AN INVESTIGATION OF A GROUP OF KHAYELITSHA PARENTS' UNDERSTANDING OF THE CAUSES AND MANAGEMENT OF THEIR CHILDRENS' EPILEPSY

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ABSTRACT

The purpose of this dissertation was to document the findings of a study on what the parents of children with epilepsy understood as the cause of their childrens' condition, and how they managed it. The study utilised the framework of medical, anthropological and eco - systemic models to gain an understanding of the causes and management of epilepsy. Twelve parents of children with epilepsy in Khayelitsha, a peri - urban township in Cape Town, were interviewed with the use of a semi - structured interview schedule. Interviews were recorded and later transcribed and data was analysed through the constant comparative method.

The interview explored the causes of epilepsy and the factors that trigger the onset of seizures of which most respondents had no understanding. It further explored the medical management of epilepsy in regard to kind of treatment received by child, understanding of required dose and when medication had to be taken.

The latter revealed that most respondents had no understanding of the medical management of their childrens' epilepsy, regardless of the fact that most respondents' children were on western medication. A major finding was a high level of lack of understanding of management of childs' epileptic characteristics in terms of understanding the importance of regular check - ups and keeping a seizure record. Most respondents had no understanding of the management of first aid during a fit and after a fit, and had a general reluctance to disclose their childrens' epileptic condition to others.

Implications for this study include the need for an integrated approach which can provide a better understanding and management of epilepsy as a "whole".

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TABLE OF CONTENTS

CHAPTER 2 : METHODOLOGY

CHAPTER 3 : FINDINGS

CHAPTER 4 : DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

LIST OF TABLES

LIST OF FIGURES

LIST OF DIAGRAMS

CHAPTER 1 : INTRODUCTION

1. BACKGROUND

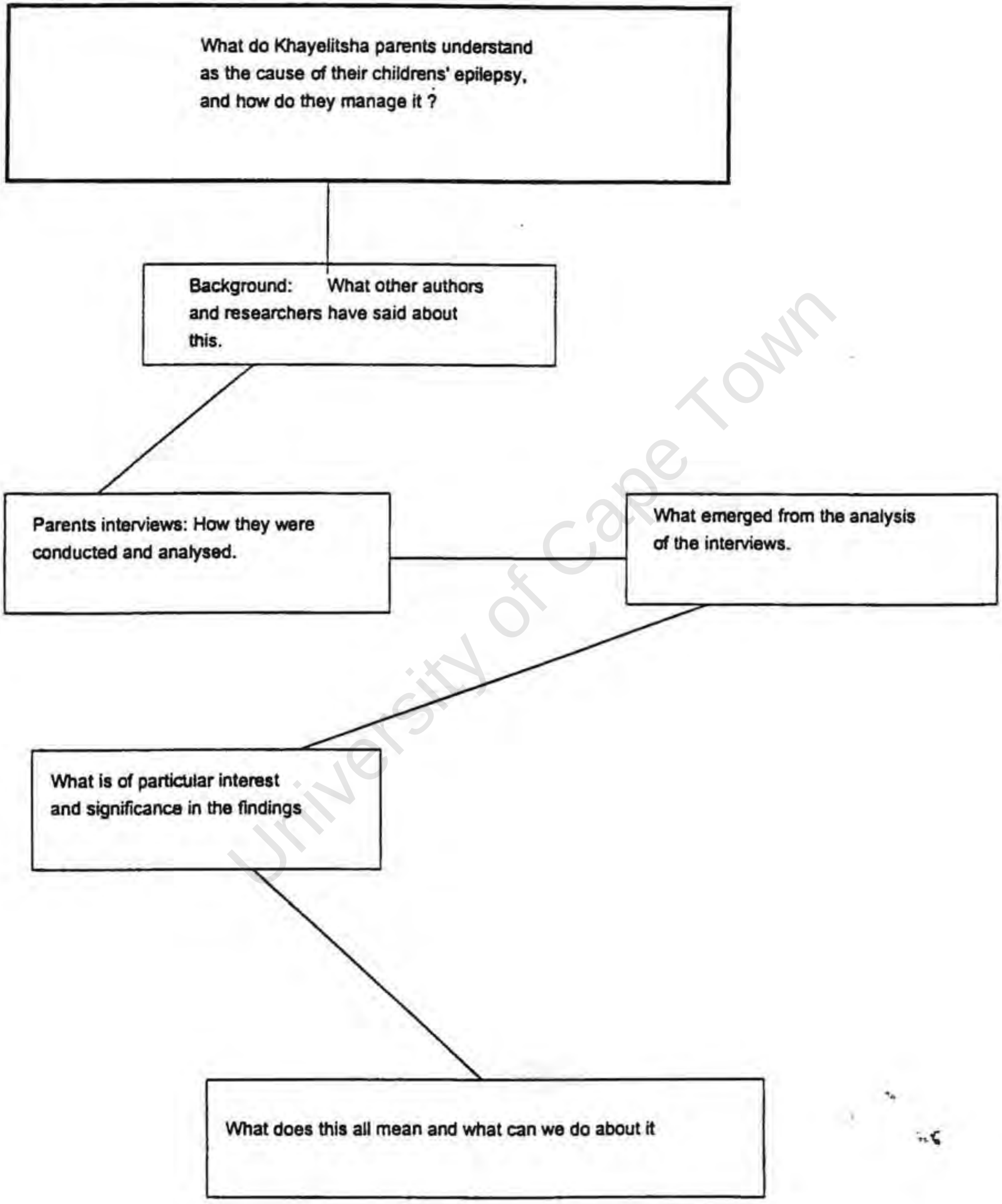
The interest to carry out research on epilepsy arose from my work context in the Zibonele Community Based Health Worker Project in Town 2, Khayelitsha. This project renders community based Primary Health Care services through Community health workers who work and reside in the areas of Town 2 and Silvertown. These Community Health Workers raised concerns regarding how parents of children with epilepsy dealt with their childrens' condition. Information received indicated that some parents removed their children from school because they felt that their children would not cope with learning. Some children were sent to rural areas to consult with traditional healers. Other parents could not disclose their childrens' condition. Due to these problems, some children indulged in the abuse of alcohol and drugs; some were withdrawn from playing with their peers; some parents left work to look after their children. Other cases of neglect were reported where a child with epilepsy was left unattended and suffered extensive burns. These are all but examples reported by Zibonele Community health workers, that indicated the need for further investigation in this area.

The purpose of this dissertation is to present the product of an investigative study into what parents understood as the cause of their childrens' epilepsy, and how they managed it. The objective is to provide guidelines for an integrated approach for management of epilepsy. Respondents were parents of children with epilepsy in Khayelitsha, a peri-urban township in Cape Town. The estimated population is about 350,000, and mainly Xhosa speaking (Mash, 1996 : 1). See Appendix A.

The first chapter begins by highlighting the background about epilepsy and giving the broad overview of the problems associated with it. Further discussions will centre around the medical aspects of epilepsy, including its cause and management from different theoretical models. Diagram 1 gives a broad view of how the thesis is structured.

MAPPING THE PROBLEM

Diagram 1



1.2.CONCEPTUALISING THE PROBLEM

" To suffer from epilepsy in Africa often means to also suffer from a very specific psychological and social trauma " (Jilek - Aall; Jilek; Kaaya; Mkhombachepa & Hillary, 1997 : 784).

