: Taking control by learning to make decisions.

**Step 1: See the situation clearly**

Right at the beginning, the client is shown an arrow (his life) with X's marked along its length as illustrated below. (Each X represents a separate situation in life, for example, an epileptic hated or rejected by his siblings).
The following assumptions underline Hines' approach:

- That life is a series of separate situations, not one continuous, formless event;
- That we have control over our own lives;
- That we are different from the people without epilepsy only in as far as the disorder is concerned;
- That we can look at, and decide about, each of life's situations by pulling it out of the life-line and examining it as though under a microscope. The symbol becomes:

![Diagram]

At this point, the client may cite a real situation from his life, for example, his parents may be so concerned about his epilepsy that they feel he should share a bedroom with them in case he experiences an attack at night. In the course of analysing these situations, another important concept emerges: There is a difference between an external situation, or fact, and an internal one, or feeling. Here the
"Facts and Feelings Person" is employed, as represented below.
Internal feelings are placed within this outline of a person and external facts outside of him. The ability to make this distinction enables clients to see that there is more than one possible feeling that can result from any given external situation, and therefore more than one way of acting in response to it. Understanding this allows them to make decisions on how to act in given situations, rather than reacting automatically. If someone laughs at an epileptic after the latter has experienced an attack, the epileptic does not have to punch him, but he can ignore him or say something to him without being aggressive.

**Step 2: Know what you want**

If one does not know what one wants, one may become enmeshed in a reaction cycle. For example, if the epileptic is told by the doctor to take medication regularly so that his condition may be controlled but the epileptic does not want to listen, this suggests that he does not know what he wants. Each situation (S) sets up a reaction (R), which causes a slightly different situation (e.g., having a seizure twice a month instead of once a week) which in turn sets up a new reaction, and so on, as depicted in the sketch below.
If the client is not aware of such cycles, someone else may be "running his show", so to speak. If the client knows what he wants, he can break those cycles. Common verbal images may be created by the client with his teacher to represent that he has been reacting, not deciding. Like a dog chasing his own tail, a jack-in-the-box, a ping-pong ball bouncing back and forth, or a fish-in-a-bowl, someone else is in charge.

At about this point, the client learns that for every problem there is a goal. When we know what we want to do about a problem we have, that becomes our goal. For example, if alcohol precipitates an attack and the person with epilepsy knows what he wants to do about this (e.g. wishes to seek external help) he has a goal.

Step 3: Expand the possibilities
There is more than one way to reach a goal, for example, when an epileptic experiences the first attack he may quickly consult a medical practitioner, a traditional healer, a priest, a friend, a relative or a social worker for help. Brainstorming is employed during the session to demonstrate how different problems can be dealt with. For example, situations or problems are stated, goals are determined, and lots of possible solutions are generated.

The symbol used here looks like the sun, its rays representing all the possible routes to a goal as depicted below. There are 360 degrees of possibilities. Clients are encouraged to discard their ideas of right and wrong, cool and stupid - for the time being - as these are internal censors that have stopped them, in the past, from seeing all the possibilities. Take the example of an epileptic who
has been told that he is good for nothing by his friends and he has therefore developed a poor self-image. He must now realise that there is a possibility of viewing himself positively.

When the client realises that many possible choices exist, he increases the probability of making a decision that will get him what he wants.

**Step 4: Evaluate and decide**

Since evaluating means weighing factors, situations, or values against each other, in this step clients learn how to deal with risks, odds, and outcomes. **Risk** is depicted as a broken heart, **odds** looks like a cross between a card and a dice, and **outcomes** is a set of arrows pointing in different directions.
Here clients are helped to become aware of values they already use to decide about situations, and are shown how to make this process a conscious one. This is also the step in which decisions are finally made.

**Step 5: Act**

Clients set up a detailed plan of action, including goals, strategies, and tactics, as well as a timeline showing when each element will take place. The client is encouraged to look back and review his plan, reviewing each of the elements so as to avoid slipping up in carrying out the plan. Finally, the client is encouraged to celebrate, or reward himself when the action is completed.

The key words are: see, know, expand, evaluate, act. Yet this is not all. Clients also work on choosing their attitudes, deciding what it means to take responsibility, and determining their economic, personal and social styles. For example, the parents of the epileptic child may wish to take part in social activities. Their first question would be what they are going to do with their child when they wish to go dancing, for instance. One strategy would be to get a baby sitter. How they go about getting one is a tactic and when this should be done is a time-line.

While there is much anecdotal evidence for the success of Thresholds, there have not been a lot of statistical studies to date. However, a group at the University of New Haven, in an unpublished study, tested two groups of inmates, one in Thresholds and a control, on measure of locus of control and self-esteem. They found that the Thresholds group significantly maintained its initial levels of internal control and self-esteem, while the control group
decreased in both (Hines, 1981:44).

Since Hines' approach is simple and straightforward social workers may train volunteers and social auxiliary workers concerned with supportive service to implement the approach. Complicated social work terms are not used in this approach and therefore people with epilepsy who happened to be experiencing learning difficulties may also benefit from the approach particularly because it uses visual symbols.

2.9.4.2 The use of the group contract in problem solving

The group contract is an extension of the initial individual contract (refer to Figure 2.1). An evaluation is then continually made as to whether the expected change has occurred or not. The treatment offered is therefore subject to alteration (Smit, 1983:7).

Smit (1983:7) is of the opinion that at the termination of the group, every group member is evaluated in terms of whether the expected change has occurred or not in relation to the initial individual contract. He further states that if the expected change has been reached in relation to a specific problem area (for example seizure control) the goal is considered as attained and noted as such on the initial individual contract.

Every identified problem can now be attended to over a number of sessions, until the expected change (target of treatment) has been achieved. The group of selected epileptics can now be brought together. Reference is made to each member's initial contract with particular reference to the identified problem which is common to each one of them. A group con-
tract is then drawn in relation to this problem. In this particular case it will be seizure control. Problems which centre around each member's poor seizure control are then identified as the short term goals of the group. This constitutes what is commonly known as the topics for discussion (Smit, 1983:5-6). Refer to figure 2.2 for further details.
### FIGURE 2.2: GROUP CONTRACT IN RELATION TO POOR SEIZURE CONTROL

<table>
<thead>
<tr>
<th>PROBLEM IDENTIFICATION</th>
<th>EXPECTED CHANGE</th>
<th>TREATMENT</th>
<th>ROLE EXPECTATIONS GROUP MEMBERS</th>
<th>ROLE EXPECTATIONS WORKER</th>
<th>TIME</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Medication (effect on epilepsy)</td>
<td>Responsibility in taking medication</td>
<td>Group-discussion show films</td>
<td>- Involvement</td>
<td>- Involvement</td>
<td>93/01/4</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Trustworthiness</td>
<td>- Give directions</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Co-operation</td>
<td>- Plan program</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Openness</td>
<td>- Give group members</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Mutual responsibility</td>
<td>- Equal chance to participate</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Regular attendance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Traditional healing (effect on epilepsy)</td>
<td>Avoid the use of double standards</td>
<td>Group discussion</td>
<td>- Role play</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Family disruption</td>
<td>Responsible parenthood</td>
<td>Group discussion</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**SOURCE:** ADAPTED FROM SMIT (1983:6)

**SIGNED:**

**GROUP WORKER:**

**PERSONS WITH EPILEPSY:**

1. 
2. 
3. 
According to Smit (1983:8) the attendance to the contracts as discussed above has the following advantages:

- Treatment is given more structure;
- The person with epilepsy knows what is going on;
- The attention offered is more problem-oriented;
- Selection of groups is facilitated;
- The treatment is continuously evaluated and the worker becomes aware of the limitations in his attention to the person with epilepsy;
- Supervision is more treatment oriented;
- The tendency to involve persons with epilepsy in treatment without a specific goal is prevented;
- The treatment programme can be terminated timely instead of aimlessly continuing with the case;
- A big case load can be attended to more easier and purposefully;
- The person with epilepsy is kept involved in the process and is aware of his responsibility.

2.9.4.3 The use of community contract in problem solving
To take the service delivery further to a larger population the social worker needs to combine the forementioned individual- and group contract. Since it will be quite difficult for the social worker in a specific community to reach agreement with the entire
functional community (all persons with epilepsy living in Mamelodi) the committees will be established for the purpose. Any agreement reached with the committees will permeate to the functional community or geographical community (all people living in Mamelodi).

The social worker gives attention to issues of public concern. For instance, if through some research or practice wisdom the social worker identifies a problem of lack of knowledge of the condition of epilepsy on the part of the public, the social worker can use the resources available in the community to meet the needs, by educating the community. The target group can be nurses, doctors, traditional healers, paramedics, churches, women's groups, teachers, service organizations, local health authorities, commerce and industry, professional associations and the general public (Jackson, 1991:1).

The expected change will be that the target group will gain more knowledge of the condition of epilepsy which in turn will improve their interpersonal relationships with persons with epilepsy by delimiting existing prejudices. The social worker may use lectures on different aspects of epilepsy, send posters to contact persons, prepare press articles and radio talks for publicity (Jackson, 1991:5). For instance, for the contract to be meaningful there should be role expectations on the part of the target groups and social worker. It will be pointless for the social worker to distribute posters which are not displayed by the contact persons and if displayed ignored by the target groups. To accomplish his task the social worker needs to plan in advance when a specific task is to be carried out (see Figure 2.3).
## FIGURE 2.3: COMMUNITY CONTRACT IN RELATION TO PUBLIC EDUCATION

<table>
<thead>
<tr>
<th>PROBLEM IDENTIFICATION</th>
<th>EXPECTED CHANGE</th>
<th>METHOD</th>
<th>ROLE EXPECTATIONS TARGET GROUP</th>
<th>ROLE EXPECTATIONS WORKER</th>
<th>TIME</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Public ignorance re: Condition of epilepsy</td>
<td>Gain more knowledge on epilepsy</td>
<td>Community work: Committee meetings, Lectures, Videos, Radio &amp; TV, Press Articles</td>
<td>- Willingness to attend meetings, - Involvement in educating employers and employees, - Willingness to enable</td>
<td>- Willingness to work overtime, - Keep appointments, - Carry out resolutions of committees</td>
<td>Jan 1993</td>
</tr>
<tr>
<td>2. Lack of facilities for persons with epilepsy</td>
<td>Provisions of sheltered and protective workshops, self-help groups, Establishment of health services, i.e. epilepsy clinics</td>
<td>Community work: Research</td>
<td>- Enabler</td>
<td>- Educator, - Broker, - Mediator, - Advocate</td>
<td>Jan 2000</td>
</tr>
</tbody>
</table>

**SOURCE:** ADAPTED FROM SMIT (1983:6)  
**SIGNED:** SOCIAL WORKER .........  
**COMMITTEE MEMBERS ON BEHALF OF THE COMMUNITY**  
1. ..................  
2. ..................  
3. ..................
In dealing with individuals, groups and communities the social worker can fulfil the following roles:

- The role of enabler: This role is used when the intervention activity is directed at enabling the client to find powers and resources within himself to achieve the objectives of the contract (Compton & Galaway, 1984:430).

- The role of educator: In this role the worker supplies information, helps the client to practice new behaviour or skills. Figure 2.3 is a good example of the educator role.

- The role of broker: This role refers to those processes by means of which the client is put in contact with the services he requires. This can be done either by finding and identifying resources in the environment (Compton & Galaway, 1984:431). In figure 2.3 lack of facilities for persons with epilepsy is identified as a problem and the broker is prepared to negotiate with authorities to make funds available by the year 2000 to provide sheltered and protective workshops or to build a special school for the epileptics, if need be.

- The role of mediator: Because of the conflict between the client and the resource, the intermediary comes between the two parties to settle the dispute (Compton & Galaway, 1984:432). If for example there is disagreement between the consumer of service and the provider of service on the aspect of tariffs to be paid for the service the mediator can play an important role in this regard.
The role of advocate (Advocacy): This role must be approached with great caution, and should only be assumed where all other roles have failed. There must be a contractual agreement with the client that the worker undertake this role (Compton & Galaway, 1984:432). The social worker's success or failure in executing these roles will be determined to a great extent by his knowledge, skill and attitude and further whether or not the elements of a good worker - client relationship, namely, empathy, warmth and congruence are present.

2.9.5 Informal support systems in treatment

Maforah (1987:265) has explored the importance of informal support systems. She states that the role of the professionals should include identifying and organizing the informal support systems to maintain the family system and to give support to families in crises. According to Maforah (1987:265) the informal support systems referred to here are the elderly, the neighbours, the religious ministers and other natural helpers as well as the community care givers such as the burial societies, the voluntary organizations, the youth clubs and the religious movements.

The social worker dealing with epileptics and their families can mobilize, for instance, youth clubs in the community to help persons with epilepsy to use the existing facilities in the community like swimming pools and gymnasiums under supervision. The religious movements can also be of service to persons with epilepsy by teaching them life skills so that they can be ready for the open labour market. The role of the social worker in this regard is vital.
Maforah (1987:265) mentioned burial societies as one of the informal support systems. In the black community death is most feared phenomenon and in preparation for a sound burial of a family member families tend to overspend in burial societies. The social worker can enable epileptics and their families to view death realistically and not to waste a lot of money on burial societies because of fear of being able to cover funeral expenses.

Short term care (STC) by Malin (1982:77-93), has been widely regarded as one of the most useful services that can be offered to families of mentally handicapped children (also to families with epileptic children). According to Malin (1982:77-78) short term care can mean many things, ranging from regular "shared care" where a child spends a regular fixed period (a week, a month, six weeks) in hospital, a hostel, or with an alternative family, to very flexible arrangements whereby parents can book half-day sessions or week-ends directly with a residential unit or alternative family.

If it is possible that the presence of an epileptic child in the family can restrict the movement of the parents, short term care can be rendered by a social worker who can place the epileptic child with an alternative family while the parents of the epileptic go on a week's holiday to enable them to have a "break" from the constant strain of caring and coping (Malin, 1982:78). However, Malin (1982:93) is of the opinion that parents may feel ambivalent about sending their child to another family, even for a short time, and one major aim of such a service would be to reinforce parents' self-confidence rather than leaving them with a sense of failure. Social workers dealing with epileptics and their families can play an important role in this regard.
The general idea behind short term care is that parents will cope longer with their child at home if they know they can obtain some respite. A secondary object is to be able to offer instant help in the event of some family crises, such as the death or illness of a parent. As such a service is non-existent in Mamelodi, it will have to be developed which could form part of community work.

Nzimande (1985:68) shares the same opinion by stating that in a crisis situation, the extended family support system renders it automatic that other members of the family group will help out whenever the welfare of the group is believed to be threatened. The result is to share as much as possible in the expression of emotional support.

It is essential that the social worker rendering service to epileptics and their families should have the knowledge of how informal support systems work. The presence of an epileptic child in a family may make the family experience the need for emotional support and this can immediately be provided by the in-laws, uncles and aunts, brothers and sisters, relatives, friends, significant others and co-workers through the mediation of a social worker.

2.10 SUMMARY

From the review of the literature it is quite evident that very little research has been done on black people with epilepsy. However, knowledge gained from studies on white respondents has been used as a base to understand the black person with epilepsy. Epilepsy is not understood by many people perhaps because it is an
invisible handicap or perhaps because its etiology is associated with supernatural powers or witchcraft. It is true that to understand the black person with epilepsy the following people should work together: the medical doctor, the nurses, the traditional healer, the teacher, the priest, the social worker and many others.

The social worker as a member of a team is not to win his way or prove his rightness but to use the different capacities brought by the different members of the team to expand his knowledge and his range of skills so that he can offer the client the best service in the direction that the client wishes to go (Compton & Galaway, 1989:610). The role of the social worker in the treatment approach based on problem solving is guided by the direction that the client wishes to go (expected change) after the problem has been identified. The proposed approach based on problem solving allows the social worker to practice social case work, social group work and community work. This approach can be called problem solving approach.

The social worker attached to any agency has the task of identifying informal support systems which may facilitate any envisaged service-delivery. Short term care can be implemented effectively if the social worker dealing with epileptics and their families can involve volunteers, relatives and friends who are prepared to look after the epileptics whilst the parents are engaged in some other activity. However, none of the services is available at present in Mamelodi.
CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

In this chapter an analysis is made of the research procedures used in the gathering of data and of how the relevant data is processed.

3.2 METHOD OF INVESTIGATION

3.2.1 Research design

Goldstein (1969:67) defines research design as follows: "Research design is the name given to the planning of a research study or scientific inquiry so that it is more than the carrying out of random observations or the drawing of incidental conclusions." The design selected by the researcher for this investigation was the exploratory study design.

According to Wechsler et al. (1981:86) exploratory designs are appropriate when little is known from prior research of the phenomenon, group, or programme to be investigated. The researcher found the exploratory design suitable for the current study because so little is known about the problem of epilepsy in the black community.

It is therefore necessary to use an exploratory study in order to build up knowledge on a research problem which is poorly understood or inadequately described (Arkava & Lane, 1983:190).
Tripodi et al. (1969:48) cite several requisites for a research design to be classified as an exploratory study:

- It should not be classifiable as either an experimental or a quantitative descriptive study.

- Relatively systematic procedures for obtaining empirical observations and/or for the analysis of data should be used.

- The investigator should go beyond the qualitative and/or quantitative descriptions by attempting to conceptualise the interrelations among the phenomena observed.

### 3.2.2 Method used in the empirical investigation

The study consisted of three major sections, namely a review of relevant literature, data collection and the analysis of the data. Relevant literature was reviewed in order to gain an in-depth understanding of the problem under study and to facilitate the compilation of the interview schedule. It was essential to include a study of the following aspects in the literature study so that the potent factors relevant to the problem under study could be considered in totality:

(i) Epilepsy as an invisible handicap.

(ii) Types of epilepsy.

(iii) Causes of epilepsy.

(iv) The incidence of epilepsy.
(v) Epilepsy and family life.
(vi) Epilepsy and school.
(vii) Psycho-social effects of epilepsy on the epileptic.
(viii) The treatment of the epileptic.

This literature study also served as a theoretical framework for the interpretation of the findings of the study.

3.3 DATA COLLECTION

3.3.1 The interview

The semi-structured interview\(^1\) was selected as the main research tool. Reid & Smith (in Silver, 1987:56) state: "The in-person interview is capable of eliciting information in larger amounts and in greater depth. It is particularly useful for obtaining data on topics that are complex, highly sensitive, emotionally laden and relatively unexplored."

The area of witnessing an epileptic attack is a sensitive area and is often fraught with pain. A questionnaire would not have been suitable because of the highly subjective nature of the subject of

\(^1\) Structured or semi-structured interview implies the presence of the interviewer and the interviewee, hence it is called in-person interview (Silver, 1987:56).
epilepsy and the individuality of the response. According to Silver (1987:57) the flexibility of the interview allows the interviewer to probe and pursue relevant areas. Silver (1987:57) adds that the interview allows for spontaneity and questions can be answered in a different order according to how the flow of the interview proceeds.

Tripodi (1983:75) lists the advantages of the interview as a research tool as follows:

- interviews provide more verifiable in-depth data than questionnaires.
- face to face interviews yield high response rates particularly with regard to sensitive information.

3.3.2 Interview schedule

(a) Setting and duration of the interview

The researcher paid visits to those families from which the sample was drawn in Mamelodi Township. Forty (40) families were visited and in each family three (3) respondents were interviewed (the epileptic respondent, one of the parents/guardians and one of the siblings). Interviews took place during the day (week-ends included). The duration of the interview was approximately three to four hours per family. Each respondent was interviewed independently in a separate room, away from the other family members.

(b) The semi-structured interview schedule

The instrument used to collect empirical
observations in the study was the interview schedule. When data are collected by means of face-to-face interviews, the instrument may be referred to as an interview schedule (Grinnell, 1981:156). Goldstein (1969:67) states that "the schedule provides a uniform means for getting the desired similarity or identity". Silver (1987:53) also maintains that the interview schedule attempts to minimise the influence of the observer on what is being observed.

An interview schedule of a semi-structured nature was devised. The questions were based on the aforementioned areas in the literature (See Annexure I).

The researcher personally administered the interview schedules.

The researcher decided that his respondents (epileptic children, parents and siblings) might find it more convenient for them to be interviewed at their homes rather than sending them questionnaires to complete. For instance, because an epileptic child of 9 years would not understand all the questions, and because most of the parents were illiterate, it was easier to interview them at their homes where they could relax and spontaneously answer questions put to them. Silver (1987:7) selected the interview as the major research tool for empirical studies because of its flexibility in probing sensitive issues; the ability to have face-to-face observations of non-verbal cues; and the ability to allow for spontaneity.
The interview schedule may have the following drawbacks:

- Unlike a questionnaire the respondent may feel threatened by the researcher in a face-to-face relationship/situation.

- The respondent is not given enough time to digest the answers because he must respond here-and-now.

- A lot of time is wasted if respondents are not found all at home like in the present study when three respondents are interviewed in one family.

The semi-structured interview schedule was administered by the researcher who recorded in writing the answers verbatim. The schedule was divided into three sections (see Annexure I).

Section A:
This section covered the identifying details of the epileptic respondent, the respondent's knowledge of epilepsy, the frequency of attacks, and the effects of epilepsy on his social functioning and medication. This section aimed at obtaining information about the presence of an epileptic child in the family, how the other family members reacted to the child with epilepsy and how the latter reacted to his parents/guardians and siblings.

Section B:
This section covered the identifying details of the parents/guardians of epileptics, the parents' opinions about the causes of epilepsy, how they felt about the diagnosis of epilepsy, what steps they took to obtain help from the medical doctors, traditional healers and social workers, and how the child's
condition affected their roles in the family. This section aimed at obtaining information about the effects of epilepsy on all the family members and the treatment suitable for the epileptic child.

Section C:
Section C was completed by the elder sibling of the epileptic child. If the epileptic was the eldest, the second eldest would complete Section C. This section covered information about the effects on the sibling's relationship with the epileptic child, the sibling's relationship with his schoolmates and other peers and the sibling's feelings about his epileptic brother/sister. This section concentrates on information about the effects of epilepsy on interpersonal relationships.

The information was processed manually by using statistical methods, viz. the tally and the distribution methods. These statistical methods made it possible for the researcher to present the information empirically mostly by way of tables.

3.4 THE SAMPLE AND SAMPLING PROCEDURE

Goldstein (1969:190) states that the purpose of sampling is to obtain from a small number of entities information that can be generalized to the larger aggregate (called the population or universe) from which the sample came: "Time and money are thus saved in that the large group itself does not have to be studied." Leedy (1980:112) likewise notes that the composition of the sample is derived by selecting units from those of a much larger population.

In terms of hospital regulations, patients' records cannot be made known unless the patient gives his consent. The researcher obtained a sample from epileptics staying in
Mamelodi who received medication either from Kalafong Hospital or the Mamelodi Clinic. The sample was not based on ethnic grouping because it would be too small for a feasibility study. It was found that families with epileptic children were reluctant to participate as they did not wish to disclose the child's condition.

The researcher did not know the number of black epileptics in the Republic of South Africa in general except an estimate of ± 315,000 and in Mamelodi epileptics were estimated at ± 1,250. There was an infinite population. The investigator, therefore, did not have a sampling frame. The accidental or availability sampling method was used. Grinnell (1981:86) states that the practitioner or researcher uses the first available appropriate sampling units. The researcher took all the respondents he could find, i.e. those forty (40) who were available for interviewing.

The researcher found availability or accidental sampling more suitable in the current study because the investigator used the first available appropriate sampling unit. For instance, epileptics who were interested in taking part in the research project were given forms to complete (See Annexure IV). The first forty (40) who completed the forms were then taken as a sample. However, the following served as preconditions: that the epileptic should be of school going age and if he did not attend school he should still be living with his parents/guardians in the same house. Wechsler et al. (1981:90) are of the opinion that findings of studies using accidental sampling may not be generalised to the whole population.

According to Wechsler et al. (1981:90-91) social work research by its nature involves the use of humans as subjects. In so doing, it must comply with legal and ethical requirements to safeguard the rights of these subjects. As a first step, informed consent must be secured before
someone is included in a sample (See Annexure IV). This in effect means that "the person must know what the research is about, what his or her participation will mean, and what the risks in the research will be" (Wechsler et al. 1981:90-91). The researcher took this a step further by obtaining formal permission by way of a form.

3.4.1. Sampling bias

There were a number of inherent biases in the sample:

- The desire on the part of epileptics and their parents to benefit directly or indirectly from participation in the study.

- Only black families were selected.

- Fear of making known to the public that the family has an epileptic child.

3.5 THE PROCEDURE

The researcher adopted the following procedure in the empirical study, namely:

- The researcher contacted the Superintendent of Kalafong Hospital to ask for permission to interview children with epilepsy living in Mamelodi who received their medication either at Kalafong Hospital or the Mamelodi Clinic (See Annexure III), since the Mamelodi Clinic falls under Kalafong Hospital.

- Permission was then granted by the Superintendent of Kalafong Hospital on condition that respondents give their consent (See Annexure IV).
Prospective respondents were given a form to complete in which they agreed to participate in the research. Because the prospective respondents were children, the forms were completed by their parents on their behalf. However, some respondents took the responsibility on their own shoulders because of their mature age (See Annexure V).

The researcher had a total of forty families in which three respondents from each family were to be interviewed (i.e. the epileptic, parent/guardian and sibling). A total of 120 respondents were initially envisaged. Six of the epileptic respondents had no siblings and therefore the total of respondents was 114.

The data was collected from the respondents at the interviews (in their own homes) during the period June 1988 to September 1988, then analysed, interpreted and conclusions were drawn.

3.6 **SUMMARY**

Although SANEL has found in 1987 that there are 315 000 South Africans with epilepsy, the problem of epilepsy among blacks has not been fully addressed. The researcher estimated the number of epileptics in Mamelodi to be 1250. The researcher found the exploratory design suitable for the current study since little is known about the problem of epilepsy in the black community. The instrument used to collect empirical observations in the study was the interview schedule. The researcher used availability sampling in this study because it was the only way in which respondents could be obtained.
CHAPTER 4

PRESENTATION, ANALYSIS AND INTERPRETATION OF EMPIRICAL RESULTS

4.1 INTRODUCTION

In this chapter the researcher gives an interpretation of the results of the empirical study and further depicts the way in which the results were processed and integrated with the findings of the theoretical study.

4.2 BACKGROUND INFORMATION ON EPILEPTIC RESPONDENTS AND THEIR PARENTS/GUARDIANS (SEE ANNEXURE I)

The background information on the respondents and their families was obtained in the following areas: age, sex and occupation. This information will now be presented by way of tables and discussions.

4.2.1 Age

The age distribution of epileptic respondents and their parents/guardians are reflected in Table 4.1.
TABLE 4.1: AGE DISTRIBUTION OF EPILEPTIC RESPONDENTS AND THEIR PARENTS/GUARDIANS

<table>
<thead>
<tr>
<th>AGE CATEGORY</th>
<th>RESPONDENTS</th>
<th>PARENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>NO</td>
<td>%</td>
</tr>
<tr>
<td>9 - 12</td>
<td>4</td>
<td>10,0</td>
</tr>
<tr>
<td>13 - 16</td>
<td>6</td>
<td>15,0</td>
</tr>
<tr>
<td>17 - 20</td>
<td>9</td>
<td>22,5</td>
</tr>
<tr>
<td>21 - 24</td>
<td>7</td>
<td>17,5</td>
</tr>
<tr>
<td>25 - 28</td>
<td>8</td>
<td>20,0</td>
</tr>
<tr>
<td>29 - 32</td>
<td>6</td>
<td>15,0</td>
</tr>
<tr>
<td>33 - 36</td>
<td></td>
<td></td>
</tr>
<tr>
<td>37 - 40</td>
<td></td>
<td></td>
</tr>
<tr>
<td>41 - 44</td>
<td></td>
<td></td>
</tr>
<tr>
<td>45 - 48</td>
<td></td>
<td></td>
</tr>
<tr>
<td>49 - 52</td>
<td></td>
<td></td>
</tr>
<tr>
<td>53 - 56</td>
<td></td>
<td></td>
</tr>
<tr>
<td>57 - 60</td>
<td></td>
<td></td>
</tr>
<tr>
<td>61 OVER</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>40</td>
<td>100,0</td>
</tr>
</tbody>
</table>

The following information can be derived from table 4.1:

The highest percentage (22.5%) is found in the age group 17-20 and that more than 50% of the epileptic respondents are older than 20 years of age.

Bird et al. (1966:175-187) refer to the high incidence of epilepsy in the age group 20-24 years while Freed (1971:89-92) indicates that the incidence of epilepsy is highest in the first year of life. The Central Statistical Services Report (1982-1986) indicates that of the 582 black epileptics who died from the condition, 302 were between the ages of one and 34 years. It would therefore seem that there is no relation between the incidence of epilepsy and age.
The following information may be derived from the same table (4.1) with regard to the parents/guardians of epileptic respondents:

- Seven of the respondents (16.5\%) were between the ages of 33 and 44 years;
- eighteen of the respondents (45.0\%) were between the ages of 45 and 52 years;
- fifteen of the respondents (37.5\%) were between the ages of 53 and 60 years.

The age groups of the people with epilepsy and their parents/guardians are significant to the social worker because knowledge of his target group will facilitate service delivery or possible referral to a suitable agency. For instance, the child of 9 years of age will be approached differently by a social worker than the child of 18 years of age. Parents/guardians of between 45 years and 60 years are fully matured people who can be able to communicate with the social worker to seek help because the presence of an epileptic child in the family may bring about hardship to the family members.

4.2.2 Sex

Figure 4.1 gives the sex distribution of the respondents.

**FIGURE 4.1: RESPONDENTS CLASSIFIED ACCORDING TO SEX**

- Female 47.5\%
- Male 52.5\%
As shown in Figure 4.1 above, 52.5% of the respondents were male while 47.5% of the respondents were female. Freed (1971:89-92) confirms the finding by pointing out that the condition of epilepsy is only slightly higher among males.

More mothers were interviewed because fathers tended to give the mothers the chance to become involved on behalf of the parents in the survey. Perhaps the fathers felt they knew very little about the child's condition. Also 27.5% of the parents were housewives which meant that the researcher would rather find them at home. Such housewives may be involved in self-help groups for mothers with epileptic children and their availability can facilitate the role of the social worker. There is an African proverb which says: "The mother of the child holds a knife at the sharpened edge" (Mmago Ngwana o tshwara thipa ka bogaleng). This is confirmed in the study since, under difficult and dangerous circumstances, the responsibility toward the handicapped child ultimately rests with the mother of the child. However, another proverb states that a female cannot take the lead: "If they are led by a female, they will fall into a donga", (Tsa etwa ke e tshadi pele di wela ka leope). This can be seen as a defense mechanism used by males in contrast to the strong position allocated to the mother of the child who takes the lead even under dangerous circumstances.

4.2.3 Occupation

Responses to questions 3 and 14 of the interview schedule requiring information on the occupation of respondents and their parents are contained in Tables 4.2 and 4.3 respectively.
TABLE 4.2: EPILEPTIC RESPONDENTS CLASSIFIED ACCORDING TO THEIR OCCUPATION

<table>
<thead>
<tr>
<th>OCCUPATION</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domestic Worker</td>
<td>1</td>
<td>2.5</td>
</tr>
<tr>
<td>Gardener</td>
<td>1</td>
<td>2.5</td>
</tr>
<tr>
<td>Sheltered employment</td>
<td>1</td>
<td>2.5</td>
</tr>
<tr>
<td>Waiter</td>
<td>1</td>
<td>2.5</td>
</tr>
<tr>
<td>Clerk</td>
<td>2</td>
<td>5.0</td>
</tr>
<tr>
<td>Piece jobs</td>
<td>1</td>
<td>2.5</td>
</tr>
<tr>
<td>Scholar</td>
<td>13</td>
<td>32.5</td>
</tr>
<tr>
<td>Work-seeker</td>
<td>13</td>
<td>32.5</td>
</tr>
<tr>
<td>Home-bound&lt;sup&gt;2&lt;/sup&gt;</td>
<td>7</td>
<td>17.5</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>40</td>
<td>100.0</td>
</tr>
</tbody>
</table>

The following information can be derived from table 4.2:

- Seven of the epileptic respondents (17.5%) were engaged in some form of work (e.g. domestic worker, gardener, sheltered employment, waiter, clerk and piece jobs);

- thirteen of the epileptic respondents (32.5%) attended school;

- thirteen of the epileptic respondents (32.5%) were work-seekers;

<sup>2</sup>Home-bound refers to epileptic respondents who neither attend school nor work because their parents/guardians prefer that they should remain at home because the latter fear embarrassment or the epileptic respondent cannot attend school because no ordinary school is prepared to take him/her because of his/her condition, or no special school is available, or the epileptic respondent cannot secure employment because s/he has been turned down by prospective employers because of his/her condition, or the epileptic respondent prefers not to attend school or work because s/he is "sick".
seven of the epileptic respondents (17.5%) were home-bound.

Although Bird et al. (1966:175-187) found epileptics working in mines the present survey according to table 4.2 showed that 82.5% of the epileptic respondents are dependent on their families. Even those working, 12.5% are doing low-income jobs which means that their families may have to help them.

Seven (7) of the respondents in the present study could not be accommodated at ordinary schools and were forced to remain at home (home-bound) because there were no special schools available for them. Bridge (1934) as cited by Bagley (1971:214) found that an emotionally disturbing situation, such as rejection by schoolmates, and in some cases by teachers, can make both the behaviour of the epileptic and the epilepsy itself worse. The social worker's approach to the "home-bound" will depend on how the family view the person with epilepsy. A family manifesting a positive outlook toward life in general and toward the person with epilepsy in particular will make the role of the social worker easier during home visit in having access to the person with epilepsy to render effective social work assistance backed by the rest of the family of the epileptic.

It is quite significant to note that 32.5% of the respondents are work-seekers. The researcher was approached to assist in helping epileptic respondents secure employment. However, it was interesting to observe that one respondent was adamant that help in securing employment suitable for people with epilepsy was not required because according to him he could do any type of work that the non-epileptic could do.
This has been seen as lack of insight on the part of the respondent in terms of his health condition.

The social worker's role in respect of the work-seekers (32,5%) will depend on the co-operation of the people with epilepsy and their families. The social worker will have to negotiate with the prospective employers. However, parents and grandparents who exercise overprotection and who view the epileptic as sick may retard the progress of the work-seeker and the social worker will be unable to mediate between the prospective employer and the work-seeker.

The social workers can therefore educate the employers and employees to accept epileptics who are workseekers in the open labour market. This can minimize the percentage of epileptics without a job. Furthermore social workers can facilitate the process whereby self help groups can be established through the protective and sheltered workshop project (Jackson, 1991:8). The social worker is expected to impart knowledge of first aid to employers and employees so that they must know what to do to help an epileptic experiencing an attack.
TABLE 4.3: PARENTS/GUARDIANS OF EPILEPTICS CLASSIFIED ACCORDING TO OCCUPATION

<table>
<thead>
<tr>
<th>NATURE OF OCCUPATION</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domestic Worker</td>
<td>8</td>
<td>20,5</td>
</tr>
<tr>
<td>Housewife</td>
<td>11</td>
<td>27,5</td>
</tr>
<tr>
<td>Messenger</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>Clerk</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>Barrier attendant</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>Town Council Police</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>Pensioner</td>
<td>7</td>
<td>17,5</td>
</tr>
<tr>
<td>Nurse assistant</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>Cleaner</td>
<td>3</td>
<td>7,5</td>
</tr>
<tr>
<td>Packer</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>Teacher</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>Cashier</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>Watchman</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>Receptionist</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>Machine operator</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>40</strong></td>
<td><strong>100,0</strong></td>
</tr>
</tbody>
</table>

Table 4.3 indicated that most parents (55%) are doing low-income work.

Although it is not known exactly how much the parents earned, it is estimated, on the basis of their occupations, that they earned between R100,00 and R700,00 per month on the average. The information was received from the Department of Manpower. It was said that the Act of Parliament was not yet passed in connection with the minimum salaries of domestic workers.