Epilepsy is a condition that has been known from the nineteenth century (Sands & Minters, 1979 : 1 - 14). Yet it is only recent that it is becoming a relatively new focus for research in international health (Kleinman, 1995 : 141). Though the study of the function of the brain in the nineteenth century identified the cerebral cortex as the part of the brain involved in epilepsy, there are still problems in the clinical analysis of the condition. This stems from the fact that epilepsy presents symptoms that are very complex, which involve a very complex organ, namely, the brain. Clearly, epilepsy is not an illness in itself. It is a symptom of whatever is the cause of disturbances in the functioning of the brain (Hunter, 1987 : 213 - 214).

Epilepsy is one of the most feared and misunderstood conditions. These misunderstandings stem from the myths and misconceptions that certain people hold about epilepsy (Hunter, 1987 : 213- 214). Some people hold the belief that people with epilepsy have a different personality than normal people. Others believe that people with epilepsy are violent, and often engage in criminal acts. Some hold the belief that people with epilepsy have a mental handicap (Burden & Schurr, 1980 : 37 -41; Fenwick & Fenwick, 1996 : 23 - 24). Although epilepsy may be associated with mental handicap, investigations done on mentally handicapped individuals revealed that about a third of such individuals suffered from epilepsy. (Kapp, 1991 : 302). However, twin studies revealed that epilepsy rarely lowers the genetic endowment for intelligence, when there is no evidence for gross brain lesions. Outpatient population studies revealed that the range of intelligence is almost normal (Lishman, 1987 : 228).

Some are of the view that epilepsy is contagious, and can be spread through saliva (Middleton, Attwell & Walsh, 1981 : 29 - 31).

Misunderstanding also stems from the fact that epilepsy is associated with mental illness. In a South African study of epilepsy, the word "mal" in grand mal and petit mal epilepsies is interpreted as " mad ". This has accounted for the labelling of people with epilepsy in that particular community as a little mad or very mad (Swartz, 1998 : 17 - 18). Epilepsy is not a mental illness, but a medical condition with a physical cause (Fenwick & Fenwick, 1996 : 23 - 24).

However, literature reveals that psychiatric problems are commonly associated with epilepsy. Reports indicate that about thirty to fifty percent of all cases of epilepsy have significant psychiatric difficulties. The incidence of psychosis has been reported to be high in individuals with epilepsy (Kaplan & Sadock, 1985 : 59).

Linking with the quotation from page 3 at the start of this section, cross cultural studies have revealed that people with epilepsy have high rates of psychological and social problems. The most common problems that people with epilepsy face are : negative attitudes about marriage, difficulty in sharing accommodation, denial from schooling and discrimination when seeking employment, as well as physical contact (Kleinman, 1995 : 147 - 151; Jilek - All Jilek, et al., 1997 : 784; Mc Queen & Swartz, 1995 : 859).

In some communities, epilepsy is regarded as a " hot illness ". For example, in Zaire, epilepsy is known as "Kifafa", and in their culture, a person who suffers from epilepsy should abstain from coitus (Feierman & Janzen, 1992 : 382).

Epilepsy is therefore an important community problem that needs social acceptance. A joint effort and responsible action by all people is needed to address problems faced by people with epilepsy in general, as well as people who may be directly or indirectly involved with them (Sands & Minters, 1979 : 43 - 52).

1.2.1. Prevalence

Epilepsy is recognised world wide as a common and significant problem. It is estimated to be up to twice as common in developing than in developed countries (McQueen & Swartz, 1995 : 860). According to the Columbia-Presbyterian Medical Centre, it is estimated that about ten million Americans suffer from epilepsy. Sixty percent of these have partial or localised epilepsy (Ottman, as cited by Columbia University Record, May 12, 1995). In the United Kingdom, it is estimated that about six in every thousand children of school going age, have epilepsy (NSE, 1996). Though epilepsy can attack at any age, it is reported to be more common in young children (Middleton, et al., 1981 : 1 - 28), and 75 % of the cases occur before the age of 20 (Sands & Minters, 1979 : 1 - 2).

In Europe, it is reported to have a prevalence of 4 - 8 per 1000. Reports indicate that in North America, epilepsy is three to five times higher in low-socio-economic conditions (Kleinman, 1995 : 147 - 151). It is estimated that about 0.6% of the general population have repeated seizures in five years, and 6% have at least one seizure during lifetime (Sands & Minters, 1979 : 1 - 2).

Equivalent statistics are not available in South Africa. However, epilepsy is assumed to be prevalent in each and every school. Within a few hundred school pupils, one or more may suffer from epilepsy (Kapp, 1991 : 260 - 261).Reports further indicate that in about seventy to eighty percent of cases of epilepsy, the cause is not known (Middleton, et al., 1981 : 29 - 39). It therefore becomes a very important problem for research as well as an important problem related to education support.

1.2.2.Epilepsy as a problem related to education support

Epilepsy presents itself in different forms. Parents and teachers are most likely the first people to recognise that a child has epilepsy. Most people are able to recognise the grand-mal attacks, which are also known as major epileptic attacks.

In a grand-mal seizure, attacks are very intense, are of long duration and the child loses consciousness (NSE, 1996). The child may also experience a warning signal prior to an epileptic attack and may sit or lie down (Gaddes, 1980 : 97 - 102).

Petit-mal seizures, also known as "absences", may be difficult to detect. The duration is usually very brief and the child may lose consciousness for a few seconds (NSE, 1996) Teachers and parents may have difficulty in recognising petit-mal seizures. The child might present with a blank "stare" which may be mistaken for day dreaming. Children may also appear vague after having lost consciousness and may be blamed for being inattentive (Donald, Lazarus & Lolwana, 1997 : 260 - 261; Blumer,1982 : 67 - 70; NSE, 1996).

In focal or partial seizures, some children might present with bizarre behaviour which may sometimes be mistaken for silliness (NSE, 1996). Other children may become aggressive and irritable according to the nature of their condition (Donald, et al, 1997: 260 - 261).

Some children with epilepsy may experience a transient seizure, which is sensational. A child may complain of a strange pain in the arm or in the stomach and may become anxious. Due to anxiety, the child may be disrupted in some activities. Transient seizures subside quickly without being noticed. The child may need support and security from the teacher (Kapp, 1991 : 260 - 261).

Problems with epilepsy can be reduced at school when there is good communication between professionals, children with epilepsy, teachers. peers and parents. What complicates the matter about epilepsy is that parents often do not fully accept their childrens' condition. Parents need to be explained that epilepsy "is not infectious". There is no reason why children with epilepsy should not mix with others, or be refused school attendance (Gaddes, 1980 : 97 - 102).

Parents frequently have difficulty in disclosing epilepsy. It is often kept as an individual or as a family secret. This is supported by the results from the study that was done by Groh & Rosenmayr, reported in (Kisker, 1985 : 312 - 315). The study revealed that forty three percent of the parents of children with epilepsy preferred to keep the condition of their child a secret. It is important that parents should disclose detailed information about their childrens condition to teachers, doctors and school nurses. Information should include the treatment that the child takes, description of seizures, and their frequency, as well as management for the child and possible side effects. Through disclosure, children with epilepsy can also receive appropriate career guidance, including care and support (Blumer, 1985: 67 - 70; NSE, 1996). Teachers and parents should guard against being too overprotective when dealing with epileptic children. Participation in all ordinary school and social activities should be encouraged. Children with epilepsy should not be restricted from leading their normal lives. A blanket restriction on the basis of their condition is very much unacceptable (NSE, 1996).