Their financial position definitely has an effect on the availability of money for medical treatment, transport and any other form of service needed.
4.3 PERSPECTIVES ON EPILEPSY

4.3.1 Epileptic respondents' knowledge about epilepsy

Question 4 of the interview schedule reads: "What have you been told about your condition by your parents?" The responses to the question can be classified as follows:

**TABLE 4.4: EPILEPTIC RESPONDENTS' KNOWLEDGE ABOUT EPILEPSY**

<table>
<thead>
<tr>
<th>INFORMATION</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>I suffer from epilepsy (Seebana, Isithuthwane)</td>
<td>8</td>
<td>20,5</td>
</tr>
<tr>
<td>Head Injury</td>
<td>3</td>
<td>7,5</td>
</tr>
<tr>
<td>Related to mental illness</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>Soft head (Hlogwana)</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>An inherited condition</td>
<td>3</td>
<td>7,5</td>
</tr>
<tr>
<td>Common condition</td>
<td>2</td>
<td>5,0</td>
</tr>
<tr>
<td>Caused by misbehaviour</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>Started as fever</td>
<td>2</td>
<td>5,0</td>
</tr>
<tr>
<td>A bewitched condition</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>It just started</td>
<td>6</td>
<td>15,0</td>
</tr>
<tr>
<td>Something wrong with blood</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>I was told nothing</td>
<td>10</td>
<td>25,0</td>
</tr>
</tbody>
</table>

TOTAL 40 100,0

From table 4.4 the following information emerged:

- Seventy-five percent (75,0%) of the epileptic respondents were given some explanation about their condition by their parents or guardians;

- Twenty-five percent (25,0%) of the epileptic respondents were not told anything about epilepsy by their parents or guardians.
However, only in 20.5% of the cases was the true condition mentioned, namely, epilepsy (Seebana, isithuthwane). (Kriel, 1967 and Dent & Nyembezi 1959). It is significant to note that some of the parents or guardians of the epileptics did not specifically mention the true condition (epilepsy) but became vague by referring to epilepsy as a "common condition" experienced by many people on earth, thereby conveying to the epileptics that their condition was not unique.

It is possible that the epileptic respondents in this study (nine of them) acquired knowledge of their condition from significant others who in the black culture can be referred to as "parents". Any person older than the epileptic respondent and whose age compares more or less with the age of the respondent's biological father or mother can be referred to as "parent".

Comparing the parents responses regarding the explanations they gave to the children, we have the following:

TABLE 4.5: EXPLANATION OF THE CONDITION OF EPILEPSY TO EPILEPTIC CHILDREN BY THEIR PARENTS/GUARDIANS

<table>
<thead>
<tr>
<th>EXPLANATION</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Condition will be outgrown</td>
<td>4</td>
<td>10,0</td>
</tr>
<tr>
<td>Common condition</td>
<td>16</td>
<td>40,0</td>
</tr>
<tr>
<td>Liver disease</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>Bewitchment: Causal factor</td>
<td>2</td>
<td>5,0</td>
</tr>
<tr>
<td>Head Injury: Causal factor</td>
<td>4</td>
<td>10,0</td>
</tr>
<tr>
<td>Misbehaviour</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>Heredity</td>
<td>2</td>
<td>5,0</td>
</tr>
<tr>
<td>Did not explain anything</td>
<td>10</td>
<td>25,0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>40</td>
<td>100,0</td>
</tr>
</tbody>
</table>
The information derived from table 4.5 corresponds largely with the information in table 4.4 above:

- Thirty (75.0%) of the respondents gave some explanation to the epileptic child of his/her condition;

- Ten (25.0%) of the respondents did not explain anything to the epileptic child concerning the condition.

It would appear that there is a difference between children's and parents' responses on this issue. For instance, if we look at the explanation: "Condition will be outgrown", it gives the impression that it was explained to the epileptic child that epilepsy will be cured. Sixteen (40%) parents/guardians explained epilepsy to their children as a common condition but only two (5%) epileptic children agreed on that. This may mean that even if the other fourteen epileptic children had been told this it did not make sense or they forgot the explanation or they learnt something else from significant others. The explanation "It just started," also, does not give the impression that the epileptic children (15.0%) in table 4.4 really gathered the information from their parents/guardians because such an explanation was not given by a single parent/guardian (See table 4.5).

The above information explains quite clearly the dynamism of any family. The social worker with his knowledge of family therapy will understand the interactional functioning of a family with different sub-systems in it and will be in a position to clarify the behaviours of the parents and the children toward the same stimulus (epilepsy will be cured or outgrown).
4.3.2 Causes of epilepsy

Questions 5, 15 and 32 of the interview schedule required the epileptic child, the parent/guardian and the sibling to respond to the question on the cause of epilepsy. The responses to the question can be classified as follows:

TABLE 4.6: CAUSES OF EPILEPSY AS GIVEN BY EPILEPTIC RESPONDENTS, THEIR PARENTS/GUARDIANS AND THEIR SIBLINGS

<table>
<thead>
<tr>
<th>CAUSE</th>
<th>ER</th>
<th></th>
<th>P/G</th>
<th></th>
<th>S</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Head injury</td>
<td>3</td>
<td>7,5</td>
<td>11</td>
<td>27,5</td>
<td>5</td>
<td>12,5</td>
</tr>
<tr>
<td>Bewitchment</td>
<td>2</td>
<td>5,0</td>
<td>11</td>
<td>27,5</td>
<td>2</td>
<td>5,0</td>
</tr>
<tr>
<td>Malfunctioning of liver</td>
<td></td>
<td></td>
<td>1</td>
<td>2,5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Punishment by gods</td>
<td></td>
<td></td>
<td>1</td>
<td>2,5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heredity</td>
<td>2</td>
<td>5,0</td>
<td>3</td>
<td>7,5</td>
<td>2</td>
<td>5,0</td>
</tr>
<tr>
<td>Alcohol and dagga</td>
<td>1</td>
<td>2,5</td>
<td>2</td>
<td>5,0</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>High fever</td>
<td></td>
<td></td>
<td>1</td>
<td>2,5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor blood circulation</td>
<td></td>
<td></td>
<td>1</td>
<td>2,5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High blood pressure</td>
<td></td>
<td></td>
<td>1</td>
<td>2,5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood in brain</td>
<td></td>
<td></td>
<td>1</td>
<td>2,5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hot sun</td>
<td>1</td>
<td>2,5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Too much running</td>
<td>1</td>
<td>2,5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Something wrong in the head</td>
<td>1</td>
<td>2,5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anger</td>
<td>1</td>
<td>2,5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don't know what the causes are</td>
<td>28</td>
<td>70,0</td>
<td>8</td>
<td>20,0</td>
<td>22</td>
<td>55,0</td>
</tr>
<tr>
<td>Only child</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6</td>
<td>15,0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>40</td>
<td>100,0</td>
<td>40</td>
<td>100,0</td>
<td>40</td>
<td>100,0</td>
</tr>
</tbody>
</table>

ER = Epileptic respondent
P/G = Parent or guardian
S = Sibling

The following information can be derived from table 4.6 with regard to the causes of epilepsy:
In contrast to the information given by epileptic respondents, eleven of the parents/guardians (27.5%) stated that head injury has been the cause of epilepsy against three of the epileptic respondents (7.5%) and five of the siblings (12.5%). However, the information implies that there is similarity in the thinking that there should be a cause of the epilepsy.

It is possible that most of the epileptic children and their siblings reflected what they learnt from their parents/guardians as causes of epilepsy. However, it is significant to note that although parents feared to tell their epileptic children that they were bewitched, they themselves gave bewitchment as one of the causes of epilepsy (27.5%).

Winterbach (1983:116) has found that the black people do not believe in the natural cause of events and urban blacks are not an exception to this: "Niks gebeur toevallig nie. Die geloof van die Swarte dat siekte deur bonatuurlike magte veroorsaak kan word, gryp diep op die Swarte se bestaan in." Although punishment by the gods (badimo) was mentioned by one parent/guardian (2.5%) as the cause of epilepsy, Gelfand (1964:4) has found that in Central Africa the most important cause of sickness is believed to be the anger of one of the departed parents. Hence, sickness is then seen as punishment for the wrong done to the dead parent.

The fact that 28 of the epileptic respondents (70.0%) did not have an idea what the cause of epilepsy was raises doubts concerning the efficacy of the medical service, the social work service or the multi-disciplinary approach, if any, to the epileptic respondents who were on medication (See figure 4.2 on
The epileptic respondents may or may not have been informed about the causes of epilepsy. If they were informed, they may not have understood anything. If they were not informed then something needs to be done by the multi-disciplinary team to rectify this situation.

It is significant to note that only a limited number of parents/guardians (8) or 20.0% did not have an idea what caused epilepsy. Twenty-two of the siblings (55.0%) who did not have an idea what had caused their epilepsy may simply not have understood the explanations given either by their parents, the social worker or the medical doctor.

4.3.3 Ways in which parents/guardians discovered that their child was an epileptic

Question 16(a) of the interview schedule (Annexure I) reads: "How did you discover that your child is an epileptic?" The responses to the question can be classified as follows:

- Twenty-four of the parents/guardians (60.0%) knew of their children's condition from the medical practitioner;

- Ten of the parents/guardians (25.0%) were told of the condition by the medicineman;

- Six of the parents (15.0%) knew of the condition from their own observations or from the observations of significant others (e.g. teachers and grandparents);

The results of the discovery of the condition of the child should not be confused with those of the first
people who treated the child with epilepsy. It may be possible that the discovery of the condition of the child was made by the medical doctor, but the parents preferred the medicineman to treat the child with epilepsy as can be seen from the next subsection.

4.3.4 First person to treat the child with epilepsy

Question 18(a) of the interview schedule reads: "Who was the first person to treat your child with epilepsy?" The information derived from the above-mentioned question is presented as follows:

- Nineteen of the respondents (47.5%) stated that the first person to have treated their children with epilepsy was the medicineman;

- Eighteen of the respondents (45.0%) stated that the first person to have treated their children with epilepsy was the medical practitioner;

- Three of the respondents (7.5%) said that the first person to have treated their children with epilepsy was the priest.

Although a larger number of medical doctors (60.0%) diagnosed the condition in relation to the number of medicinemen (25.0%), almost an equal number of medical doctors and medicinemen was given in response to who the first person was to treat the child with epilepsy (45.0% and 47.5% respectively).

The results of this study are confirmed by Schweitzer (1980:28) who holds that the traditional healer (igqira) did not choose this role but was called to the profession by the ancestors. According to him
patients who were treated unsuccessfully by Western trained doctors then visited a traditional healer (Iggira) as a last resort and found satisfaction. The idea is that the medicineman and the medical practitioner may be equally important to the patient, depending on the nature of the illness. Schweitzer (1980:28) found that Western medicine has an important role to play in conditions such as epilepsy and post-traumatic psychosis. Janzen (in Edgerton, 1980:167-189) also found that recourse is either to a traditional healer (nganga) or to a practitioner of Western medicine.

Respondents may prefer the medicineman because according to Riga (1983:1) sickness, pain, bodily suffering and well-being are all interpreted as the net result of a fine balance between the living and the dead. The cultural belief system of the African people is based on a firm conviction of the existence of the spirits of their departed forefathers. Their departed ones (Abaphansi) can influence their lives for better or for worse, in health and diseases, as well in prosperity as in adversity. It is precisely because of this central belief that in times of crisis the African turns to those very spirits for help. To support what Riga has stated, Winterbach (1983:119) says the following: "As 'n toordokter bepaal dat 'n siekte in verband met die houding van die voorouergeeste staan, moet hy die rede daarvoor te wete kom en 'n optrede met die oog op die herstel van die versteurde verhouding, voorskrif. Die optrede is gewoonlik 'n offer wat aan die voorouergeeste in die vorm van 'n ritueel gemaak moet word."

Mutwa (1966:340) states the following: "According to Bantu belief, a race or tribe is as good as are the Gods, or God, in which it believes. We consider that
if a tribe is successful in any way, in battle, material prosperity or in other blessings, it is a sure sign that the Gods or Ancestral Spirits of that tribe are truly powerful." The medicineman, however, is the person who possesses the knowledge of how these Gods operate. For the possible team-approach, the medical practitioner will have to consult with the medicineman and vice versa, because the research findings indicate that the respondents regard them as being equally important (See paragraph 4.3.4).

4.3.5 The perceived cause of the condition in the epileptic child

- Thirty-four of the respondents (85,0%) indicated that their children were epileptic since birth;

- Six of the respondents (15,0%) indicated that their children became epileptic due to trauma, for example, car accident or assault.

The results can be interpreted in two different ways. Firstly, 15,0% of the respondents are aware of the origin of the condition in their children because epilepsy manifested itself after the child was involved in a car accident and sustained head-injury, for instance, or was assaulted by hooligans during the night and started to experience epileptic attacks. Secondly, 85,0% of the respondents cannot exactly state how the condition manifested itself because it was difficult to trace the origin.

4.3.6 The frequency of epileptic attacks

Table 4.7 gives an indication of the frequency of epileptic attacks.
TABLE 4.7: THE FREQUENCY OF EPILEPTIC ATTACKS

<table>
<thead>
<tr>
<th>FREQUENCY/RESPONSE</th>
<th>ER</th>
<th></th>
<th>P/G</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Two times a day</td>
<td>2</td>
<td>5,0</td>
<td>2</td>
<td>5,0</td>
</tr>
<tr>
<td>Three times a day</td>
<td>1</td>
<td>2,5</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>Once a week</td>
<td>1</td>
<td>2,5</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Twice a week</td>
<td>1</td>
<td>2,5</td>
<td>3</td>
<td>7,5</td>
</tr>
<tr>
<td>Thrice a week</td>
<td>1</td>
<td>2,5</td>
<td>2</td>
<td>5,0</td>
</tr>
<tr>
<td>Once a month</td>
<td>11</td>
<td>27,5</td>
<td>13</td>
<td>32,5</td>
</tr>
<tr>
<td>Twice a month</td>
<td>6</td>
<td>15,0</td>
<td>4</td>
<td>10,0</td>
</tr>
<tr>
<td>Every two months</td>
<td>2</td>
<td>5,0</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>Once in three months</td>
<td>5</td>
<td>12,5</td>
<td>4</td>
<td>10,0</td>
</tr>
<tr>
<td>Once in six months</td>
<td>4</td>
<td>10,0</td>
<td>5</td>
<td>12,5</td>
</tr>
<tr>
<td>Once in 12 months</td>
<td>2</td>
<td>5,0</td>
<td>3</td>
<td>7,5</td>
</tr>
<tr>
<td>Once in 24 months</td>
<td>4</td>
<td>10,0</td>
<td>2</td>
<td>5,0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>40</td>
<td>100,0</td>
<td>40</td>
<td>100,0</td>
</tr>
</tbody>
</table>

ER = Epileptic respondent
P/G = Parent or guardian

The following information is evident from table 4.7:

- Six of the epileptic respondents (15,0%) experience epileptic attacks within a short space of time, which means that even if they take medication the condition will still take time to be controlled (for example two times a day, three times a day, once a week, twice and thrice a week);

- Nineteen of the epileptic respondents (47,5%) have relatively long periods between attacks (for example once a month, twice a month and bi-monthly);

- Fifteen of the epileptic respondents (37,5%) have attacks either once in three months, or once in six months, once in twelve months or once in twenty-four months.
A child who experiences an epileptic attack twice or thrice a day may bring about family disorganisation to the extent that a working mother may stop working to give more attention to the epileptic child, particularly if there are no community resources to meet the child's needs.

The responses given by the parents/guardians of epileptic children on the frequency of epileptic attacks (see table 4.7 above) indicated that the information correlated considerably well with those given by epileptic children. Where there is a significant difference, this may have been caused by the fact that most of the epileptic children experienced major attacks which tended to affect their memory to some extent. The frequency of attacks may increase as some epileptics were under the mistaken impression that if they did not have an epileptic attack for a month or two they were cured and could stop taking medication as prescribed. Livingston (1963:45) also refers to this aspect by stating that withdrawal of anti-epileptic drugs may bring about an epileptic attack.

4.3.7 Medication

Question 8(a) of the interview schedule reads: "Are you on medication for epilepsy?" The responses to the question can be classified as follows:

FIGURE 4.2: NUMBER OF RESPONDENTS ON MEDICATION

- On medication 85,0%
- Not on medication 15,0%
As shown in figure 4.2, above 34 epileptic respondents (85.0%) took medication, whereas six (6) epileptic respondents (15.0%) did not take medication. It is commonsense that the condition of the epileptic who takes medication may show considerable improvement whereas the condition of the epileptic who does not take medication may deteriorate.

The practical wisdom and experience of medical social workers rendering a service to people with epilepsy such as Mare (1986:16) reveals that sometimes such people do not take medication because they are preoccupied with questions like: "Why am I sick? Why should I take medication? Until when am I going to take medication? Why am I not cured?" Chinkanda (1986:6) believes that there is always a reason why epileptics do not take medication. She states that ordinary medication may sometimes not be easy to come by because of long distances, lack of transportation or lack of funds. A person with epilepsy, for instance, either pays R5.00 or R8.00 every month when he gets his medication at Mamelodi Hospital. Although the hospital is not very far from the rest of the township, taxi fares or bus fares are needed to help them reach the hospital safely and on time.

According to the parents/guardians of the epileptic respondents (refer to question 17(a)) 34 epileptic children (85.0%) were on medication, whereas six of the epileptic children (15.0%) were not on medication. Since the same findings were obtained from the epileptic children themselves (figure 4.2) the information can be classified as reliable. The social workers can help these people to apply for a disability grant.
4.3.8 Names of Medicines

Table 4.8 clearly indicates that most respondents know the names of the medicine given to the children.