In conclusion, epilepsy places much demand on parents, family, teachers and peers. It is crucial that parents and all those who interact with children with epilepsy, should understand the condition. Understanding the problem reduces the frustrations on both the parent, the child and others. Parents become able to help their children towards better accomplishments (Lerner, 1988 : 147 - 157).

1.2.3.Problems faced by children with epilepsy at school

Most children with epilepsy are educated in mainstream schools. Problems may occur during school hours and can be managed if teachers and other pupils are well informed about the condition (NSE, 1996).

Children with epilepsy often present with learning and social adjustment problems (Donald, et al., 1997 : 260 - 261; Kapp, 1991 : 260 - 261). Most of the learning problems centre around the child's mental functioning, the type of seizure, relationship problems in school, as well as behaviour and emotional problems (Kapp, 1991 : 260 - 261).

Other problems that children with epilepsy experience is when injury to the brain affects the part responsible for cognitive functioning. For example, language, and communication problems may arise (NSE, 1996). Other difficulties resulting from disturbances of speech and thought may occur, and the child may experience difficulty in thinking coherently, may mix things and may be greatly confused. Poor memory may occur as a result of seizures that affect the temporal lobe (Lishman, 1987 : 207 - 265).

Frequent epileptic attacks may interfere with the child's concentration and productivity at school. This may create expectations that children may underachieve. Some parents may link their children's under achievement to mental retardation (Gaddes, 1980 : 97 - 102). The view that people with epilepsy have a low intelligence has been corrected over years (Lishman, 1987 : 207 - 265). Children with epilepsy do show the same range of intelligence as the normal population (Kirk, Gallagher & Anastasiow, 1993 : 514 - 515; Kapp, 1991 : 260 - 261).

It is important that teachers and parents should understand the nature of epilepsy and how it can be managed. Teachers need to know more than that a particular child "has epilepsy". This fact alone is not adequate for better understanding and rendering supportive care to children with epilepsy (NSE,1996). Children with epilepsy have a range of needs like all other children (Donald, et al., 1997 : 260 - 261; Kirk, et al., 1993 : 530 - 540; Clough & Lindsay, 1991 : 1).

Seizures that occur during school hours can be an upsetting experience for the child. All children need a supportive environment that is conducive to their learning process. According to Clough & Lindsay (1991 : 17), supportive care should include the child with special needs, teachers, other pupils and parents. Support can be achieved from within the school and from without the school environment. A supportive principle calls for the removal of all kinds of barriers to education in the classroom and the school, without removing the children themselves (Clough & Lindsay, 1991 : 1).

It is important that parents should participate fully in the education of their children. Through participation, parents can be able to monitor the educational policies, and can ensure that the rights of their children are not infringed (Donald, et al, 1997 ; Lazarus & Donald, 1994 : 5 - 11: NCSNET & NCESS, 1997 : 8 - 11) Education support principles takes into account the notion of a non-discriminatory approach to all learners, including children with special needs. It also ensures that holistic preventive, promotive and curative care is built into the general curriculum. This is geared at accessing resources to address the special needs of all children (Donald & De Jong, in press : 10 - 11; De Jong, 1996 : 114). In this way, supportive services can be developed to render a co-ordinated health promotive and preventive care to all children with special needs (Donald, et al., 1997 : 25).

1.2.4.<u>Epilepsy as a special need</u>

Children with special needs are defined as those who have a learning difficulty which calls for a special provision to be made (Mc Intyre, 1993 : 22 - 32). Special needs have been previously understood as needs that were present only in children with internal disabilities. Conceptualisation of special needs in this regard, ignored other factors that were also contributing to their development (Donald, 1996 : 71 - 77).

Special needs include both the needs of the learner and the system. Limitations within the system often leads to the need to provide for special needs that are not catered for in the general curriculum (Mc Intyre, 1993 : 22 - 32). A meaningful interpretation of special needs should be understood in the context of the child's total life (Jordan, 1994 : 72 - 73). Provision for special needs therefore takes into account the social structure and emotional climate in which education takes place. It also means that all learners should be able to access, on full or part time basis, all the resources that are necessary and appropriate to meet the child's needs (Fish, 1989 : 28).

Recent policy proposals have highlighted the need for integrated services. Emphasis is on a move towards a more holistic developmental approach, that focuses on community, organisation, school and general curriculum development within a broader social context (Donald, et al, 1997 : 82 - 107; NCSNET & NCESS, 1997 : 8 - 11). Parents of children with epilepsy (special needs), have decisions to make for their children. Decisions may be based on what services are needed, what those services are, and what services are available to meet the child's needs. Parents should not feel shy to request for services or to speak out when refused access to resources. If special needs have to be addressed, a collaborative consultation between parents and teachers is needed (Jordan, 1994 : 72 - 73). This involves a multi disciplinary approach for sharing expertise, ideas, mutual planning, development of skills and joint decision making (Jordan,1994 : 4; du Toit, 1996 : 16).

1.3. MEDICAL ASPECTS OF EPILEPSY

Epilepsy is one of the least understood of all medical conditions. The different medical terms used to describe epilepsy tend to increase the confusion. Terms like: turns, jerks, convulsions, spasms and seizures are used interchangeably, and yet refer to the same condition (Hunter, 1987 : 213 - 214).

1.3.1. Epilepsy defined medically

From the medical point of view, epilepsy is defined as a chronic condition characterised by repeated seizures (Plein, Truscott, Cottrill, Kirby & Strätling, 1992 : 213 - 214; Kaplan & Sadock, 1998 : 59 - 62; Salam - Adams & Adams, 1980 : 131 - 137). It occurs as a result of disturbed brain function (Kisker, 1985 : 312 - 315; Kirk, et al, 1993 : 514 - 515; Werner, 1987 : 233- 242). The sudden abnormal neuronal discharges may affect one part of the brain (partial seizures), or parts of the brain, (Jacksonian seizures), or may involve the whole brain simultaneously, (generalised seizures) (Plein, et al., 1992 : 213 - 214). Seizures are usually temporary in nature, and may present in dramatic abnormal symptoms that are uncontrollable. A sensory or perceptual disorder, disturbances of behaviour, loss of consciousness or incontinence may occur (Kaplan & Sadock, 1988 : 59 -62; Salam - Adams & Adams, 1980 : 131 - 137; Lishman, 1987 : 265 - 276).

1.3.2. Classification of types of seizures

The importance of classifying epilepsy according to the type of seizures is important in deciding the kind of treatment for the people with epilepsy. Although classification has been reported to be complicated and complex, it has repeatedly changed over years (Rutter, Taylor & Hersov, 1994 : 182 - 187; Lishman, 1987 : 265 - 276). The International League Against Epilepsy (ILAE), distinguishes between two types of seizures, namely, the generalised and partial seizures (Commission on Classification and Terminology of ILAE, 1981).

Generalised seizures affect the greater area of the brain, and include the generalised tonic - clonic seizures (grand mal) and absence seizures (petit mal) (Rutter, et al., 1994 : 182 - 187 ; Fenwick & Fenwick, 1996 : 3 - 14).