**TABLE 4.8: NAMES OF MEDICINES TAKEN BY EPILEPTIC RESPONDENTS**

<table>
<thead>
<tr>
<th>NAME OF MEDICINE</th>
<th>ER</th>
<th></th>
<th></th>
<th>P/G</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Carbamazepine</td>
<td>9</td>
<td>22,5</td>
<td>9</td>
<td>22,5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phenytoin Sodium</td>
<td>8</td>
<td>20,0</td>
<td>8</td>
<td>20,0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phenobarbitone</td>
<td>6</td>
<td>15,0</td>
<td>6</td>
<td>15,0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paracetamol</td>
<td>1</td>
<td>2,5</td>
<td>1</td>
<td>2,5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nitrofurantoin</td>
<td>1</td>
<td>2,5</td>
<td>1</td>
<td>2,5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Epanutin</td>
<td>2</td>
<td>5,0</td>
<td>2</td>
<td>5,0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Folic acid</td>
<td>1</td>
<td>2,5</td>
<td>1</td>
<td>2,5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Garoin</td>
<td>3</td>
<td>7,5</td>
<td>3</td>
<td>7,5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tegretol</td>
<td>1</td>
<td>2,5</td>
<td>1</td>
<td>2,5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pills: Don't know name</td>
<td>2</td>
<td>5,0</td>
<td>2</td>
<td>5,0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No medication</td>
<td>6</td>
<td>15,0</td>
<td>6</td>
<td>15,0</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>40</td>
<td>100,0</td>
<td>40</td>
<td>100,0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

ER = Epileptic respondent
P/G = Parent or guardian

- Thirty-two of the epileptic respondents (80.0%) were able to produce the containers or the medicines they received as prescriptions;

- The same number of parents/guardians (80.0%) were able to give the names of medicines produced by their epileptic children;

- Two of the epileptic respondents (5.0%) could not produce either containers or medicines but only stated that they (the epileptic children) received pills.
In support of the notion that epilepsy in the family is the concern of the family as a whole, the epileptic children and their parents knew where the medicines were placed. In this study, the most commonly used medicines were:

- Carbamazepine;
- Phenytoin sodium;
- Phenobarbitone;
- Garoin;
- Epanutin.

4.3.9 Prescriptions

Question 8(c) of the interview schedule reads: "Do you take your medicine as prescribed?" Alternatively, question 17(c) reads: "Does your child with epilepsy take his medicine as prescribed?" The responses to the questions can be classified as follows:

**FIGURE 4.3: THE MANNER IN WHICH EPILEPTIC RESPONDENTS TAKE THEIR MEDICINE**

- Not as prescribed 10,0%
- As prescribed 75,0%
- No medication 15,0%

The figure reveals the following:
- Thirty epileptic respondents (75,0%) took medicine as prescribed;

- Four epileptic respondents (10,0%) did not take medicine as prescribed;

- Six epileptic respondents (15,0%) did not take medicine at all.

There are serious consequences for epileptic children who do not comply with the prescriptions. Voeller & Rothenberg (in Appolone, 1978:139-148) stated that the most common cause for lapses in seizure control was the failure of parents to comply with medication. Medical social workers found in their practice that if children with epilepsy became troublesome mothers began to give them bigger doses in the hope that this would make the affected child better.

The epileptic respondents (Figure 4.3) gave valid and reliable information concerning the taking of medicine as prescribed because their parents/guardians gave exactly the same information.

However, the reasons given by the four epileptic respondents who did not take medicine as prescribed, were the following:

- "I stopped taking medication regularly since August 1988 because I thought I was cured;

- My prescription states four times a day but I prefer three times a day because I find the medicine very strong;

- I do not take it regularly because it cannot be mixed with alcohol when I want to drink liquor;
- My parents stopped me temporarily from taking medication so that I could receive treatment from the traditional healer."

When analysing the first reason given by the epileptic respondent above, it is quite clear that the epileptic took the decision without consulting his medical doctor. Furthermore, his parent/guardian was not informed because the latter disclosed that his epileptic child had stopped the medication since August 1988 for no apparent reason. The respondent obviously thought (albeit erroneously) that a seizure-free period of about 12 months meant that his condition was cured. This reveals the preoccupation of the epileptic who always worries about how long he will have to take medication.

It is not advisable for the epileptic to adjust his prescription to suit his condition without consulting his medical doctor. If the medication is very strong for one particular epileptic, the matter should be taken up with the doctor. However, some approval must have been obtained from the parent/guardian because the parent stated that the epileptic child had found the pills too strong for him.

The third epileptic respondent must have realized that alcohol intake precipitates seizure and then decided to take medicine at regular intervals so that it could not be mixed with liquor. The parent knew about this, although there was nothing he could do to stop the epileptic from drinking liquor. "He avoids medicine particularly if he wants to drink liquor." Hence he will keep on fulfilling his "sick role" because he will now create a vicious circle. It is quite easy for the epileptic who works or who receives a disability grant to buy himself liquor at
any time he wishes. However, his condition obviously becomes worse under these circumstances.

4.3.10 The after-effects of convulsive seizures

Question 7 of the interview schedule reads: "How do you feel immediately after the seizure?" Six possible responses were listed on which respondents could mark yes/no. The findings are presented in the table below:

**TABLE 4.9: THE AFTER-EFFECTS OF CONVULSIVE SEIZURES EXPERIENCED BY EPILEPTIC RESPONDENTS**

<table>
<thead>
<tr>
<th>AFTER EFFECTS</th>
<th>YES</th>
<th>NO</th>
<th>TOTAL</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Tongue painful</td>
<td>32</td>
<td>80,0</td>
<td>8</td>
<td>20,0</td>
</tr>
<tr>
<td>Headache</td>
<td>38</td>
<td>95,0</td>
<td>2</td>
<td>5,0</td>
</tr>
<tr>
<td>Mouth dry</td>
<td>31</td>
<td>77,5</td>
<td>9</td>
<td>22,5</td>
</tr>
<tr>
<td>Dizzy/confused</td>
<td>40</td>
<td>100,0</td>
<td>0</td>
<td>0,0</td>
</tr>
<tr>
<td>Slumbering</td>
<td>38</td>
<td>95,0</td>
<td>2</td>
<td>5,0</td>
</tr>
<tr>
<td>Tired</td>
<td>32</td>
<td>80,0</td>
<td>8</td>
<td>20,0</td>
</tr>
</tbody>
</table>

The analysis of the table reveals the following after effects:

- Dizzy/confused (100%)
- Headache 95%
- Slumbering 95%
- Tongue painful 80%
- Tiredness 80%
It is significant to take note of other minor after-effects which were mentioned by the clients. They are the following:

- Painful limbs
- Backache;
- Lack of fresh air;
- Short-temper edness;
- Loss of appetite;
- Need to be alone;
- Motionless and still;
- Frightened;
- Ashamed;
- Felt as if "I am going to die".

4.3.11 Control and discipline

Question 9 of the interview schedule reads: "Are you of the opinion that your parents treat you differently from your siblings?" The findings are presented in the figure below:

FIGURE 4.4: OPINIONS OF EPILEPTIC RESPONDENTS CONCERNING THEIR TREATMENT BY THEIR PARENTS/GUARDIANS

- Treated differently 37,5%
- Treated the same 47,5%
- Only child 15,0%
Barnard (1966:1023) stated that even in immediate family circle, the young epileptic child soon finds that he is considered "different". He may be treated as sick or delicate, be pampered and spoiled, and be given preferences over his healthy siblings, to the detriment of his relationship with them. In this survey however, only 37.5% of the epileptics felt that they were treated differently.

The epileptic respondents who thought that they were treated differently by their parents gave their reasons as follows:

- "My father thinks I am mad, and so he does not treat me like other children;
- When I was ill they did not want me to do anything; They do not want any of my siblings to make me angry and they do not want me to play soccer;
- My mother feels I should not be alone because I may get hurt when I experience an attack;
- They do not want me to go out with friends although my siblings enjoy their freedom;
- They took me out of school;
- There are a lot of restrictions on my movements but the other children do not have such restrictions;
- They do not want me to leave the yard;
- My mother does not talk hard with me."

Out of responses it is clear that the epileptics have
two problems, namely, relationship with father and over-protection. According to theory when conflict between father and child exists because of the stubbornness of the epileptic child, this may force the father to react aggressively toward the epileptic child. Lechtenberg (1984:111) stated that epilepsy in a child unavoidably disturbs the normal relationship in the family. The disturbance grows out of the child's self-image as well as the way the rest of the family sees the child.

In over-protection Lechtenberg (1984:115) found that restricting the epileptic child's autonomy backfires in most cases because the child eventually either rebels against all rules or becomes passive and dependent upon the restrictive parents. The parents treat the epileptic child as helpless regardless of his or her real abilities and needs.

Parents, nevertheless, tend to protect their epileptic children from failure. Lechtenburg (1984:116) found that the most routine tasks, such as preparing food, shopping, and choosing clothing, may be taken over by the parents in the unspoken belief that the epileptic child could not do them without failing. Hence, the epileptic child may feel socially isolated or rejected by his family members, especially his parents.

Lechtenberg (1984:91) states that whatever family problems and conflicts result from epilepsy in a child usually depend on the severity of the epilepsy. Well-controlled seizures may pose few real problems; poorly controlled seizures may become the focus of all family activities. With poor seizure control, parents often feel obliged to restrict the child's life and sometimes their own lives as well. This
same over-protectiveness sometimes forces an epileptic child into the role of being the permanently "sick" member of the family. The epileptic child, therefore, may experience pseudo-seizures in order to maintain the "sick role". These pseudo-seizures or fictitious seizures are mostly contrived so that the epileptic can gain attention and sympathy or avoid responsibilities (Lechtenberg 1984:153). Hence, over-protectiveness can be detrimental to the development and growth of the epileptic child.

4.3.12 Perception of siblings regarding the discrepancy in treatment of epileptic and other children

As shown in figures 4.5 and 4.4 there is no difference in the perception of epileptics and siblings regarding the treatment they receive from their parents.

Fifteen of the siblings (37.5%) who thought that their parents treated them differently from their brother/sister with epilepsy gave their view as follows:

- The epileptic is allowed to drink liquor;
- Parents avoid making epileptic angry;
- Parents over-protective towards child with epilepsy;

- Epileptic allocated lighter chores, for example cleaning the toilet;

- Epileptic not allowed to cook;

- Epileptic restricted;

- Different treatment justified.

The siblings indicated how they felt about the manner in which their parents treated them (i.e. the siblings) (see question 34):

- Felt jealous of the epileptic;

- Felt dissatisfied;

- Felt confident in parent;

- Felt helpless;

- Felt rebellious against epileptic.

Although the results from figures 4.4 and 4.5 were similar, the difference could perhaps be traced to the reasons respondents gave which explained why they thought their parents treated them differently. For instance, some of the siblings thought the difference in treatment was somehow justified when they considered the fact that the parents did so because they were fully concerned with the welfare of their children (epileptic or non-epileptic). Although a feeling of resentment on the part of some siblings cannot be left out, it is also equally important to
note that several siblings felt confident in their parents.

4.3.13 Discipline of epileptic child and non-epileptic
children by parents

Question 22(a) of the interview schedule to parents reads: "Is there any difference in the discipline of your child with epilepsy and that of your non-epileptic children?" The responses to the question can be classified as follows:

<table>
<thead>
<tr>
<th>DIFFERENCE IN DISCIPLINE</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difference exists</td>
<td>16</td>
<td>40,0</td>
</tr>
<tr>
<td>No difference exists</td>
<td>17</td>
<td>42,5</td>
</tr>
<tr>
<td>Uncertain</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>Only child</td>
<td>6</td>
<td>15,0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>40</td>
<td>100,0</td>
</tr>
</tbody>
</table>

The results in table 4.10 show a slight difference regarding discipline of the child with epilepsy and that of the non-epileptic child (2,5%). However, the results of figures 4.4 and 4.5 appear significant because the epileptic children and their siblings gave exactly the same opinions concerning their treatment by their parents. The same number of children with epilepsy and their siblings thought that they were treated differently (37,5%); whereas the same number of children with epilepsy and their siblings thought that they were not treated differently (47,5%). Here, the human factor plays an important part because the parents of the epileptic children show 2,5% difference with regard to discipline whereas the epileptic children and their
siblings show a 10,0% difference with regard to discipline. Most probably, each of the respondents will give his subjective view of the situation out of his own needs.

Nevertheless, the difference with regard to discipline was characterised by the following:

- The child with epilepsy should not be made angry;
- The child with epilepsy is seen as different from others;
- The epileptic child is seen as being cheeky and stubborn;
- The epileptic child is seen as being over-protected;
- Fear that punishment of the epileptic child may precipitate a convulsive attack;
- Movement of the epileptic child to be restricted.

Lechtenberg (1984:112) states that some of the reasons (which are given by the parent, for example, not making the epileptic child angry, the epileptic child is seen as being different from others and the fear that punishment of the epileptic child may precipitate a convulsive attack), stem from the manipulation of parents by epileptic children. Children quickly realise that parental fears and guilt are easily played upon. Any attempt to discipline the epileptic child can be subverted by the threat that such treatment will cause a seizure. "A child who can bring on his own seizures is in a powerful bargaining position in the family. He has
the option of simply becoming sick if the adults do not do what he wants" (Lechtenberg 1984:113).

However, parents who treated their children (epileptic and non-epileptic) equally did so in order to avoid possible sibling rivalry. Or they did so simply because they loved their children equally. It is the duty of the parent, for instance, to attend to the epileptic child who is found to withdraw from family interaction and also to show interest in what the non-epileptic children do (Ritchie, 1981:66).

4.3.14 The relationship between the epileptic child and the non-epileptic child as perceived by the epileptic child, parents and siblings

Questions 10, 25 and 38 asked the epileptic respondents, the parents and the siblings respectively to explain the type of relationship between the epileptic child and the non-epileptic child. The table reflects the findings in response to these questions.

TABLE 4.11: THE RELATIONSHIP BETWEEN THE EPILEPTIC CHILD AND THE NON-EPILEPTIC CHILD

<table>
<thead>
<tr>
<th>RESPONSE</th>
<th>ER</th>
<th></th>
<th>P/G</th>
<th></th>
<th>S</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Warm and friendly/positive</td>
<td>22</td>
<td>55,0</td>
<td>24</td>
<td>60,0</td>
<td>24</td>
<td>60,0</td>
</tr>
<tr>
<td>Not warm and friendly/</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>negative</td>
<td>12</td>
<td>30,0</td>
<td>10</td>
<td>25,0</td>
<td>10</td>
<td>25,0</td>
</tr>
<tr>
<td>Only child</td>
<td>6</td>
<td>15,0</td>
<td>6</td>
<td>15,0</td>
<td>6</td>
<td>15,0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>40</td>
<td>100,0</td>
<td>40</td>
<td>100,0</td>
<td>40</td>
<td>100,0</td>
</tr>
</tbody>
</table>

ER = Epileptic respondent
P/G = Parent or guardian
S = Sibling
The majority of epileptic respondents (55%), parents (60%) and siblings (60%) rate the relationship as warm, friendly and positive. Burden (in Smith, 1969:20) stated that an important factor in the development of the epileptic child is the way in which siblings react to the presence of the handicapped child in the family (over-protective and jealous). In this research it became evident that the majority of siblings (60%) felt positive about their epileptic brother/sister although negative feelings were prevalent in about 25% of the cases.

The results indicate that the majority of parents/guardians of epileptic children and the epileptic children themselves were satisfied with the relationship between the child with epilepsy and his brother and sister. However, the difference of 5% may be due to the fact that epileptic children had the difficult task of evaluating themselves objectively like their parents/guardians perhaps did. Any child, and more so a disabled child, needs love and care. Mbiti (1973:179) to support the idea, stresses the following: "Love for the disabled child will do for him more than what anything else will. It will give him a feeling of being wanted, accepted, and respected as an individual in spite of his disability".

The siblings' positive feelings were characterised by the following elements: "he should get cured; he should attend school; he should not lag behind his peers; feel pity for him/her; he needs guidance". Their negative feelings, however, were characterised by the following elements: "feeling helpless and hopeless; feeling jealous; I hate him; feel ashamed of him".
The results obtained from the siblings correlate with those obtained from parents/guardians. It is significant to note that the exact percentage of parents/guardians and the siblings (60,0%) felt positively about the relationship between the epileptic child and his siblings. It can be said that the results revealed the harmonious and stable relationship prevailing within 60,0% of the families under study. The siblings like their parents/guardians must have evaluated their brother's/sister's condition objectively, although Hines (1981:42-44) stresses that an element of subjectivity cannot be totally eliminated because of the "facts and feelings person". This means that within the outline of a person are placed internal feelings, and outside of him, external facts.

It is equally important not to lose sight of the fact that there is no problem-free family. Minuchin (1974:18-45) has found this to be true because some element of sibling rivalry may be evident even in the so-called stable family.

4.3.15 Role-fulfilment by the epileptic child

Question 11(a) of the interview schedule reads: "Do you think you are able to do things on your own although you are a person with epilepsy?" The responses to the question can be classified as follows:

- Thirty-six of the epileptic respondents (90,0%) thought they were able to do things on their own despite their condition;

Things the epileptics regard themselves as able to do, are:
- Work as a domestic worker;
- Do gardening;
- Engage in piece jobs on week-ends;
- Clean house and wash dishes;
- Do art (drawing)
- Wash before going to school;
- Sheltered employment work;
- Waiter;
- Do shopping;
- Cook food;
- Do clerical work;
- Play soccer;
- Help in my father's business;
- Dress myself.

- Two of the epileptic respondents (5.0%) thought were unable to do things on their own;

- Two of the epileptic respondents (5.0%) were not quite sure whether or not they were able to do things on their own.

The respondents who were not sure of their ability or inability to do things on their own remarked that
they were not given the opportunity to prove themselves. Hence, they gave the following reasons:

- "I was forced to leave school in Std I because the other school children were afraid of my seizures;

- My mother does not want me to cook for fear that I may burn myself."

Naturally, the epileptic child differs from other children in so far as he is subject to epileptic seizures. This must inevitably cause him to feel that he is indeed different from others. It may arouse a feeling of inferiority in him and he may become shy in the presence of his school-fellows, especially if they do not understand his seizures and tease or mock him about them, as often happens. This may easily lead to an attitude of hostility which may cause clashes with other children. Such a child, if not handled correctly, may easily become maladjusted and develop into an aggressive, quarrelsome person or become negative and aloof, displaying unfriendly, moody or obstinate traits (Barnard 1970:14).

There is a strong belief among blacks that once the epileptic person burns himself the chances of his condition being controlled or cured are very slim. Hence, the mother does not allow her child to cook for fear that she may burn herself and thereby delimit the chances of her condition being controlled or cured.

It is, however, significant to note what epileptic people think other epileptics should not be permitted to do the following (in response to question put to them):

- "climb on top of roofs;
- smoke or drink liquor;
- play rough games;
- rock one’s head;
- be allowed to swim;
- work in very hot sun;
- drive cars;
- run fast;
- ride a bicycle."

The statements given by the epileptic respondents revealed their personal experiences. The epileptic respondents who thought it better to avoid, for instance, climbing on top of roofs or working in the hot sun, consider the situations as precipitating factors to epilepsy. But a person with epilepsy who is somehow irresponsible may render himself incapable of fulfilling his roles by smoking and drinking liquor, knowing very well that the substances will precipitate a seizure.

Livingston (1975:67) allowed epileptic patients to go swimming if they cared to do so, but only under supervised circumstances, such as in the presence of a guard or a competent swimming companion. Hopkins (1981:116-117) states that all children like to climb trees. At school they may be required to climb ropes in the gym. Those with frequent seizures should be discouraged from doing so.
4.3.16 Willingness or unwillingness to reveal the condition of epilepsy to other people

Questions 11(e) and 31(a) of the interview schedule ask epileptics and their parents respectively whether the condition is discussed with other people. The table reflects the findings in response to these questions.

TABLE 4.12: EPILEPTICS' AND THEIR PARENTS' WILLINGNESS OR UNWILLINGNESS TO REVEAL THE CONDITION OF EPILEPSY TO OTHER PEOPLE

<table>
<thead>
<tr>
<th>RESPONSE</th>
<th>ER</th>
<th>P/G</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Talk about it</td>
<td>8</td>
<td>20,0</td>
</tr>
<tr>
<td>Do not talk about it</td>
<td>32</td>
<td>80,0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>40</td>
<td>100,0</td>
</tr>
</tbody>
</table>

ER = Epileptic respondent
P/G = Parent or guardian

The table reveals that:

The epileptic children and their parents/guardians felt almost the same about revealing or not revealing the condition to other people. A five percent difference is seen as a slight difference indeed. It is significant to note that 80,0% of the epileptic children concealed the disorder as opposed to 85,0% of the parents/guardians. However, Hurst et al. (1961:758) found the opposite with their study because their respondents (Africans living in Meadowlands) did not conceal the disorder. Hopkins finds it common to tell or not to tell other people about a child's disorder: "A major problem that
someone with epilepsy has to decide, therefore, is how much to tell and to whom" (Hopkins 1981:119-120).

The epileptic respondents who did not talk about their disorder gave their reasons as follows:

- "I feel ashamed;
- I do not think it is necessary;
- I have a speech defect;
- I do not feel confident about myself;
- Tsotsis may take advantage of me when I have received my disability grant from the office;
- I fear being mocked;
- I have not experienced an attack for the past two years".

The reasons given imply that the epileptic children felt isolated, uncertain, cast out and lonely and these in turn affected their role-fulfilment negatively. For instance, it may be difficult for the epileptic child to mix freely with other children at school because he feels ashamed or he feels he has a speech defect or his self-concept is poor. He may fear to take his girl-friend out or to have one for that matter for fear that he may be too exposed or he may experience an attack while with her.

This latter point is stressed in one of George Eliot's novels (1982:130-131):

"So had his way of life:- he invited no comer to
step across his door-sill, and he never strolled into the village to drink a pint at the Rainbow, or to gossip at the wheelwright's: he sought no woman or man, save for the purposes of his calling, or in order to supply himself with necessaries; and it was soon clear to the Raveloe lasses that he would never urge one of them to accept him against her will—quite as if he had heard them declare that they would never marry a dead man come to life again... he was arrested, as he had been already since his loss, by the invisible wand of catalepsy."

However, the parents/guardians who did not talk about the child's disorder gave their reasons as follows:

- Felt ashamed;
- Felt ashamed to tell anybody outside the church;
- People look down upon epileptics;
- Did not feel it necessary to talk;
- People blame the parents of children with epilepsy.

Anyone who talks badly about the handicapped child hurts the parent. In order to defend the ego a parent may adopt an attitude of not talking about the child's disorder to anybody except a fellow-church-goer whom he trusts will support him instead of blaming him for the child's condition. The plight of the epileptic is also illustrated, in literature, for example, in Marco Polo (Humble, 1975:39), where the emperor of the Mongols became angry after his son experienced an attack in the presence of Marco while they were hunting. Emperor Khan was so furious that
he promised to kill Marco because according to him, he who sees his son having seizures should die because since then that person will despise his son. But when Marco told him that the seizure is a sign of greatness the emperor became happy because he believed that his son had a sign of greatness.

In the novel, Silas Marner, George Eliot depicts the opposite because according to him cataleptic fits symbolize both Silas's inability to adjust to reality, and a break in his personality (Eliot 1982:XV). It is true that the two statements may bring about confusion in the readers of the two novels but definitely the authors in the two novels had different objectives to achieve.

4.3.17 The form of Epilepsy

Question 16(d) of the interview schedule reads: "Describe the form of epilepsy the child experiences?" The responses to the question can be classified as follows:

<table>
<thead>
<tr>
<th>DESCRIPTION</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Screams and body jerks</td>
<td>33</td>
<td>41.25</td>
</tr>
<tr>
<td>Falls down and becomes unconscious</td>
<td>18</td>
<td>22.50</td>
</tr>
<tr>
<td>Clinches teeth</td>
<td>4</td>
<td>5.00</td>
</tr>
<tr>
<td>Face becomes blue</td>
<td>6</td>
<td>7.50</td>
</tr>
<tr>
<td>Mouth foams</td>
<td>12</td>
<td>15.0</td>
</tr>
<tr>
<td>Bites tongue</td>
<td>3</td>
<td>3.75</td>
</tr>
<tr>
<td>Urinates</td>
<td>2</td>
<td>2.50</td>
</tr>
<tr>
<td>Absent minded</td>
<td>1</td>
<td>1.25</td>
</tr>
<tr>
<td>Objects fall from hand</td>
<td>1</td>
<td>1.25</td>
</tr>
<tr>
<td>TOTAL</td>
<td>*80</td>
<td>100.00</td>
</tr>
</tbody>
</table>

* For explanation of total of 80 see p.130.
The total number of responses has increased to 80 because one respondent could give more than one response to certain items.

The following information can be derived from table 4.13:

- Thirty-three of the responses (41.25%) indicated that screaming and body jerking were the most common characteristics of children with epilepsy;

- Eighteen of the responses (22.50%) indicated that falling down and becoming unconscious were noticeable among children with epilepsy;

- Twelve of the responses (15.00%) showed that foaming at the mouth was also common among children with epilepsy;

- Six of the responses (7.5%) showed that epileptic children's faces sometimes turned blue; (The blueish face frightened the respondents because they thought the epileptic child was going to die).

It is important to remember that the responses given were the least the respondents could remember. For instance, it does not necessarily mean that only four children with epilepsy clinched their teeth under epileptic attacks (5.00%). According to table 4.9, 32 epileptic respondents indicated that their tongues were painful, which gave the impression that they bit their tongues, although according to the description given by their parents/guardians, only three bit their tongues (table 4.13). Perhaps only when the parents/guardians could see blood from the children's mouths did they regard this as an indication that
they had bitten their tongues. However, it may be quite embarrassing to state that his/her child with epilepsy urinates or soils his undergarments. Hence, the two responses may represent those respondents who felt free to give the exact description. Characteristics such as absent-mindedness and the falling of objects from the hand (2.5%) could have been given with ease because they are not laden with emotions.

4.3.18 Effect of attack on parents/guardians

The parents/guardians of epileptic children were asked how they feel when the child gets an attack in question 17(e). The findings are presented in the table below:

<table>
<thead>
<tr>
<th>NATURE OF FEELING</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Felt worried</td>
<td>18</td>
<td>45.0</td>
</tr>
<tr>
<td>Felt sad</td>
<td>8</td>
<td>22.5</td>
</tr>
<tr>
<td>Felt helpless and hopeless</td>
<td>6</td>
<td>15.0</td>
</tr>
<tr>
<td>Felt angry at witch</td>
<td>2</td>
<td>5.0</td>
</tr>
<tr>
<td>Felt guilty for birth of child</td>
<td>4</td>
<td>10.0</td>
</tr>
<tr>
<td>Felt God will help</td>
<td>1</td>
<td>2.5</td>
</tr>
<tr>
<td>TOTAL</td>
<td>40</td>
<td>100.0</td>
</tr>
</tbody>
</table>

From the above it is evident that parents experienced negative feelings: they felt worried, sad, hopeless, angry and guilty at the situation. These feelings are understandable.

However, their feelings cover most of the core problems social workers need to address when dealing
with people with epilepsy and their families. The parents felt genuinely worried about their epileptic children because they wondered whether the children would lead a normal life, by say, getting married, or whether the child would get cured.

The results according to table 4.14 confirm Barsch's (1968:8) observation, namely that some parents feel personally responsible for the child's defect. Others are relieved by the knowledge that an accident over which they could not possibly have control is the responsible agent. The parent who leaves a small child alone on a bed and the child then falls down on his head may definitely feel guilty if the child later in life experiences epileptic attacks. Burden & Schurr (1980:52-53) also state that a condition such as epilepsy, which may well be life-long and carry all sorts of emotional overtones, makes an indelible mark on the family history. Some parents spend a great deal of time worrying about their personal responsibility for this misfortune, this "blemish" in the family.

The moment the parent thinks the epileptic child is going to die he or she may feel horrified and frightened. Barrow & Fabing (1966:26) support the above statement by stating that upon learning that their child has epilepsy, parents usually are horrified and frightened. They have heard of the stigma attached to the condition.

Being horrified and frightened can put mothers in a terrible position because there is a strong belief among the rural blacks in and around Lebowa that a parent (especially the mother of the child) who cries because her child is ill can cause the child to become disabled when he recovers from the illness.
But on the contrary, it is also believed by the rural blacks in the same area that crying has therapeutic value because the person who cries "decreases the overflow of soup from the head" (Go lla go fokotsa moro wa hlogo).

4.3.19 Treatment of epileptic child

4.3.19.1 Treatment in the past

Respondents were asked to explain the kind of treatment received by the epileptic children in question 18(b). The analysis in response to question 18(b) can be drawn from the table below:

TABLE 4.15: THE KIND OF TREATMENT THE CHILD WITH EPILEPSY RECEIVED IN THE PAST

<table>
<thead>
<tr>
<th>KIND OF TREATMENT</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Traditional healing</td>
<td>19</td>
<td>47,5</td>
</tr>
<tr>
<td>Medical treatment</td>
<td>10</td>
<td>25,0</td>
</tr>
<tr>
<td>Medical treatment and traditional healing</td>
<td>8</td>
<td>20,0</td>
</tr>
<tr>
<td>Traditional healing and faith healing</td>
<td>2</td>
<td>5,0</td>
</tr>
<tr>
<td>Faith healing</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>40</strong></td>
<td><strong>100,0</strong></td>
</tr>
</tbody>
</table>

The results correlate very well with those in paragraph 4.3.4 concerning the first person to treat the child with epilepsy. Nineteen of the respondents (47,5%) stated that the first person to have treated their children with epilepsy was the medicineman. The same number of respondents in table 4.15 stated that the child with epilepsy received traditional healing in the past (47,5%). There has been a great decrease in the use of medical treatment in table
4.15 (25.0\%) compared to the results in paragraph 4.3.4 where the medical doctor was rated the second person to treat the child with epilepsy by 45\% of the respondents.

Furthermore, the results reveal the typical nature of the black person being influenced by the different social institutions in his environment. For instance, he receives a prescription from the hospital but on the other hand he receives medicine from his traditional healer (Sangoma). During the day he receives treatment from the faith healer but during the night when it is dark he is free to consult his family doctor (maine). He does not know where he stands. He is desperate. His condition or the condition of the child may deteriorate because of his application of double standards. This is valuable knowledge to social workers.

Traditional healers nowadays possess certificates which enable them to operate openly. It is not necessary, according to them, to be consulted at night because they are registered with the South African Dingaka Association. Any black person irrespective of his status or position in the community has at one time or another consulted the traditional healer: "Do not for one moment think that it is only the unsophisticated black people who consult witchdoctors and faith-healers, thousands of highly-educated blacks do, and any black man or woman who says that he or she has never had anything to do with witchdoctors is merely pulling your leg and indulging in hypocrisy as so many educated people often do" (Mutwa 1974:79). This is also very important for the social worker because hypocrisy may retard the progress in any service-provision.
However, the majority (77.5%) now have their children treated by a medical doctor. Schweitzer (1980:28) stated that organically based conditions such as epilepsy and post-traumatic psychoses require medical care. Perhaps it is due to this factor that the traditional healers could not help their patients.

4.3.19.2 Involvement of a social worker: Question 19(a) of the interview schedule to parents reads: "Is there a social worker involved in the care of your child with epilepsy?" The responses to the question can be classified as follows:

**FIGURE 4.6 THE INVOLVEMENT OF A SOCIAL WORKER IN THE TREATMENT OF CHILDREN WITH EPILEPSY**

- No social worker involved 62.5%
- Social worker involved 37.5%

From the above it is evident that social workers are only involved in 37.5% of the cases.

People with epilepsy who received medical treatment at Mamelodi Hospital, for instance, did not automatically receive social work service. Some were referred to a social worker by the medical personnel depending on the problems the family experienced at that time (especially psycho-social problems). The assumption that some epileptics or their families did not even know that there was a social worker attached to the hospital could not be ruled out.
The findings did not differ much from the study by Khambule (1990:113-114) who found that more than two-thirds of the sampled black male boardcases prisoners (69.5%) had had no contact with either a social worker or a social auxiliary worker during the course of their current imprisonment.

Blacks do not easily use the services of a social worker if they were not orientated on how to see the social worker and what they will benefit from their contact with the social worker. Furthermore they prefer to be called for interviews rather than to take the initiative of contacting a social worker whenever they experience psychosocial problems they cannot solve on their own. They view the social worker as an outsider and not quite easy to share their problems with him.

4.3.19.3 Nature of parents' contact with social workers: The frequency of parental contact with social workers was as follows:

- Four of the respondents (10.0%) did not make appointments to see the social worker because they could only see the social worker during working hours;

- Five of the respondents (12.5%) had contact with the social worker once a month;

- Six of the respondents (15.0%) had contact with the social worker whenever there was a need.

---

3The prisoners who have been sentenced to effective terms of imprisonment ranging from periods of two or more years (Khambule 1990:15).
All fifteen respondents who had contact with the social worker were satisfied with the services rendered by the social worker. Thirteen (13) of the fifteen (15) respondents were satisfied because their epileptic children were helped to receive disability grants. This forms a very small fraction of the role of the social worker but in this study it appears to be the most important role of the social worker as experienced by the respondents. The other two parents were also satisfied with the services of the social worker because the social worker could listen to their problems empathically and with non-judgemental attitude. Hence they felt they were of great worth.

4.3.19.4 Opinions of parents regarding family assistance: Question 19(e) of the interview schedule to parents reads: "What kind of help do you get from the family members in the treatment of the child with epilepsy?" The responses to the question can be classified as follows:

- Fourteen (14) of the respondents (35,0%) received financial assistance from family members for the treatment of the child with epilepsy;

- Sixteen (16) of the respondents (40,0%) received some other form of help from family members (for example, looking after the child during the parents' absence; emotional support, advice-giving and loving).

- Ten (10) of the respondents (25,0%) did not receive any help from family members.

Martin & Martin (in Tshabalala, 1986:73) confirm the results of this study by stating that an African
family is characterised by an inter-dependent kinship system which is welded together by a sense of obligation to relatives. The support system is stable. When responding to the question 19(f): "What other resources in the community are available for the care of epileptic children?", thirty-four (34) of the respondents (85.0%) made mention that they did not know of any resource in the community for the care of epileptic children. However, they expressed the wish that a school for epileptic children or for mentally retarded children in Mamelodi would be most welcome.

4.3.20 Epilepsy and the epileptic child's school performance

The parents of epileptic children were asked to indicate whether or not epilepsy affects the child's school work in question 21(a). The findings are presented as follows:

- Eight (8) of the respondents (20.0%) stated that epilepsy affected the child's school work;

- Five (5) of the respondents (12.5%) stated that epilepsy did not affect the child's school work;

- Twenty-seven (27) of the respondents (67.5%) stated that their epileptic children did not attend school at the time they were interviewed.

The parents who stated that epilepsy affected the children's school work gave the following reasons:

- Child tends to forget easily;

- Child fails standard twice or thrice;
- Child cannot attend classes regularly due to frequent attacks.

Barnard (1970:4-5) and Pryse-Phillips (1969:77) agree that epilepsy can affect the child's school work, but this should not be a passport to a special school before considering the merits of the individual case.

4.3.21 Independent functioning of epileptic child

In answering the question on the independent functioning of epileptic child the parents gave the following responses:

- Fourteen (14) of the respondents (35.0%) let the child with epilepsy go out alone despite the condition;

- Twenty-six (26) of the respondents (65.0%) did not let the child go out alone because of epilepsy.

A pupil of Jan Kriel School for Epileptics once remarked as follows: "Dit het een keer gebeur dat ek gaan kamp het, maar voordat ek by die huis weg is, is daar gereël dat een van die kampeerders na my moet kyk" (Jan Krielskool: Jaarblad, 1971:113).

The parents/guardians who did not let their children with epilepsy go out alone gave their reasons as follows:

- My child may get hurt;

- My child may get lost.

However, the parents/guardians who let their children with epilepsy go out alone despite the condition gave
the following reasons:

- The condition is seen as minor;
- Parents are optimistic about the child's condition;
- The child is seen as a grown-up person;
- Condition is regarded as being under control;
- The child gets a 'sign', i.e. an indication that an attack is about to occur;
- The child experiences seizures only during the night.

These parents were more relaxed because they provide a better climate for the epileptic child to be independent.

4.3.22 Effect of epilepsy on the parents' movement

In answering the question on their own movements the parents responded as follows:

- Sixteen (16) of the respondents (40,5%) stated that the child's condition had a great effect on their movements;
- Fifteen (15) of the respondents (37,5%) stated that the child's condition has nothing to do with their movements;
- Nine (9) of the respondents (22,5%) stated that the child's condition restricted their movements occasionally.
The findings revealed that twenty-five of the respondents (62.5%) are convinced that their movements are restricted because of the child's epilepsy. It may be assumed that restricted movements are brought about by overprotection on the part of parents/guardians of children with epilepsy. Lerman (in Appolone, 1978:139) identified overprotection as one of the main problems in causing maladjustment in epileptic persons. However, it could also be that these are the parents of the children who had the highest rate of attacks. For instance, if an epileptic child experiences attacks at the rate of two per day (table 4.7) it may be difficult for the parent to take part in any extra-mural activities or to continue working, particularly the mother. Here the aspect of overprotection may be quite irrelevant because the actual situation definitely restricts the movements of the parent to a great deal, given that the welfare of the child is at stake. The findings compare favourably with those in paragraph 4.3.20 because a restricted parent will definitely not allow an epileptic child to go out alone.