Partial seizures (focal), may be simple or complex, and a smaller area of the brain is affected. In simple partial seizures, symptoms involve sensory or motor function, and consciousness is not lost. In complex partial seizures, consciousness is lost even if higher functions are not involved (Rutter, et al., 1994 : 182 - 187).

1.3.3.Distinguishing between types of seizures

Petit-mal seizures

Petit-mal seizures occur mostly in children. Seizures of this nature occur without evidence of gross brain lesion. There are usually no after effects at the end of the seizure. Attacks are more frequent and may occur daily, at a frequency of five to ten attacks per day (Fenwick & Fenwick, 1996 : 3 - 13) Petit-mal absences are also referred to as "simple absences".

There are three types of petit-mal seizures, referred to as the "petit-mal triad". The Complex, Akinetic and the Generalised myoclonic jerks. A single person may display all three forms in different situations (Lishman, 1987 : 265 - 276). Complex absences are characterised by lip-smacking, mouthing, chewing or fumbling. Vocalisation may also be present. The duration is longer. Akinetic absences involve posture. A child may suddenly or abruptly slump in the chair or fall on to the ground. There is usually no warning signal and the duration is very brief. The child may suffer some bruises and emotional shock (Fenwick & Fenwick, 1996 : 3 - 13).

In the generalised myoclonic jerks, the child may experience jerks in the neck, arms and shoulders. When the leg or trunk is affected, the child may fling off balance and the objects held at that time may be dropped. In these type of absences, it is uncertain whether consciousness is lost or retained because the jerks only last for a fraction of a second (Lishman, 1987 : 265 -276).

Grand mal seizures

Grand-mal seizures are characterised by an abrupt loss of consciousness. Some epileptics may be aware of an imminent attack. For example, some persons with epilepsy may experience general malaise, tension, nausea and headache (Lishman, 1987, 265 - 276 ; Plein et al., 1992 : 213 - 214 ; Salam - Adams & Adams.,1980 : 131-137). In grand-mal seizures, all parts of the body are involved. A person with epilepsy usually fall into a deep sleep at the end of the fit. Some may experience mental confusion and loss of memory for some time after a fit (Lishman, 1987 : 265 - 276).

Focal or Partial seizures

Focal seizures are characterised by an aura which is a warning signal of the imminence of a fit. The duration is usually brief. In these type of seizures, there is usually evidence of a localised disease or focus in the brain. Seizures may be simple, where there is no loss of consciousness, or may be complex with loss of consciousness (Lishman, 1987 : 265 - 276 ; Fenwick & Fenwick, 1996 : 3 - 13).

Other types of seizures

There are different forms of seizures, namely, febrile convulsions, reflex seizures, tonic gelastic and diencephalic or autonomic seizures. Febrile convulsions are other form of seizures that occur as a result of high fever. Children between eighteenth month and five years of age are usually affected (Plein, et al., 1992 : 213 - 214).

The tonic seizures are characterised by a spasm that may affect the whole limb. Groping and grasping of a limb may occur. Due to the bizarre nature of tonic seizures, this may be suggestive of a psychogenic disorder (Lishman, 1987 : 265 - 276).

The gelastic type of seizures, are usually preceded by uncontrollable laughter. A person with epilepsy may suddenly bend the head, and may giggle for no apparent reason. This kind of behaviour may be mistaken as a habit and may not be detected as a symptom of epilepsy, until the definite symptoms occur.

It is assumed that laughter is evoked by the emotional content of a brief temporal lobe aura (Lishman, 1987 : 265 - 276).

The diencephalic or autonomic type of seizures may occur as part of generalised seizures or in isolation. A person with epilepsy may feel hot flushes and may sweat for few minutes and may feel cold and shivery after a fit. Slight mental confusion may occur (ibid).

1.4. CAUSES OF EPILEPSY

1.4.1.Models explaining the causes of epilepsy

Anthropological model

Definition of the "cause" of disease from the Anthropological point of view takes into account the ability to recognise the disease, the kind of illness including its name [what it is], and how the illness occurred, and being able to identify the responsible agent [what produced it] as well as the reason for its occurrence (Sindzingre & Zempléni, 1992 : 315 - 318).

Medical anthropologists and epilepsy researchers did a study to investigate the collective experience of people with epilepsy in China. Eighty people with epilepsy from rural and urban areas of China participated in the study. Results revealed that respondents had great variations on the way the causes of epilepsy were understood. Causes ranged from heredity, head injuries, possession, poverty and reaction to anger and fright. Respondents gave different interpretations for reasons of the cause and subsequent epileptic attacks. Most referred to overwork and strong affects as reasons for the cause of epilepsy (Kleinman, 1995 : 152 - 156). It is important to take into account the ways in which individuals understand their illness (Swartz, 1998 : 14 - 15).

In my work context, epilepsy is referred to as "ukuxhuzula" in Xhosa. The name describes the jerky movements that occur during a fit. "Ukuxhuzula" or fits in Xhosa is believed to be caused by "Amafufunyana" (evil spirits). Other explanations regarding the cause of epilepsy in Xhosa relates to seeing or visualising bad things like a snake or a mermaid. Fits may also occur as a result of a "bad wind", or "imiya emdaka" (Loveday, 1990 : 193 - 194). According to the Xhosa traditional healer, fits may occur when a "bad wind" or "impundulo" is created to work against somebody, and such a person with epilepsy may cry whilst sleeping or may feel odd sensations. Epilepsy may be associated with untreated sexually transmitted diseases like gonorrhoea. Failure to communicate with ancestors is also seen as a predisposing factor for the occurrence of fits (Kandekana, 1997).

Medical model

The medical model distinguishes between two types of causes of epilepsy. It holds the view that epilepsy can occur as a result of unknown (idiopathic) causes that are associated with genetic and hereditary factors (Middleton, et al., 1981 : 30 - 31; Sands & Minters, 1979 : 15 - 19). Idiopathic epilepsy is also described as essential, cryptogenic, primary, genetic and hereditary (Kisker, 1985 : 312 - 315). A recent study identified a specific gene to be responsible for the cause of epilepsy. A one single family study was done to investigate the cause of epilepsy in three generations of the same family. Individuals within the family had three successive generations affected by partial epilepsy. Results revealed that the responsible gene was linked to chromosome 10. Individuals of the same family developed epilepsy between the ages of eight and nineteen years. All members of the family presented with similar type of seizure and a similar characteristic aura (hearing a ringing or humming sound prior to a fit).

Analysis was restricted to one single family, and proportions of familial epilepsy susceptible to a genetic link cannot be estimated (Ottman, as cited by Columbia University Record, May 12 1995).

Heredity is also reported to be playing an important role in the aetiology of epilepsy. Results from twin studies revealed that amongst identical twins, when one twin suffers from epilepsy, there is a likelihood that the other twin will have epilepsy. Results also revealed that epilepsy tend to occur between sixty and ninety percent in identical twins, and less than ten percent in non - identical twins (Kisker, 1985 : 312 - 313).

In the aetiology of known cause, epilepsy occurs as a result of a pathological condition of the brain which may occur early in life as a result of strokes, head injury during birth, infections like measles, whooping cough and meningitis, lack of oxygen and poisons (Burden & Schurr, 1980 : 37 - 40; Sands & Minters, 1979 : 15 - 19; Fenwick & Fenwick, 1996 : 15 - 17). Other infections that may cause seizures in children include diphtheria and mumps (Middleton, et al., 1981 : 29 - 39).