4.3.23 Financial position of the family

Question 27(a) of the interview schedule to parents reads: "How would you describe your financial position?" The responses to the question can be classified as follows:

- Two (2) of the respondents (5.0%) regarded the financial position of the family as good;

- Thirty (30) of the respondents (75.0%) regarded the financial position of the family as average;
Eight (8) of the respondents (20,0%) regarded the financial position of the family as poor.

Eight of the respondents (20,0%) stated that the child's condition has an effect on the poor financial position of the family. Chinkanda (1986:7) confirms the findings by stating that ordinary medication may sometimes not be easy to come by because of long distances, lack of transportation or lack of funds.

The respondents who stated that the child's condition has an effect on the poor financial position of the family gave the following reasons:

- They pay R8,00 per month for the medication;

- The respondent pays R50,00 and more per month for prescriptions;

- Payments of between R100 to R300 are made for traditional medicines until such time as the child is cured.

Concerning the question on the financial position of the family, the siblings responded as follows:

- Nine (9) of the respondents (22,5%) thought that their brother's/sister's condition had an effect on the financial position of the family;

- Sixteen (16) of the respondents (40,0%) did not think it had any effect on the financial position of the family;

- Nine (9) of the respondents (22,5%) stated that the epileptics financed themselves because they received disability grants.
It is significant to note that the findings from siblings correspond with those from parents in respect of the condition of the epileptic child having an effect on the financial position of the family.

However, it is not surprising to obtain such findings, because if people live just above the breadline and do jobs as per tables 4.2 and 4.3 one can assume that they receive meager salaries and any additional costs or a child who cannot become independent will pose an additional burden to the family.

4.3.24 Grandparent-grandchild relationship

When asked about the nature of grandparent-grandchild relationships the parents responded as follows:

- Eighteen (18) of the respondents (45.0%) stated that their children with epilepsy had warm relationships with their grandparents;

- Twenty-two (22) of the respondents (55.0%) stated that their children with epilepsy did not have grandparents.

Although the respondents lived in an urban area they also had ties with their families of origin because the grandparents had regular contact with their grandchildren even if the grandparents stayed in the self-governing territories, like Lebowa, Kwa-Zulu, Gazankulu, Ka-Ngwane and Kwa-Ndebele. The importance of the extended family system is not evident in terms of the results of this study.
4.3.25 People outside the family circle

Question 29 of the interview schedule to parents reads: "How do people who know that the child is an epileptic, behave towards him?" The responses to the question can be classified as follows:

**TABLE 4.16: BEHAVIOUR OF PEOPLE TOWARDS EPILEPTIC CHILDREN ACCORDING TO PARENTS' VIEWPOINT**

<table>
<thead>
<tr>
<th>OPINION</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>People behave positively</td>
<td>27</td>
<td>67,5</td>
</tr>
<tr>
<td>People behave negatively</td>
<td>6</td>
<td>15,0</td>
</tr>
<tr>
<td>Difficult to notice reaction</td>
<td>7</td>
<td>17,5</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>40</td>
<td>100,0</td>
</tr>
</tbody>
</table>

The majority (67,5%) of the parents experienced other people's behaviour towards their epileptic children as positive.

Question 30 of the interview schedule reads: "How do people who do not know that the child is an epileptic behave towards him during an attack?" The responses to the question can be classified as follows:

**TABLE 4.17: BEHAVIOUR OF PEOPLE WHO DO NOT KNOW THAT THE CHILD IS AN EPILEPTIC DURING AN ATTACK**

<table>
<thead>
<tr>
<th>OPINION</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Felt pity but could not help</td>
<td>17</td>
<td>42,5</td>
</tr>
<tr>
<td>Frightened</td>
<td>15</td>
<td>37,5</td>
</tr>
<tr>
<td>Prejudiced</td>
<td>4</td>
<td>10,0</td>
</tr>
<tr>
<td>Minor condition unnoticed</td>
<td>4</td>
<td>10,0</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>40</td>
<td>100,0</td>
</tr>
</tbody>
</table>
The following information can be deduced from table 4.17:

- Seventeen (17) of the respondents (42.5%) stated that people who did not know that the child was an epileptic felt pity for him although they did not know what to do to help an epileptic child;

- Fifteen (15) of the respondents (37.5%) stated that the people who did not know about the condition of the child were frightened;

- Four (4) of the respondents (10.0%) stated that the people who did not know about the condition of the child were prejudiced;

- Four (4) of the respondents (10.0%) stated that the condition was so minor that it ran its course unnoticed by people who did not know about the child's condition.

The researcher can conclude from the results that 90.0% of the respondents felt people who did not know about the child's condition could not help the epileptic child because of lack of knowledge about epilepsy. It may be assumed that people who did not know about the condition of the child thought that the epileptic child is going to die and as a result became frightened. Or because they did not know what was wrong with the child (invisible handicap), they thought that the child had taken liquor and that he was drunk or had smoked dagga or had taken some type of drug, hence they became prejudiced. It is difficult to say whether or not the results deviated from the communal orientation of African societies, as stated by Tshabalala (1986:73), which dictates that people should help one another.
The idea which also emanates from the results is that people respond differently depending on their knowledge of epilepsy and maybe also on the nature of the attack. Laidlaw & Laidlaw (1980:45) state that it must be accepted that there is still considerable fear of and prejudice against the person with epilepsy. They agree, however, that to watch a major convulsion for the first time may be a terrifying experience. Much of this prejudice is due to simple ignorance about epilepsy.

4.3.26 Siblings' peergroup relations

Question 35(a) of the interview schedule focusing on siblings, reads: "Does your brother's/sister's condition have an effect on your relationship with schoolmates?" The responses to the question can be classified as follows:

<table>
<thead>
<tr>
<th>OPINION</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>It has an effect</td>
<td>9</td>
<td>22,5</td>
</tr>
<tr>
<td>It has no effect</td>
<td>14</td>
<td>35,0</td>
</tr>
<tr>
<td>Does not attend school</td>
<td>11</td>
<td>27,5</td>
</tr>
<tr>
<td>Only child</td>
<td>6</td>
<td>15,0</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>40</td>
<td>100,0</td>
</tr>
</tbody>
</table>

If it is assumed that epilepsy has an effect on the relationship of sibling with his/her schoolmates, the schoolmates may be reacting in accordance with what they learnt from their parents that epilepsy is contagious and they therefore fear to have anything to do with the brother/sister of the epileptic at
school or elsewhere.

Burden & Schurr (1980:54-55) state that there have been a number of attempts to measure attitudes towards epileptic children and adults. The most reliable recent study was conducted by the Gallup Organisation in the United Kingdom in March 1979. The question asked was: "Would you object to having any of your children associated in school or elsewhere with people who sometimes had seizures (fits) or not?" (Burden & Schurr, 1980:54-55). The answers to the questions were as follows:

<table>
<thead>
<tr>
<th></th>
<th>1979</th>
<th>1969</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would object</td>
<td>5%</td>
<td>15%</td>
</tr>
<tr>
<td>Would not object</td>
<td>88%</td>
<td>68%</td>
</tr>
<tr>
<td>Don't know</td>
<td>7%</td>
<td>17%</td>
</tr>
</tbody>
</table>

The study mentioned by Burden & Schurr (1980:54-55) shows the influence of attitudes towards epileptics. It is true that parents who have positive attitudes towards epileptics would not object to seeing their children associated in school or elsewhere with the brother's/sister's of people who sometimes had seizures or fits.

The reasons given by the siblings on whether or not their brother's/sister's condition had an effect on their relationship with schoolmates (question 35(b)), were as follows:

- Relationship with sibling not known by schoolmates;
- Schoolmates talk positively about epileptics;
- Schoolmates think condition is contagious;
- They think the epileptic is troublesome;
- They accept the epileptic as a person;
- They felt pity for the epileptic;
- They did not know he is an epileptic;
- They think the epileptic is a drunkard;
- They took the epileptic as an object of mockery.

If parents are ignorant of epilepsy, their children will follow suit because the latter acquire knowledge, firstly, from the parents and secondly, from the teachers or from significant others. The social worker, therefore, has a great role to play as an educator, interpreter, mediator, observer, advocate, broker and guide.

Question 36(a) of the interview schedule to siblings reads: "Does your brother's/sister's condition have an effect on your relationship with your fellow church-goers?" The findings are presented in the table below:

<table>
<thead>
<tr>
<th>OPINION</th>
<th>NUMBER</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>It has an effect</td>
<td>3</td>
<td>7,5</td>
</tr>
<tr>
<td>It has no effect</td>
<td>17</td>
<td>42,5</td>
</tr>
<tr>
<td>Uncertain</td>
<td>1</td>
<td>2,5</td>
</tr>
<tr>
<td>Not a church-goer</td>
<td>13</td>
<td>32,5</td>
</tr>
<tr>
<td>Only child</td>
<td>6</td>
<td>15,0</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>40</strong></td>
<td><strong>100,0</strong></td>
</tr>
</tbody>
</table>
If one compares the results of tables 4.18 and 4.19 it becomes quite clear that the atmosphere at a school differs from the atmosphere at a church. Fellow church-goers are more positive than schoolmates. Here the role of religion plays an important part in approaching the "haves" and the "have-nots". With regard to those who do not attend church, Riga (1983:1) states that African people's general lifestyle is based on the firm conviction of the existence of the spirits of their departed forefathers (badimo). It is therefore not surprising to see so many non-church-goers (32.5%) because their church is right where they are, at home, in terms of their own religion.

The reasons given by the respondents on whether or not their brother's/sister's condition had an effect on their relationship with fellow church-goers were as follows:

- Condition unknown;
- Do not want to witness an attack;
- Father negative about condition;
- Epileptic should get cured;
- Epileptic to be given moral support;
- Pray for epileptic.

It is significant to note that the idea that epilepsy is contagious did not come to the fore with fellow church-goers as it did with schoolmates. This shows that the fellow church-goers are optimistic about the problem of epilepsy, compared to the schoolmates whose attitudes reflect pessimism.
4.4 SUMMARY

4.4.1 Profile of epileptics

More than 50% of the epidemic respondents are older than 20 years of age. It has been found that the condition of epilepsy is slightly higher among males. The present survey showed that 82.5% of the epidemic respondents are dependent on their families. Work-seekers were 32.5%.

4.4.2 Profile of parents/guardians

Parents/guardians of between 45 years and 60 years are fully matured people who can be able to communicate with the social worker to seek help whenever necessary. More mothers were interviewed because fathers tended to give the mothers the chance to become involved on behalf of the parents in the survey. Also 27.5% of the parents were housewives which meant that the researcher would rather find them at home. The survey indicated that most parents (55.0%) were doing low-income work.

4.4.3 Views about the causes of epilepsy

Epilepsy is seen as a medical problem. Although it is not yet clear what the causes of epilepsy are, a diagnosis from the medical doctor will suffice.

Divergent views on causes of epilepsy were received from the empirical study. Head injury and bewitchment were given by the parents as the most important causes. A great number of epileptic children (70.0%) and their siblings (55.0%) did not know the causes of epilepsy.
4.4.4 Epilepsy and medical treatment

It became clear from the study that the traditional healer and the medical practitioner may be equally important to the patient, depending on the nature of the illness. In as far as epilepsy is concerned Schweitzer (1980:28) found that Western medicine has an important role to play.

The findings of the study reveal that eighty-five percent of the epileptic respondents took medication whereas fifteen percent of them did not take medication. It is interesting to note that seventy-five percent of the epileptic respondents who took medication took it as prescribed whereas ten percent of them took medication not as prescribed. Here the social worker can apply individual contract, group contract and community contract in dealing with the epileptic and his family.

The parents of epileptic children have the tendency of applying double standards by taking the epileptic child to a traditional healer whilst the same epileptic child takes medication from a hospital or clinic. The majority of parents (77,5%) have their epileptic children treated by a medical doctor because traditional healers could not help them.

4.4.5 Epilepsy and family life

It is significant to note that the same percentage (47,5%) of epileptic respondents and their siblings felt that their parents did not treat them differently from their siblings or from their brother/sister with epilepsy. However, forty-two and half percent of the parents acknowledge that they applied the same discipline to epileptic respondents and their sib-
lings.

The presence of an epileptic child in the family does not necessarily affect the atmosphere in the home negatively. This is evident from the findings of the study because it is found that fifty-five percent of the epileptic respondents were convinced that their relationship with their siblings was warm and friendly. Sixty percent of parents and siblings regarded the relationship between the epileptic child and his siblings as positive. The implication can be that epileptic children think positively about themselves. The fact that ninety percent of the epileptic children thought they were able to do things on their own despite their condition shows that they have positive self-image.

A person outside the family circle is seen as an intruder and therefore eighty percent of the epileptic children are not in favour of revealing their condition of epilepsy to an outsider whereas eighty-five percent of the parents feel the same as their epileptic children. However, the implication can be that the epileptic child can experience adjustment difficulties in a larger society than in his small home environment.

4.4.6 Epilepsy and school

The findings revealed that 62.5% of the parents are convinced that their movements are restricted because of the child's epilepsy. Sixty-five percent of the parents then did not let the child go out alone because of epilepsy. It may be assumed that restricted movements are brought about by overprotection on the part of parents/guardians of children with epilepsy.
The study reveals that a small number of epileptics (17.5%) could not be accommodated at ordinary schools and were forced to remain at home because there were no special schools available for them.

4.4.7 Epilepsy and finance

The chronic nature of the condition of epilepsy can have an effect on the poor financial position of the family. If an epileptic child is to take medication for the rest of his life (paying R8,00 per month) financial resources of the family can be deeply affected, when taking into account that the parents earned an average income of between R100,00 and R700,00 per month.

4.4.8 Epilepsy and informal support systems

The siblings felt that their fellow church-goers were more positive than their school-mates even if they knew that the siblings had an epileptic brother/sister. However, 32.5% of the siblings who are not church-goers pose a matter of great concern to Mamelodi community.

Seventy-five percent of the parents received some form of help from the family members and informal support systems. Help came in the form of finance, keeping company, emotional support, encouragement, care of the epileptic child in a form of relief and moral support. Eighty-five percent of the parents wishes that a school for the epileptic children could be built in Mamelodi because there are no resources in the community for the care of epileptic children.
4.4.9 Epilepsy and social work attention

The study brought to light the fact that social workers were only involved in 37.5% of the cases. There has been poor referral of epileptics to social workers attached to Mamelodi Hospital although the patients experienced psychosocial problems that can be addressed by the social workers.

CONCLUSION
Since epilepsy is a medical condition the doctor and the nurse are the appropriate people to explain the causes of epilepsy. For the epileptic to lead a normal life and be able to adapt to his immediate environment he must first and foremost feel accepted by his family, his school mates and his fellow church-goers. As a psychosocial being the epileptic is forced to interact with people outside the family and his self-image and self-esteem can be developed positively or negatively. The medical doctors are found to be more helpful than the traditional healers in as far as the treatment and management of epilepsy is concerned. However, if traditional healers were to work hand in hand with Western medicine, many patients would be saved from complications of epilepsy.
CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

This chapter seeks to highlight the conclusions which were reached in the light of the preceding chapters. Recommendations, are made on the basis of these conclusions.

The interview schedule was used as a method of data collection in this study. The researcher visited the epileptic respondents, their parents and their siblings at their homes to complete the interview schedules. In order to prevent one respondent influencing the responses of the others, each respondent was interviewed alone, without the presence of the other family members. Forty (40) families participated in the study and in each family the epileptic, one parent and one sibling were interviewed. In order to arrive at relevant conclusions in this study, an endeavour will be made to give an exposition of the value of the literature study, and to take a closer look at the objectives and assumptions of the study and the results of the study.

5.2 CONCLUSIONS

5.2.1 Conclusions in terms of objectives

5.2.1.1 Objective 1: to add to the body of knowledge regarding epilepsy, its nature, causes and implications for the individual, the family and society
(a) Modern Trend:

From the literature which gave attention to the study of epilepsy among whites it is clear that epilepsy is an organic condition. Hence there is an agreement among authors that epilepsy is a medical problem. However, there is still a considerable difference of opinion as far as the causes of epilepsy are concerned. In some cases the causes are not known whereas in others the causes are known.

The seat of epilepsy is the brain. Laidlaw & Laidlaw (1980:7-8) are of the opinion that people are born with brains with widely differing sensitivities. Some have very stable brains and are most unlikely to have fits. Although the aspect of cure is not easily mentioned in the literature it is nevertheless believed that the taking of the correct medication in the prescribed manner can help in the control of epilepsy, particularly in cases of brain damage.

Any attempt on the treatment of epilepsy is done by the medical staff and the other members of the team like the social workers, psychologists, educationists, priests can follow later. However, this study did not explore deeper into the medical aspects of epilepsy because that was not included in its objectives.

Nevertheless the study revealed that 85,0% of the epileptic respondents took medication and 80,0% of them know the medicines they received even though 75,0% of the epileptic respondents took medicine as prescribed.
(b) **Traditional beliefs and Epilepsy:**

The studies done on blacks concerning epilepsy do not give as clear a direction as the modern trend does. The traditional beliefs cherished by blacks concerning events happening around them sometimes make the treatment of epilepsy by the medical staff more difficult. The beliefs are rational to the person who cherishes them. So to argue with such a person that his beliefs are unfounded can be a waste of time.

If we take into account the point made by Winterbach (1983:116) that black people do not believe in a natural cause of events, then it is quite unlikely that the black parent who believes in supernatural powers will agree that his child suffers from epilepsy due to brain injury. Instead, the condition of the child will be interpreted as punishment by his gods or as an act of witchcraft and magic.

The traditional beliefs can compel parents of the epileptic child to consult the medicineman, "sangoma or inyanga". From the study 60.0% of the parents of epileptic children knew of their children's condition from the medical practitioner but a larger group of these parents (47.5%) preferred to take their children to the traditional healer for treatment. However, Schweitzer (1980:28) forcefully argues that there are organically based conditions requiring medical care, such as epilepsy and post-traumatic psychoses. Although some parents applied double standards in this study (by consulting the medical doctor and the traditional healer) the gist of the matter is that the majority of the parents seem to realise that the medical
doctors are in a better position to render treatment to their epileptic children than the traditional healers.

(c) **Informal support systems**

Based on the theory of cultural realities, literature has revealed that blacks traditionally tend to pursue group rather than individual goals. Hence the importance of informal support systems cannot be over-emphasized. It has been brought to light by literature that parents of epileptic children are restricted in the movements because they cannot leave the epileptic child alone and go for shopping. The findings revealed that 62.5% of the parents of epileptic children are convinced that their movements are restricted because of the child's epilepsy. Informal support systems (relatives and friends) through the assistance of social worker can be utilized to take care of the epileptic child until the parents come back from shopping. The social worker can educate the public to contribute anything for the interest of epileptics in society. On the basis of the fact that relevant recent literature on epilepsy in black communities is limited or non-existent it will be unreasonable to state categorically that objective one has been fully achieved, however, valuable information on traditional and cultural beliefs about diseases and their causation has been gained.

5.2.1.2 **Objective 2: To add to the body of knowledge concerning the role of the social worker regarding work with the epileptic**
An effort was made through the literature and empirical study to describe the role of the social worker in dealing with the epileptic and his family. Various ways of intervention in dealing with the epileptic were also covered in the literature study.

From the survey it is evident that there is a great need for the epileptic and his family to have constant contact with the social worker because only 37.5% of the cases had contact with the social worker at Mamelodi Hospital. The results can be interpreted in various ways but one of the possible reasons can be that a majority of the cases did not know that there was a social worker at the hospital and if they knew they did not know how the social worker could be of help to them because they were not orientated about the role of the social worker.

The main aim with this knowledge concerning the role of the social worker is to equip the social workers attached to any agency with the necessary knowledge, skills and attitude in dealing with epileptics and their families. It does not matter whether the social worker performs his duties as a member of a team or not.

The treatment approach based on contracting in problem solving takes into account all basic social work methods, namely, casework, groupwork and community work and also the secondary methods, namely, social work administration and social work research. The steps were discussed in detail.

The second objective was achieved because any social worker dealing with the problem of epilepsy at any agency can refer to this suggested treatment approach based on contract in problem solving. Alternatively,
thresholds can be adopted to suit any situation where individuals and groups are involved.

Since a large percentage (62.5%) of the cases did not have contact with the social worker this implies that there is a lack of knowledge regarding the assistance which a social worker can render. However, by describing the role that the social worker can play is sufficient evidence that the objective has been achieved.

5.2.1.3 Objective 3: To conduct research into the experience of and the effects of epilepsy on black families with special reference to Mamelodi

The perspectives, experiences and effects of epilepsy on black families in Mamelodi were many and varied and it will suffice to give attention to a few of them at this stage:

(a) Knowledge and treatment of epilepsy

- Seventy-five percent of the epileptic respondents were given some explanation about their condition by their parents or guardians.

- Common causes of epilepsy mentioned by parents and siblings of epileptic respondents were head injury and bewitchment.

- The majority of parents consulted the medicineman first to treat their child with epilepsy and thereafter the medical practitioner.
Eighty-five percent of the parents of epileptic children indicated that their children were epileptic since birth.

The frequency of epileptic attacks mentioned by majority of epileptic respondents and their parents was once a month.

More than eighty percent of the epileptic respondents received medication and among them seventy-five percent took medication as prescribed.

Hundred percent of the epileptic respondents felt dizzy and confused after an attack.

More than forty percent of the epileptic respondents and their siblings felt they were not treated differently by their parents.

Fifty-five percent of the epileptic respondents were convinced that their relationship with their siblings was positive.

Ninety percent of the epileptic respondents thought they were able to do things on their own despite their condition.

A great majority of epileptic respondents and their parents stated that they did not talk with other people about their disorder and or child's disorder.

Forty-five percent of the parents of epileptic respondents felt very worried about their child with epilepsy during an attack.
Before parents of epileptic children received social work assistance most of them took their children to traditional healers whereas some took them to the medical practitioners. Nevertheless some parents applied double standards they went for medical treatment and traditional healing.

Social workers were involved in cases just above thirty-seven percent.

(b) Social effects

The study by Hurst et al (1961:758) found that no relatives of blacks in Meadowlands were ashamed of having epilepsy in their family and as a result they did not conceal the disorder. The current study revealed the exact opposite because a person outside the family circle was seen as an intruder and therefore 80,0% of the epileptic children were not in favour of revealing their condition of epilepsy to other people and 85,0% of their parents felt the same way. This can affect the epileptic's interpersonal relationships in future with friends and other people.

It is advisable for the teacher of the child with epilepsy to know the child's condition to save him, the class and the epileptic child from embarrassment.

The reality is that in Mamelodi there are no facilities, like a special school for epileptic children with the result that 17,5% of the epileptic children in the study could
not be accommodated at ordinary schools and were forced to remain at home. This has negative effects on the individual, the family and society at large.

- Ritchie (1981:62) has shown that the epileptic child has been found to withdraw from family interaction. If this is carried through to the school, the church, clubs and meetings, the epileptic child will experience adjustment difficulties in the social milieu. Social interaction of the epileptic child has been negatively influenced by his parents according to the study, because 65,0% of the parents did not let the child go out alone for fear that the child may get lost or get hurt.

- The independent functioning of the child with epilepsy was disturbed because it was found that in 65,0% of the cases the epileptic children were not allowed to go out alone, for example on camping trips, because parents feared the child would get hurt or get lost.

- Knowledge of first-aid to the person with epilepsy may encourage association between non-epileptics and epileptics on any level of life or any social situation.

- The majority of parents of epileptic children (62,5%) were convinced that they could not go to social gatherings or entertainment because their movements were restricted by the child's epilepsy.
- People outside the family circle who knew something about the condition of the child (70.0%) behaved positively towards him. However, people who did not know about the condition of the child were frightened (37.5%) and some felt pity but could not help (42.5%) when the child experienced an attack.

- Fellow church-goers (42.5%) were more accepting of epileptics, according to the siblings, than the siblings' schoolmates (35.0%). The assumption which summarises the social effects of epilepsy is the following: "Epilepsy does not hurt, prejudice does" (SANEL: Poster).

(c) Financial effects

The chronic condition of epilepsy implies that the financial resources of the family with an epileptic child can easily be exhausted. If the epileptic child needs to receive medication for the rest of his life, it is advisable for such a family to receive medication from an agency such as SANEL (if accessible, of course). If we assume that the families of children with epilepsy earned between R100,00 and R700,00 per month, it is quite clear that very little, if any, will be set aside for medical treatment.

The findings from this research, therefore, reflect the respondents' and the families' experiences regarding epilepsy and the effects these had on their belief regarding the causes and the treatment, their social interaction with people outside and inside the family, the schools, friends and church; and on
their financial situation. Objective three has been achieved.

5.2.1.4 **Objective 4: To make recommendations regarding a possible model for intervention by social workers**

Recommendations in this regard are submitted under the section on recommendations viz in paragraph 5.3.

5.2.2 **Conclusions in terms of assumptions**

5.2.2.1 **Assumption 1: The traditional beliefs of the black people have a significant influence on the causes and management of epilepsy**

Literature has quite clearly proved that black people do not believe in the natural cause of events. If there is a mishap in the family the family members begin to ask themselves some of the following questions: Why it happens to us? What did we do that offended our ancestors? Who are our enemies? Bewitchment as a cause of epilepsy was mentioned by a majority of parents and siblings of epileptic children. The study showed that the parents of epileptic children consulted both doctor and medicineman (using double standards) and one of them permitted his child to stop taking medication to first go to sangoma. This surely would bring about a delay in the progress and management of the condition of the child with epilepsy.

If the parents of the epileptic children cherish the belief that a witch has caused the disorder in their children, it will be difficult for the social worker or medical doctor to convince them to allow the children to take medication so that seizures can be
controlled. This assumption is confirmed.

5.2.2.2 Assumption 2: The presence of the epileptic child in the family has a negative influence on the entire family

The literature study revealed that a condition such as epilepsy, which may well be life-long and carry all sorts of emotional overtones, makes an indelible mark on the family history. If the family's immediate environment believes that epilepsy is contagious association of the epileptic child with other children at school, church, swimming club and elsewhere can be negatively affected.

The fact that 80,0% of the epileptic respondents and 85,0% of their parents did not prefer to talk about the condition shows an element of negative attitude on their part.

The parents of children with epilepsy felt worried, sad, guilty for birth of child and angry at witch during an attack (97,5%).

Twenty percent of the parents felt that epilepsy affected the epileptic child's school performance negatively.

Twenty-six (26) of the respondents (65,0%) did not let the child go out alone because of the fear of epilepsy.

The findings revealed that twenty-five of the respondents (62,5%) are convinced that their movements are restricted because of the child's epilepsy.
The empirical study revealed that the finance of the family with epileptic child is affected negatively because only 5,0% regarded the financial position of the family as good.

Epileptic attacks triggered negative responses to people who do not know that the child is an epileptic during an attack because 90,0% of the respondents felt pity but could not help, they felt frightened and prejudiced. The above assumption is therefore confirmed.

5.2.2.3 Assumption 3: A team approach in the treatment of the epileptics helps the social worker to render meaningful service to the epileptics

If we agree that epilepsy is first and foremost a medical problem, it is then quite clear that the social worker will hear from the doctor or nurse that the patient has been diagnosed as an epileptic. The social worker dealing with the epileptic and his family at any agency cannot on his own assess that the patient is an epileptic without an official diagnosis from the medical experts.

The social worker will realise that consultation and referral are very important components of teamwork. Literature has brought to light that a well recognised fact in psychotherapy is that the person who is most knowledgeable about the patient's value system is best able to be of help. The traditional healer is such a person because he is knowledgeable about the beliefs of black people concerning the causes of epilepsy.

In the most ideal circumstances the team should consist of the neurophysician, nurse, clinical
psychologist, social worker, priest, occupational therapist, technicians and secretaries and significant others who will each play his specific and unique role.

From the literature study it is evident that the assumption that a team approach in the treatment of the epileptics helps the social worker to render meaningful service to the epileptics is therefore confirmed.

However, in this research, it was found that a team does not exist, nor does doctor or nurse refer the parents to a social worker. Although the above assumption is true in theory, a team approach was non-existent in treating the respondents and their families.

5.3 RECOMMENDATIONS

On the basis of research and the results obtained, the researcher wishes to make the following recommendations:

5.3.1 Social work treatment approaches

The results of the study indicate that in 62.5% of the cases no social worker was involved. The epileptic respondents and their families did not know that there was a social worker. Furthermore social workers failed to inform patients about their role and tasks by not explaining their role to the newly admitted patients.

It is recommended that social workers in private welfare agencies and health care settings should not work in isolation but should be integrated into a multi-disciplinary team so that possible referrals by
the doctor or nurse can be done smoothly.

The treatment approach fully discussed in Chapter 2 and highlighted in objective 2 based on contract in problem solving is highly recommended because it is a total approach including all social work methods and can be applied by social workers in any welfare agency. The five-step approach (Thresholds - taking control by learning to make decisions) formulated by Hines (1981:42-44) can be adopted for use by the agencies employing volunteers and social auxiliary workers because the approach can be easily transformed into a personal and social skills programme in which people with epilepsy and their families are taught how to control and manage epilepsy, as no sophisticated social work techniques are necessary in administering the programme. The social auxiliary workers and volunteers are supposed to render supportive service to the epileptics and their families under the supervision of social workers in a specific agency. An effective treatment model needs to be developed and these two approaches discussed could be used as a point of departure.

It is highly recommended that SANEL as the sole organization responsible for the improvement of the quality of life of persons with epilepsy should take the initiative of administering courses targeted at social workers. The study has shown that very few cases contacted the social worker. It may be that black social workers could not expose themselves with confidence because they felt they were not adequately trained to help the epileptics.

5.3.2 South African National Epilepsy League (SANEL)

Social workers need knowledge about epilepsy and SANEL with its mission statement that it is a volun-
tary charitable organization dedicated to improve the quality of life of the person with epilepsy in family and community context has developed programmes which enable their social workers to incorporate case work, group work and community work in their service delivery to epileptics and their families. Social workers in private welfare agencies and health care settings should use these programmes as a basis for the development of their own programmes (see figure 5.1).

5.3.3 Community awareness

From the results of the study 80,0% of the epileptic respondents and 85,0% of their parents preferred to hide the existence of epilepsy in the family because among other things they felt ashamed, they did not feel confident about themselves, they feared being mocked at and they also felt it was not necessary to reveal the condition.

Through making the community aware of the existence of epilepsy the barriers of prejudice, ignorance, discrimination and rejection which prevent individuals with epilepsy from leading a normal life can be broken down.

The study revealed that people who did not know that the child is an epileptic during an attack felt pity but could not help (42,5%), some became frightened (37,5%) whereas others were prejudiced (10,0%). A focus on developing community awareness about epilepsy would therefore provide the people with relevant information about the person with epilepsy and how the person can be helped during and after an attack.
FIGURE 5.1: SANEL (Durban and Coastal Areas): Programme

WELFARE PROGRAMME

COMMUNITY AWARENESS SUB-PROGRAMME
- Community awareness project at macro and mezzo level
- National epilepsy week project
- Agency alert project

HEALTH SERVICES SUB-PROGRAMME
- Epilepsy clinics project
- Nhlabumkhosi project

THERAPEUTIC SERVICES SUB-PROGRAMME
- Therapeutic Intervention project
- Inter-agency Social relief project
- Epicare project

EDUCATION SUB-PROGRAMME
- Teacher alert project
- Pupil alert project
- Learning disability project

EMPLOYMENT SUB-PROGRAMME
- Self-help project
- Protective and sheltered workshop

5.3.4 Health services

Sixty percent of the parents of epileptic children knew of their children's condition from the medical practitioner compared to 25.0% of them who were told of the condition by the traditional healer. However, the majority (47.5%) of the parents stated that the first person to have treated their children with epilepsy was the traditional healer and thereafter the medical practitioner.

Social workers must be aware of the traditional beliefs of the black communities which have negative effects in the control and management of epilepsy and they must encourage good co-operation between professionals and traditional healers through referrals of patients between them (professionals and traditional healers). The objectives regarding health services can inter alia be:

- To reduce seizures;
- To increase the understanding and acceptance of the condition of epilepsy;
- To improve compliance to medication; and
- To increase the knowledge of the psychosocial problems experienced by the patients.

The results of the study further revealed that the medical doctor and the traditional healer were equally important as seen by the parents of persons with epilepsy. In her study Bodibe (1988) recommended the inclusion of the traditional healer in a mental health team because of the valuable contribution the traditional healer can make particularly with regard to the traditional beliefs cherished by most families having persons with mental illness. This means social workers should not
undermine the knowledge and expertise of traditional healers on matters of entrenched beliefs because such beliefs are rational to people who cherish them. At some stage the traditional healers will be consulted and the latter in turn will have to refer cases they cannot handle to the professionals. Such an agreement should be reached between the professionals, for example, doctors, nurses, social workers and traditional healers.

5.3.5 Therapeutic services

It is recommended that in his service delivery the social worker should concentrate more on the epileptics, the parents, the siblings, the school mates, the fellow church-goers and people who do not know that the child is an epileptic during an attack.

5.3.5.1 The epileptics

From the study 55,0% of the epileptic children were satisfied with the relationship between them and their siblings. This positive feeling experienced by the epileptic children can be mobilized by the social worker to enable the epileptic children to view life positively. Furthermore, 90,0% of the epileptic respondents thought they were able to do things on their own despite their condition. This area will have to be explored by the social worker so that the epileptics can be taught different skills in accordance with their capabilities and limitations so that they can earn a living. Since social workers seek to mobilize resources within the individual for his own benefit the establishment of self-help groups in Mamelodi
spearheaded by SANEL: Northern and Eastern Transvaal Branch is recommended. SANEL needs not do the work for the community but it can guide the community to embark on projects that can empower the person with epilepsy and his family to lead a normal life.

A large number of the epileptics (70.0%) did not know the causes of epilepsy. The social worker and the nurse will be in a better position to interpret to the epileptics what causes their condition in more simpler terms. In rendering therapeutic service to the epileptics, individual differences and cultural beliefs will have to be taken into account. For instance, if parents are ignorant of epilepsy, their children may follow suit because the latter acquire knowledge, firstly, from the parents and secondly, from the teachers or from significant others. It is important that they be educated about the causes and management of epilepsy so that they can be able to look after themselves. This can be done at school through videos or group discussions or even individual attention. The families of persons with epilepsy need education and training, too because it is possible to live with the handicapped child for the rest of their lives. It is important to know exactly what to do before, during and after the attack. The task can be carried out by volunteers and social auxiliary workers in any agency. Because of the uncertainty of their disorder 80.0% of the epileptic children concealed the disorder. When rendering therapeutic service the social worker should consider several factors in analysing and understanding the behaviour of the epileptics
who conceal their disorder because their past experiences in their interaction with strangers or what they had been taught at home may be responsible for their negative reaction towards other people and not necessarily that they have developed a poor self-image.

5.3.5.2 The parents of epileptics

The social worker in his service delivery should understand that the parents who have an epileptic child in the family will most probably experience a lot of psychosocial problems and therefore need the assistance of the social worker quite desperately. The findings of the study revealed that 85,0% of the parents of the epileptics concealed the disorder. Almost the same number of epileptic children (80,0%) did the same thing. Here the social worker will have to study the parent-child relationship intensively in order to be of meaningful help to the entire family. In other words, he will have to follow a holistic approach to the problems brought about by the presence of an epileptic child in the family.

It became evident from the study that the movement of parents of children with epilepsy was affected by the presence of an epileptic in the family. Once more the establishment of self-help groups will be of value and the social worker can lead and guide such groups. However, parents will first have to be prepared to accept self-help groups.
To emphasize the necessity of self-help groups Loerber (1991:4) states that within the context of lay organizations there came the establishment of self-help programmes in many countries. He believes that the important reason for this development is the gradual emancipation of the patient. He further points out that this factor is not limited to persons with epilepsy but people are generally more aware of their individual rights, especially the right to make decisions regarding health care.