Epilepsy may also occur in later life as a result of cerebral tumours, brain infections, birth trauma, drugs and severe dehydration (Lishman, 1987 : 265 - 276; Werner, 1987

: 233- 242; Salam - Adams & Adams., 1980 : 131 - 137). Other causes may be related to accidents (Burden & Schurr, 1980 : 37 - 40).

From South African studies, Mc Queen & Swartz (1995 : 859 - 864) interviewed 16 respondents of the Mamre community on psychosocial aspects of epilepsy. Results revealed that 7 persons did not know the cause of their epilepsy; 3 gave explanations for the cause as tension, ethanol withdrawal and high blood pressure; 6 reported head injury as the cause of their epilepsy. The study concluded that there is a general lack of knowledge about epilepsy.

1.4.2. Factors precipitating the onset of seizures

There are several factors that are known to be having the ability to trigger the onset of seizures. These factors are not the cause of fits, but are able to trigger fits in someone who is already suffering from epilepsy.

Drugs like LSD and alcohol, and factors like sleep deprivation and starvation may trigger the onset of fits (Middleton, et al; 1981 : 29 - 39; Kisker, 1985 : 312 - 315; Plein, et al., 1992 : 214). Other precipitating factors are related to low blood sugar, boredom and unpleasant thoughts and feelings (Fenwick & Fenwick, 1996 : 15 -17).

According to Lishman (1987 : 265 - 276), emotional disturbances such as shock, surprise, stress or tension may stimulate the onset of seizures. From analysis of situations that might precipitate seizures, results indicated that twenty three percent were environmental, six percent were situations that involved physical and mental activities and twenty three percent were as a result of conflict, and eighteen percent occurred due to emotional trauma, horror or fear. Other sensory stimulants, for example, music of emotional significance, can trigger epilepsy, including flickering of television screen (ibid).

Failure to take medication and flashing lights are also precipitating factors for the onset of seizures, including reading, especially when the tasks involve both eyes and hands whilst the person is thinking. For example, when solving arithmetic problem or reading quickly (Middleton, et al, 1981 : 29 -39). Menstruation is also identified as a factor that can trigger fits (Plein, et al., 1992 : 214).

It is clear that epilepsy is a complex condition, and cannot be understood from the strict medical point of view only.

1.4.3. African beliefs regarding the cause of epilepsy

The causes of epilepsy range from the primitive spirit possession to the current emphasis in psychogenic and physiogenic factors (Kisker, 1985 : 312 - 315).

These beliefs are traced as far back as the Middle Ages, and are reported to have some similarity throughout the African continent (Jilek - All, et al., 1997 : 783-785). For example, the Senufo strongly belief that epilepsy is caused by evil spirits (Sindzingre & Zempléni, 1992 : 302).

Some studies revealed that there are some contradictions regarding the cause, treatment and cure for epilepsy. An investigative study that was done to determine the beliefs held by Malawians regarding the traditional explanations for the cause, treatment and cure of epilepsy. Participants were 112 rural Malawians. Results revealed that respondents held medical as well as traditional beliefs with regard to the cause, treatment and cure of epilepsy (Shaba, Maclachlan, Carr & Ager, 1993 : 165 - 167).

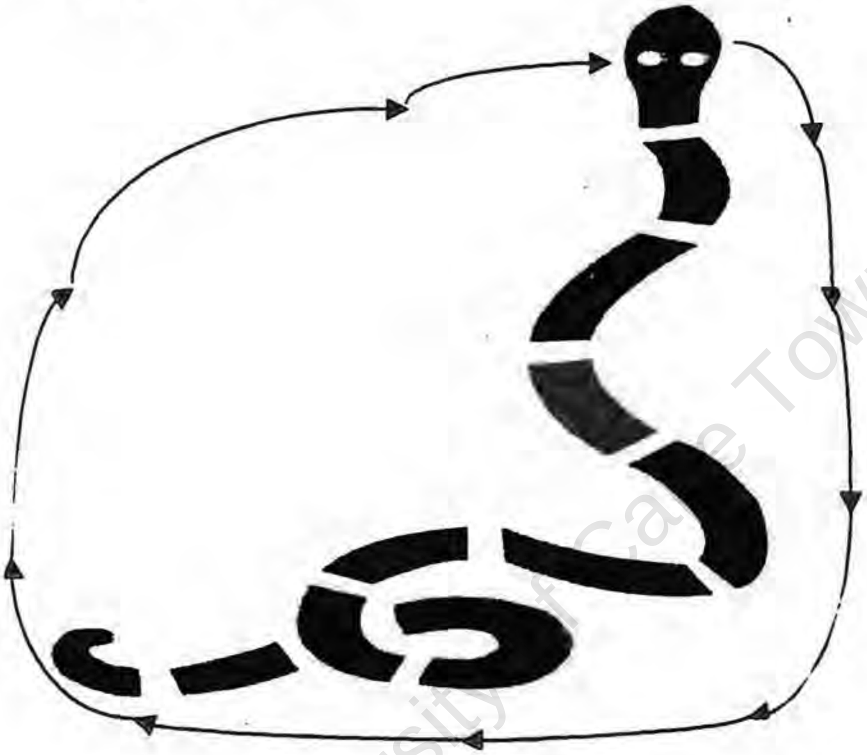
Similarly the study that was done in Nigeria revealed that respondents still held the belief that epilepsy is caused by supernatural powers, and cannot be treated by western medicine (Jilek - All, et al., 1997 : 783 - 785).

1.5 MANAGEMENT OF EPILEPSY

In my work context, community health workers have a unique Xhosa expression that relates to the way of analysing and solving problems in the community. That is "***Xa ufuna kubhulala inyoka, ufanele uciniseke ukuba ubhulele intloko***". Translated in English, the above expression simply means that in order to be sure that one has indeed killed the snake, one should ensure that the head is crushed. The head is understood as the root of the problem. The root should be addressed together with its stems to prevent the problem from spreading to other parts. One should not attempt to hit the tail nor the body only.

The tail and the body represents parts of the problem which are connected to each other, and cannot not be addressed in isolation from the head. The Xhosa expression describes the holistic understanding of analysing and solving problems from a communities' point of view.

Diagram 2 describes the holistic notion of analysing and solving problems from a communitys' point of view.



(The arrows in the diagram indicate the recursive ways in which problems repeat themselves and affect other parts).

From the analogy above, it is important to understand that epilepsy is not an individual problem, a parent or a school problem. It is a problem that is of major concern to the community as a whole. It cannot be addressed at one level only, but need a contextual approach, namely, the individual level, the family, the community including the cultural and religious values, policies as well as resources needed to address the problem.

1.5.1 Models of management of epilepsy

Eco - systemic model

The child with epilepsy is an important member of the society, and is dependent upon other parts of the system for survival. Interactions within, between and outside the system have a great influence on the development of the child with epilepsy. For example, negative attitudes towards children with epilepsy can have detrimental effects on the growth and development of the child with epilepsy. Attitudes, knowledge and perceptions that govern the individuals behaviour should be taken into account because peoples perceptions are largely shaped by the cultural values prevailing in the particular community (Donald, et al; 1997 : 18). For example, in African culture, the traditional healer plays an important role in family therapy. The individual is never seen as being responsible for his own actions. It is believed that external factors have great influence in causing the individual to default. The traditional healer therefore takes into account the circular ways in which problems occur (Bodibe, 1992 : 90 - 96).

The family as part of the system, is seen as a unit where the child has to be supported to be able to grow and develop. The way in which the child's needs are satisfied, has a great influence on the way the child gets along with the world. In my own Tswana culture, when someone has epilepsy, "go swa mototwana", he or she is not allowed to come near the fire because too much heat may trigger fits. This kind of rearing teaches a person with epilepsy to become dependent on others. Over protectiveness from parents can make the child to lack self-confidence and learn a helplessness behaviour

(Apter, 1982 : 158 - 172). It is important that the family should interact and function positively for the development of other family members. This include good communication between and within members of the family and development of skills to deal and cope with problems (Magwaza, 1992 : 49 - 51).

The eco-systemic thinkers hold that problems should be addressed at all levels of the system, that is, at individual level, the family, the school, community and society. This means that any problem should not be addressed in isolation from the environment in which it occurs. Problems should not be addressed linearly, but should be addressed in a circular way, taking into account that problems tend to repeat themselves in cyclical patterns. From the eco-systemic point of view, a holistic approach for addressing problems is important. The holistic notion means that preventative, promotive and curative interventions are all interdependent (Donald, et al, 1997 : 34 - 39; Sibaya, 1996 : 86 - 89). It takes into account the ecology of ideas and the ways in which they interact with each other, that is : past experiences, perceptions ,world views and beliefs. The holistic approach acknowledges the fact that the ecology of ideas confer meaning on the life and experiences of people (Kotze & Kotze, 1997 : 61 - 67).

Medical management versus traditional management of epilepsy

The medical practice is reported to be quite different from the traditional management. The difference stems from the way illness is diagnosed, how the relationship between the doctor and the client is established, the taking of history and ways of referral. For example, in Zulu culture, when someone is ill, the inyanga visits the client at home and history is usually given by the family. Visiting the client at home gives the inyanga the opportunity to observe and understand the illness in the context of the home environment. Inyanga can thereafter decide whether to treat or to refer the client to the diviner, who may treat the cause of illness. The inyanga consults the whole family, whilst the medical practice restricts itself to the client (Ngubane, 1992 : 362 - 375).

In medical practice, the history as well as description of the symptoms is expected to be given by the client or the person accompanying the client. A clinical examination follows with minimum communication. The doctor will then prescribe the medication, giving little or no explanation about the diagnosis (Ngubane, 1992 : 366 - 375). For example, instructions are only given on the emphasis of "take pills, two or three times a day, do not forget them" (Blumer, 1982 : 67 - 70). This way of management deprives clients with epilepsy to have thorough explanations of why the medication has to be taken over a lengthy period of time. Clients often leave the consultation with uncertainty, and with frustrations that clients are often reprimanded for wasting time by consulting with traditional healers. The doctor-client relationship is therefore not established as clients choices and decisions are often despised (Ngubane, 1992 : 366 - 375).

The medical management is usually carried out by health professionals, with little involvement from the patient side. The health professional prescribes the criteria to be followed by the client without a contextual understanding of the factors that may influence the client's behaviour. For example, considering clients as merely illiterate and needing to be filled in with information that is specifically selected by health professionals themselves (Craig, 1983 : 564 - 570). Medical management of epilepsy puts more emphasis on what should be done, and any deviation from the clients point of view is condemned without investigating the reasons. It is important therefore that any management that puts emphasis only on compliance, or giving selected information to achieve compliance, should be discouraged. Management of epilepsy should aim at establishing partnerships as opposed to rendering the parents, or the children with epilepsy, powerless (ibid).

LEVELS OF MANAGEMENT

Primary level

The aim of management of epilepsy at primary level is to address the problem in its ecological context, and to modify conditions that might be detrimental to the child's development, and to provide resources that are necessary for prevention.

For example, creating public awareness about epilepsy and challenging the myths that undermine the dignity and rights of children with epilepsy. This can be achieved through conducting surveys to find out what the general public knows about epilepsy, and by setting interventions that can enhance the publics understanding of epilepsy. Primary management should focus on educating the public on how to recognise when the child is having a seizure, and first aid management of seizures. Media can also be persuaded to provide factual information about epilepsy. For example local magazines, newspapers, television and movies that can portray positive opinions about epilepsy (Sands & Minters, 1977 : 43 - 52; Felner & Felner, 1989 : 13 - 43). Health promotion interventions that strengthens community action and participation are very important (Sibaya, 1996 : 87 - 88).

Other areas that are important to include at primary level of management is to help the community to understand the causes and factors that may trigger epilepsy, especially during pregnancy. Smoking and taking of alcohol and drugs should be avoided during the pregnancy period. Children should not be exposed to fever for a long time. Urgent referral is necessary when the child's fever cannot be reduced (Loveday, 1990 : 193 - 199). Public should be made aware of the importance of immunising children against infectious diseases. Much emphasis should also be put on prevention of accidents at home, school and within the broader environment (Burden & Schurr, 1980 : 49 - 50).

Secondary level

The aim of management at secondary level is to ensure that the condition is contained. This cannot be achieved through medication only, but through developing supportive mechanisms to assist the child with epilepsy, the parent, the teacher and the general community. The principal goals of supportive mechanisms at all levels of the ecological system aims at helping children with epilepsy to understand the nature of their condition, as well as enabling them to become resilient (Donald et al, 1997 : 148 - 149).

The child should be encouraged to lead a normal life. Parents should avoid overprotection and treat the child like all other children. When managing the child with epilepsy, it is important that parents should stress the things that the child can do and be open to the childs needs. The child should be told factual information about epilepsy in a straightforward manner. It is important that the child should be told the right name of the condition, "epilepsy", not replacing its name by something else. The child should be allowed to ask questions and honest answers should be given.. This helps children to develop positive views about themselves. Such children tend to be competent and do much better at school. They are able to engage in friendlier relationships and have more friends. As the child gets older, medication can be discussed with the child to encourage responsibility and gradually reduce dependency (Plein et al, 1992 : 214 - 215; Sands & Minters, 1977 : 71 - 79; Fenwick & Fenwick, 1997 : 145 - 147).

The family plays an important role in the life of the child with epilepsy. Parents do not easily talk openly about epilepsy at home. Information that is shared amongst members of the family is usually vague. Yet appropriate information given to all members of the family can ally fears and anxieties about epilepsy, and can actually help to strengthen a healthy supportive environment.

Parents are usually concerned with the fact that the child may die during a seizure, or may become insane. This preoccupation with the childs condition makes the parent to suffer from feelings of guilt, frustration, worry, childs future and stigma attached to epilepsy (Fenwick & Fenwick, 1997 : 143 -162; Burden & Schurr, 1980 : 51 - 53).

Children with epilepsy should be encouraged to attend school regularly. Parents should inform teachers about the child's condition and ask the teacher to treat the child like all normal children. Teachers should be informed about specific activities where the child has to be excluded or where supervision may be needed.

If the teacher does not know anything about epilepsy, the parent should give relevant information as well as what the teacher has to do in the event of a seizure. It is important that the child should continue with normal classwork after having recovered from a seizure. The idea of sending children home should be discouraged because children may use epilepsy as an excuse for not attending school.

Parents should also ask the teacher to inform them about any change in the behaviour of their children. If medication has to be taken during school time, the teacher should be informed of the time, dose and the name of the medication.