Malin's (1982) idea of short term care (STC) should be bought by social workers to be implemented in any agency dealing with persons with epilepsy and their families. Because of short term care rendered by informal support systems 75% of the parents could get care givers during their absence, could receive emotional support, advice, love from family members and financial support.

In this regard Martin & Martin as cited by Tshabalala (1986:73) confirm the importance of a support network by stating that an African family is characterised by an interdependent kinship system which is welded together by a sense of obligation to relatives. The support system is stable among blacks. Social workers, therefore, will have to understand how this interdependent kinship system works among blacks so that when dealing with a nuclear family social workers should not lose sight of the role to be played by brothers, sisters, cousins, aunts, uncles, grandmothers, grandfathers and many other relatives of the extended family.
It became clear from the study that most parents (55,0%) did low-income work and earned between R100-00 and R700-00 per month. Because such families would experience financial difficulties the epileptic patients could be helped to apply for disability grants as a measure of relief.

5.3.5.3 The siblings

The study revealed that epilepsy has an effect on the relationship of siblings with their school-mates. However, no sibling rivalry has been noticed. It is the task of the social worker attached to a school to explain the condition of epilepsy to teachers and school children so that they can understand the epileptic in their school better. Once more, a holistic approach by the social worker is recommended so that the epileptic in the family should not be seen by other family members as a trouble-maker or as spoiled. The family members should have understanding that they too play an important role in the management, control and treatment of the epileptic. This can be achieved through the assistance of a competent social worker.

5.3.5.4 School-mates

The social worker attached to a school can help school-mates who have misconceptions about epilepsy to change their attitudes towards the epileptic in a class-room. If we consider school-mates who think the condition is contagious, who think the epileptic smokes dagga and who mock at an epileptic they can experience tense atmosphere at school which may need the
therapeutic intervention of a social worker or an educationist for that matter.

5.3.5.5 Fellow church-goers

Fellow church-goers can be used by social workers as support systems for persons with epilepsy and their families because from the study it is evident that siblings of persons with epilepsy received support from their fellow church-goers for living with an epileptic brother or sister.

It is significant for the social worker to use fellow church-goers as resources because according to the study 42.5% of the siblings felt fellow church-goers manifest a positive relationship toward the epileptic. Hence the findings can be interpreted that the atmosphere at church is more positive than at school and the social worker should capitalise on this in his service delivery. Fellow church-goers who are optimistic about the problem of epilepsy provide a support base for the social worker assisting the epileptic and his family.

5.3.5.6 People who do not know that the child is an epileptic during an attack

People who do not know that the child is an epileptic during an attack felt pity and helpless because of lack of knowledge about epilepsy. Community awareness projects should be initiated by social workers where community involvement should be a prerequisite and people
can be enlightened about the condition of epilepsy. The social worker, therefore, has a great role to play as an educator, interpreter and guide.

5.3.6 Focus on education

According to the study 32.5% of the epileptic respondents attended school. Due to the inherent constraints of this study (i.e. only 40 families were interviewed) it was not possible to establish exactly how many epileptic children cannot attend ordinary schools. It is a sure case, however, that 32.5% of the epileptic respondents attended ordinary schools because there is no special school for epileptics in Mamelodi. If there were such a school, perhaps 17.5% of the epileptic respondents who were home-bound could increase the percentage of those who attended school to 50%. The need for a special school for epileptics in and around Pretoria should be further researched by any interested person or body or else that teachers be trained to deal with epilepsy and have knowledge of epilepsy in regular schools.

Twenty percent of the respondents stated that epilepsy affected the child's school work. For fear that the child with epilepsy might get hurt or lost 65.0% of the parents did not let the child go out alone and this meant that the epileptic child could not attend school if there was nobody to look after him all the time.

Education can help epileptic children with learning disability and can make teachers and pupils alert on aspects pertaining to epilepsy like what to do if an
epileptic child experiences an attack in a class. Furthermore, through pupil alert project the pupils can be taught that epilepsy is not contagious and as such they can play freely with children with epilepsy.

Although this study does not give evidence in as far as the behaviour of the teacher in a classroom with an epileptic child is concerned, it can be assumed that very few teachers will be able to handle a situation where one of the students experiences an attack in a classroom. Knowledge of epilepsy is vital to all teachers in ordinary or special schools to avoid embarrassment.

It is recommended that the teachers' training institutions should provide short courses for teachers who teach at ordinary and special schools to equip them with knowledge of how to handle an epileptic pupil because these children are regarded as disabled children. SANEL staff can be invited by principals of schools to teach school children first aid needed for children with epilepsy so that when one of them experiences an attack, they should not be frightened to death but should know exactly how to apply first aid to the child with epilepsy.

5.3.7 Employment

According to the study 32,5% of the epileptic respondents were work-seekers. Social workers attached to any agency can educate the employers and employees to accept people with epilepsy who are workseekers in the open labour market.
Ninety percent of the epileptic respondents thought they were able to do things on their own despite their condition. This factor is important for any social worker in the placing a person with epilepsy in protective and sheltered employment because economic empowerment can be achieved with motivated clientele.

It is recommended that the employability of people with epilepsy be investigated by interested persons or organisations so that their right to earn a living can be guaranteed. The fact that these people are motivated to do things for themselves needs experts in the field of human resources to mobilize these resources within them for their own survival.

However, it is true that unemployment is rife in our country but social workers in Mamelodi Hospital and in welfare agencies can take the lead in enabling people with epilepsy to form clubs with the aim of helping themselves become financially self-supportive through learning of different life-skills, for example, sewing, woodwork, signwriting and art.

5.3.8 Volunteers and social auxiliary workers

More than half of the cases experienced the need to contact the social worker in this study.

According to the National Council for Mental Health (1989:1) professionals employed to provide the services are bound by South Africa's welfare policy and the constitutions of their own organisations to involve volunteers. These volunteers are assigned
tasks which are non-professional and the administration of programmes can be quite suitable for them and the social auxiliary workers. They cannot deliver their services properly and effectively if they are not educated and trained on how to deal with epileptic children and their families.

Volunteers and social auxiliary workers can render supportive service to social workers because they work under the supervision of a social worker. Social auxiliary workers and volunteers can be able to administer a written programme to the epileptics, for instance, first aid to the person with epilepsy. Because of their limited knowledge of social work they are not expected to do intensive service delivery.

The South African Council for Social Work has started giving courses for social auxiliary workers on social auxiliary work, group care and individual attention. Welfare agencies are therefore advised to encourage their potential social auxiliary workers to register for the courses with the Council to be well-equipped in their supportive role to social workers.

5.4 SUMMARY

Although the results of this study cannot be generalised to the entire black population of this country, the findings, however, should add to the body of knowledge concerning the role of the social worker regarding work with the epileptic. It is time to undertake more research into the effects of epilepsy on black families. This study has merely scratched the surface because of its exploratory
nature and because of the lack of previous studies on black communities. This study can serve as a point of departure for more studies in the field of epilepsy among blacks, a field which is at present sadly neglected.


Criminology Department. 1985. Seminar on Family Preparedness. UNISA.


Sher, Dr. 11/12/1986. TV Series on Aids.


TITLE: THE EFFECTS OF EPILEPSY ON FAMILIES LIVING IN MAMELODI WITH SPECIAL REFERENCE TO THE ROLE OF THE SOCIAL WORKER

INTERVIEW SCHEDULE

INTRODUCTION

In any family a person with epilepsy may affect the existing structure and functioning of the family and he may also be affected by his immediate environment in the family circle. The roles of father and mother may be changed to accommodate the presence of the person with epilepsy. For instance, the working mother may have to stop working in order to give more attention to the child with epilepsy. To cope with the changes the family as a unit may need the intervention of the social worker.

The interview schedule, therefore, purports to investigate the effects of epilepsy on families living in Mamelodi with a view to making knowledge and insight available for incorporation in the practice of social work and to indicate the role that the social worker can play in this regard, especially with Black epileptics.

INSTRUCTIONS FOR THE COMPLETION OF THE INTERVIEW SCHEDULE

The interview schedule will be administered by the researcher to forty (40) families. It will consist of three sections. Section A will be completed by people with epilepsy (epileptics) in the family; Section B will be completed by parents of the child (either
father or mother) whereas Section C will be completed by the elder sibling to the person with epilepsy. If the epileptic is the eldest the second eldest will complete section C.

SECTION A: PEOPLE WITH EPILEPSY

1. Age of the person with epilepsy:

   Years

2. Sex of the person with epilepsy:

   Male
   Female

3. Occupation of the person with epilepsy:

4. What have you been told about your condition by your parents?

5. How would you explain the cause of epilepsy
6. How often do you experience the attack?

_________________________________________________________________________
_________________________________________________________________________

7. How do you feel immediately after the seizure? (Mark Yes or No).

<table>
<thead>
<tr>
<th></th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tongue painful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Headache</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mouth dry</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dizzy/confused</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Slumbering</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tired</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

8. (a) Are you on medication for epilepsy?

Yes  | No

(b) If yes, what is the name of the medicine?

_________________________________________________________________________

(c) Do you take your medicine as prescribed?

Yes  | No
(d) If NO, give reasons:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

9. Are you of the opinion that your parents treat you differently from your siblings?

<table>
<thead>
<tr>
<th>YES</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>NO</td>
<td></td>
</tr>
</tbody>
</table>

Explain: __________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

10. Do you think that the fact that you have epilepsy has an effect on your brothers' and sisters' behaviour towards you? Explain:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

11. (a) Do you think you are able to do things on your own although you are a person with epilepsy?

<table>
<thead>
<tr>
<th>YES</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>NO</td>
<td></td>
</tr>
<tr>
<td>Not sure</td>
<td></td>
</tr>
</tbody>
</table>
If yes,

(b) What are you able to do on your own? Specify:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

(c) Not sure, explain:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

(d) Do you think there are certain things epileptics should not be permitted to do? Explain:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

(e) Do you talk about your disorder with other people?

<table>
<thead>
<tr>
<th>YES</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>NO</td>
<td></td>
</tr>
</tbody>
</table>

Explain:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
SECTION B: PARENT (one only)

12. Father ❑ Father ❑ Guardian ❑

13. Age of respondent

YEARS ❑

14. Occupation of respondent: ————

15. What do you think is the cause of epilepsy? Explain:

————

————

————

————

16. (a) How did you discover that your child is an epileptic?

————

————

————

————

(b) Was he an epileptic since birth or due to trauma, e.g. car-accident or assault?

————

————

————

————
(c) How often does your child experience an epileptic attack?

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

(d) Describe the form of epilepsy the child experiences?

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

(e) How do you feel when the child gets an attack?

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

17. (a) Does your child with epilepsy take any medication for his/her illness?

<table>
<thead>
<tr>
<th>YES</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>NO</td>
<td></td>
</tr>
</tbody>
</table>

(b) If yes, what is the name of the medication?

____________________________________________________________________

(c) Does your child with epilepsy take his medicine as prescribed?

<table>
<thead>
<tr>
<th>YES</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>NO</td>
<td></td>
</tr>
</tbody>
</table>
18. (a) Who was the first person to treat your child with epilepsy?

(b) What kind of treatment did he receive in the past?

(c) What kind of treatment does he receive now?

19. (a) Is there a social worker involved in the care of your child with epilepsy?

   YES  
   NO

(b) If yes, how often do you see her?
(c) Are you satisfied with the services rendered by the social worker?

<table>
<thead>
<tr>
<th>N.a</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
</table>

(d) Explain why you answer 'yes' or 'no'  

______________________________  
______________________________  
______________________________  
______________________________  
______________________________

(e) What kind of help do you get from the family members in the treatment of the child with epilepsy?

______________________________  
______________________________  
______________________________  
______________________________  
______________________________

(f) What other resources in the community are available for the care of epileptic children?

______________________________  
______________________________  
______________________________  
______________________________  
______________________________
20. Who else is involved in the treatment of your child with epilepsy?

<table>
<thead>
<tr>
<th>Psychologist</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical doctor</td>
<td></td>
</tr>
<tr>
<td>Priest</td>
<td></td>
</tr>
<tr>
<td>Medicinemen</td>
<td></td>
</tr>
<tr>
<td>Other, specify</td>
<td></td>
</tr>
</tbody>
</table>

If this child is attending school,

21. (a) Does epilepsy affect the child's school work?

<table>
<thead>
<tr>
<th>YES</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>NO</td>
<td></td>
</tr>
<tr>
<td>N.A</td>
<td></td>
</tr>
</tbody>
</table>

(b) If yes, how?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

(c) How do you try to deal with this?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
22. (a) Is there any difference in the discipline of your child with epilepsy and that of your non-epileptic children?

<table>
<thead>
<tr>
<th>YES</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>NO</td>
<td></td>
</tr>
<tr>
<td>Uncertain</td>
<td></td>
</tr>
</tbody>
</table>

(b) If yes, how does it differ?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

(c) If no, explain:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

23. (a) Do you or did you let your child go out alone irrespective of his epilepsy?

<table>
<thead>
<tr>
<th>YES</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>NO</td>
<td></td>
</tr>
</tbody>
</table>

(b) Explain 'yes' or 'no':

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

24. How did you explain your child's condition to him?


25. In your opinion, what is the nature of the child's relationship with his/her brothers and sisters?


26. Does your child's condition restrict your movement?

<table>
<thead>
<tr>
<th>Yes, a great deal</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No, not at all</td>
<td></td>
</tr>
<tr>
<td>On occasion</td>
<td></td>
</tr>
</tbody>
</table>

27. (a) How would you describe your financial position?

<table>
<thead>
<tr>
<th>Good</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Average</td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td></td>
</tr>
</tbody>
</table>

(b) If poor, did the child's condition have an effect on this?

| Yes |   |
| No  |   |
| Uncertain |   |
(c) If yes, explain?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

(d) Does the child's condition result in any financial burden on the family?

<table>
<thead>
<tr>
<th>Yes</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Uncertain</td>
<td></td>
</tr>
</tbody>
</table>

28. What is the relationship of the grandparent(s) with the child with epilepsy?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

N.A. No grandparent

29. How do people who know that the child is an epileptic behave towards him?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
30. How do people who do not know that the child is an epileptic behave towards him during an attack?


31. (a) Do you talk about the child's disorder with other people?

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
</table>

(b) Explain:


SECTION C: SIBLINGS (one only)

The elder sibling will complete the section. However, if the epileptic is the eldest the second eldest will complete this section.

32. How would you explain the causes of epilepsy?


33. (a) Do your parents differ in their treatment of you and your brother/sister with epilepsy?

| YES | NO |

(b) If yes, how:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

34. How does the treatment in 33(a) above make you feel?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

35. (a) Does your brother's/sister's condition have an effect on your relationship with schoolmates?

| Yes |  |
| No |  |
| Uncertain |  |
| Do not attend school |  |

(b) Describe:

________________________________________________________________________
36. (a) Does your brother's/sister's condition have an effect on your relationship with your fellow church-goers?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Uncertain</td>
<td></td>
</tr>
<tr>
<td>Not a church goer</td>
<td></td>
</tr>
</tbody>
</table>

(b) Describe:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

37. Do you think that your brother's/sister's condition has an effect on the financial position of the family?

Explain? ________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
38. How do you feel towards your brother/sister with epilepsy?

THANK YOU FOR YOUR CO-OPERATION
H.P. Ramaboea
Baviaanspoort Prison
Private Bag XI
LYNN EAST
0039

Dear Sir

INFORMATION : EPILEPSY IN THE BLACK COMMUNITY

I regret to inform you that at present we at SANEL still do not know much about epilepsy in the Black community.

The only person in Pretoria who will possibly be able to help you in this regard, is Dr. Günderpfeffing, a neurologist. His telephone number is 012-449758.

I also include the address of Mrs. M. van Deemter, who will gladly give you information, if possible. Please contact her at:

Cottage No. 34,
Fairhaven
Humewood Extension
Port Elizabeth
6001

I trust that they will be able to help you.

Yours sincerely

K. Meyer
MISS K. MEYER
COUNSELOR
Geagte Heer/Dame

NAVORSING OOR EPILEPTICI WOONAGTIG TE MAMELODI EN/OF ATTERIDGEVILLE

125. Hiermee doen ek beleefd aansoek om navorsing te doen oor epileptici wat medikasie by u hospitaal ontvang (buite-pasiënte).

126. Ek stel belang om die ondersoek in so 'n mate te stel sodat die probleem in terme van die familie in die samelewing verstaan kan word.

127. Gedurende 'n bespreking met my studieleiers te UNISA, 'n groot behoefte was geïdentifiseer om met afhanklikes (veral kinders) te begin.

128. Ek verkies om met families wat by Mamelodi woonagtig is te begin want hulle is naby Baviaanspoort.

129. 'n Ligafdruk van die brief van UNISA Maatskaplike Werk Departement, word hierby aangeheg vir u inligting en beslissing.

Die uwe

P H Ramaboea
Student Nr. 235-030-0
Mnr P H Ramaboea
Baviaanspoort Gevangenis
Privaatsak XI
Lynn East
0039

Meneer

MA (SW) : STUDIE - INLIGTING OOR EPILEPTIESE PASIËNTE

Goedkeuring word verleen dat u voorsien kan word van die name en adresse van epileptiese pasiënte wat Mamelodi kliniek besoek. Dit sal geskied nadat die pasiënte of voorge skrifdelik aan ons toestemming verleen het en onderworpe aan strenge vertroulikheid in soverre dit die publikasie van name van pasiënte betref.

Die uwe

HOOFSUPERINTENDENT
ANNEXURE V

RESEARCH PROJECT: EPILEPSY AND FAMILIES

I the undersigned ................................ hereby agree that details of my condition of Epilepsy, as well as my address, be divulged to Mr P H Ramaboea of U.N.I.S.A. for the purposes of a special study of the effects of epilepsy on the families living in Mamelodi.

I understand that Mr Ramaboea will visit my home for discussions regarding the above.

NAME: ..................................................
ADDRESS: ..................................................
..................................................
..................................................
..................................................

SIGNATURE: ..................................................

DATE: ..................................................