The teacher, parent and the child should also talk openly about careers that the child with epilepsy can follow. This helps the parent and the child to have appropriate vocational preparation for the future (Middleton et al; 1981 : 136 - 151; Fenwick & Fenwick, 1997 : 143 - 162; Burden & Schurr, 1980 : 61 - 64).

APPROACHES TO SEIZURE CONTROL

Collaborative approach

Epilepsy is a community problem. Neither the parent nor the child with epilepsy can manage it alone. Teachers, parents, children with epilepsy, peers, doctors, school nurses, counsellors, traditional healers and other professionals need to work as a team to identify needs in terms of resources and life skill development for adequate management of epilepsy.

Collaboration aims at reducing fragmentation of services; assessing special needs of children and their families; sharing expertise, encouraging parents to participate and become involved and addressing the needs of the child across the whole curriculum. Collaboration fosters a conducive environment to effect change and ensures that people dealing with children with epilepsy have requisite knowledge and skills to work effectively with such individuals and their families (Lacey & Lomas, 1993 : 16 - 23 ; Donald, et al; 1997 ; 130 -131; Sibaya, 1996 : 88 - 89).

It is therefore important that western trained practitioners should work hand in hand with traditional healers on therapeutic approaches that operate within a holistic paradigm. The meeting and mating of cultures could be very important in designing appropriate interventions that are geared to address the whole person (Bodibe, 1992 : 90 - 96

Peer networks and support groups

The formation of peer networks and social support groups is an important strategy where children learn about epilepsy through role plays, stories and information provided in school libraries. The strategy aims at increasing awareness about epilepsy, improving learning environment and encouraging other children to participate in ways that are supportive to children with epilepsy (Werner, 1987 : 427 - 441; Donald, et al; 1997 : 149 - 150., Cauce & Srebnik, 1989 : 243 - 250).

The child's epilepsy can affect the psychological well being and coping mechanisms of other family members. Support groups play an important role in the provision of counselling, and fosters a conducive environment for discussions and sharing of experiences, a feeling of selfworth and a sense of belonging (Rutter et al, 1994, 182 - 187; Fenwick & Fenwick, 1997 : 75 - 90).

CONCLUSION

The chapter highlighted the broad background of epilepsy, and gave a detailed discussion about what other authors and researchers said about the problem.

CHAPTER 2 : METHODOLOGY

The study aimed to investigate what the parents of children with epilepsy understood as the cause of their childrens' condition, and how they managed it. This was done through interviews and analysis of responses. The participants consent was obtained, and the ethical issues of confidentiality and anonymity were ensured.

2.1. Sampling

After identifying the problem, the Zibonele community health workers were consulted to find out how participants will be identified. These Community health workers, who work in the Zibonele Community Health Worker Project, which serves the areas of Silvertown and Town 2, in Khayelitsha, knew 12 parents of children with epilepsy. They agreed to find out whether these parents would be willing to participate in the study. All parents agreed. The fact that all parents of children with epilepsy known to these community health workers agreed to participate, helps make this sample representative , even though it is small.

Characteristics of respondents in the study.

Table 2.1. describes the characteristics of respondents in the study. All 12 participants were females (mothers). Their mean age was 42.4, with ages ranging from 24 - 54.

Table 2.1 Age distribution of respondents

Age in Years	n	%
24-28	2	17
29-33	2	17
34-38	1	8
39-43	2	17
44-48	2	17
49-53	2	17
54-58	1	8

Employment status

Table 2.2 describes the respondents employment status. 67 % of the respondents were unemployed.

Table 2.2. Employment status of respondents

Employment Status	n	%
Unemployed	8	67
Part- time employment	2	16
Full time employment	2	16

Characteristics of respondents' epileptic children

Sex and Age distribution

Table 2.3 describes the characteristics of the respondents' epileptic children. 75% were females and 25% were males. The mean age was 18.3 with ages ranging from 2.5-24.

Table 2.3 Characteristics of respondents' epileptic children

Characteristics	n	%
Females	9	75
Males	3	25
Age in years	**n**	**%**
2-6	2	17
7-11	1	8
12-16	4	33
17-21	4	33
22-26	1	8

School attendance of respondents' epileptic children

Table 2.4 describes the characteristics of the epileptic children's school attendance. Is important to note that 25% had attended school but had left, whilst 33% had never attended school at all.

Table 2.4 School attendance of respondents' children

Children school attendance	n	%
Attending school	2	17
At Pre-school	1	8
Attended school and left	3	25
Never attended school	4	33
Not yet at school	2	17

2.2. Developing the interview schedule

The schedule of questions, (Appendix B & C), was designed in an open way to allow respondents to share their experiences in a non- threatening way. In Section A, the question was aimed at finding out what respondents knew about the causes of epilepsy. The factors that trigger epileptic attacks were explored further in Section B of the interview schedule.

In Section C, the interview began by asking the kind of treatment that the child takes, and Section D question explored how western medication was managed. The management of childs' epilepsy was explored in Section E.

In Section F, respondents were asked on how they manage first aid during and after a fit. The last section further explored the respondents views regarding the importance of their childrens' epileptic condition being known by others. Questions were drawn to elicit one response, and double barrelled questions and leading questions were avoided.

Questions were similarly structured and sequenced, beginning with simple questions and ending with sensitive ones. (For example, finding out the respondent views regarding their children's' epileptic condition known by others).

Questions addressing the same topic were grouped together for the purpose of simplifying categorisation of themes developed from data. The interview guide was developed in English and then translated into Xhosa. (Appendix B & C). The duration of the interview was determined by the amount of data required, the number of questions, establishment of rapport and the interviewees willingness to respond.

2.3. Data Collection

Prior to the actual data collection, a pilot was done to check whether the questions were understandable or not. 2 community health workers volunteered to role play as parents of children with epilepsy. At the end of the interview, comments were shared. It was decided not to change any questions.

The interview opened up in a friendly manner to establish rapport and to make introductions. The purpose of the interview was stated and consent to record the interview was requested. Confidentiality and assurance of protecting identity of respondents was ensured. After gaining consent, questions were posed in a friendly manner, and the guide followed. Probes were made in an empathetic manner to gain clarification on specific issues. During a pause, respondents were encouraged to carry on with the conversation in an empathetic manner. The sequence of the questions depended upon the flow of the interview. Responses were tape recorded from the onset and the time noted.

After the last question, respondents were made aware that the interview had ended, and were asked to give any further input regarding the conversation. Respondents were thanked for their time and participation. The tape was replayed for respondents to check the information shared, and whether respondents had other clarifications to make. The other purpose was to ensure that the interview was recorded. At the end, of the interview, tapes were labelled, field notes completed, date and length of interview recorded , and demographic questions completed.

2.4. Transcription

Transcription was done after all interviews were completed. The recorded interviews were transcribed from Xhosa into English after listening several times to the tapes. Words were written down in the exact manner as were said by respondents, including symbols for pauses. Transcripts were read several times to check for accuracy and to to compare with field notes. Transcripts were typed and photocopies made for use in analysis (Burnard, 1991 : 461 - 465., Hitchcock & Hughes, 1989 : 166 - 167).

2.5. Data analysis :Constant comparative method *

Each transcript was read word by word and paragraph by paragraph to get the general content of the interview. Ideas that emerged from each transcript were identified by drawing a line with a coloured pen, and marking the page number and the interviewee code for the purpose of being able to identify between each piece of transcript.

The data was then examined through an inductive process for the purpose of constructing themes. After the themes were developed, the coded parts of the interviews were cut from each transcript and grouped together. (For example, parts falling under causes of epilepsy were grouped together). Each piece of response was cut in the context of the interview, to avoid loosing the meaning of what the interviewee said.

The cut sections were pasted onto charts under the appropriate categories. These were checked as to whether responses from interviewees fit within the identified categories and adjustments were made where necessary. Ideas were later compared within and across categories to check for differences and similarities.

During the process of analysis, responses that did not address the research questions were left out. However, complete transcripts were kept for reference purposes (Appendix D).

* (Maykut & Morehouse, 1994 : 126 - 148).

2.6.Limitations

The study had limitations based on the fact that there were only 12 interviewees. This limits the findings of this study to be generalised as it may not be representative of the whole population of Khayelitsha.

Other limitations are based on the fact that the time to conduct the study was too short, and this restricted the researcher. A single interview of such a sensitive problem could not elicit rich information needed to understand the problem more fully.

Other limitations centred around the researcher being conversant but not fluent in Xhosa language which was used in conducting interviews. The researcher could also not probe efficiently in Xhosa, and was restricted to ask questions as set out in the interview schedule. Another bias could result from the fact that the researcher worked in the area and was known by some respondents.

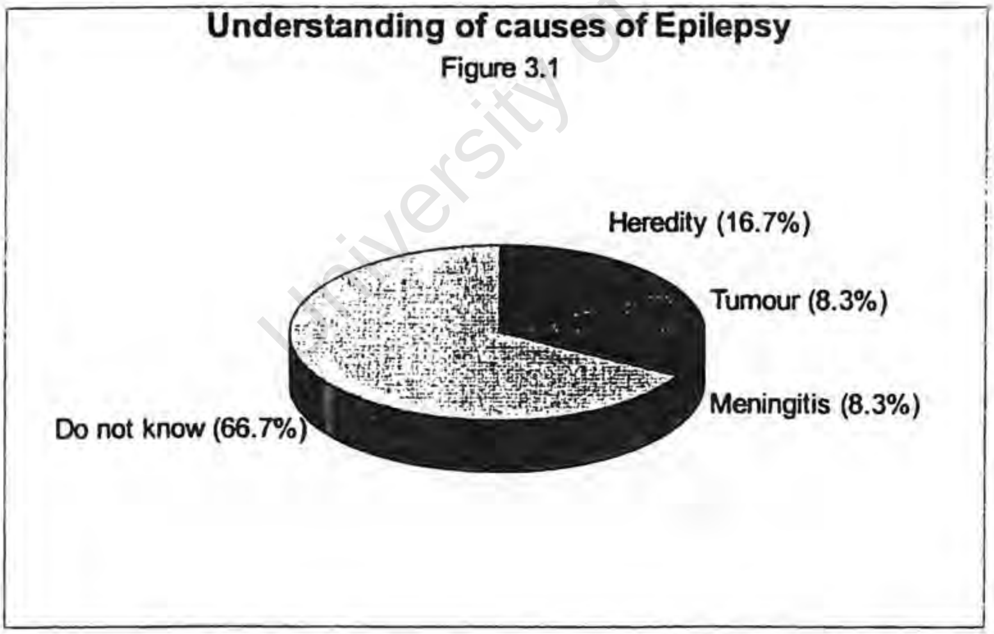
CHAPTER 3 : FINDINGS

3.1 CAUSES OF EPILEPSY

Table 3.5 and Figure 3.1 describe the respondents' understanding of the cause of their childrens' epilepsy. Results revealed that 67 % of the respondents did not know the cause of their childrens' epilepsy.

Table 3.5 Respondents' understanding of the causes of their childrens' epilepsy

Causes of epilepsy	n	%
Heredity	2	17
Tumour	1	8
Meningitis	1	8
Do not know	8	67

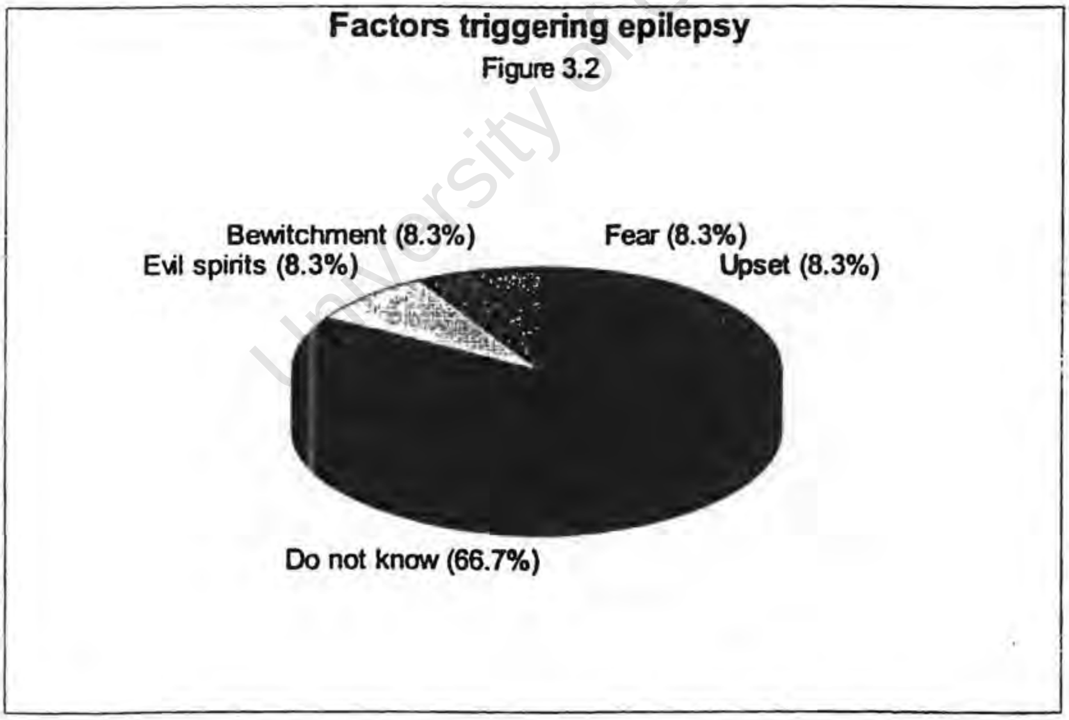


3.2 FACTORS TRIGGERING EPILEPSY

Table 3.6 and Figure 3.2 describe the respondents understanding of factors that trigger their childrens epilepsy. 67% of respondents did not know the factors that trigger their childrens' epilepsy.

Table 3.6 Respondents' understanding of factors triggering epilepsy

Factors triggering epilepsy	n	%
When child has fear	1	8.3
When child is upset	1	8.3
Evil spirits	1	8.3
When child sees a bewitched parent	1	8.3
Do not know	8	67



3.3 KIND OF TREATMENT RECEIVED BY CHILD

Table 3.7 and Figure 3.3 describe the respondents understanding of the kind of treatment received by child. 83 % of respondents reported that their children were on prescribed medication.

Table 3.7 Respondents' understanding of the kind of treatment received by child

Treatment received by child	n	%
Western & Traditional	1	8.3
Traditional	1	8.3
Western	10	83.3

Kind of treatment received by child

Figure 3.3

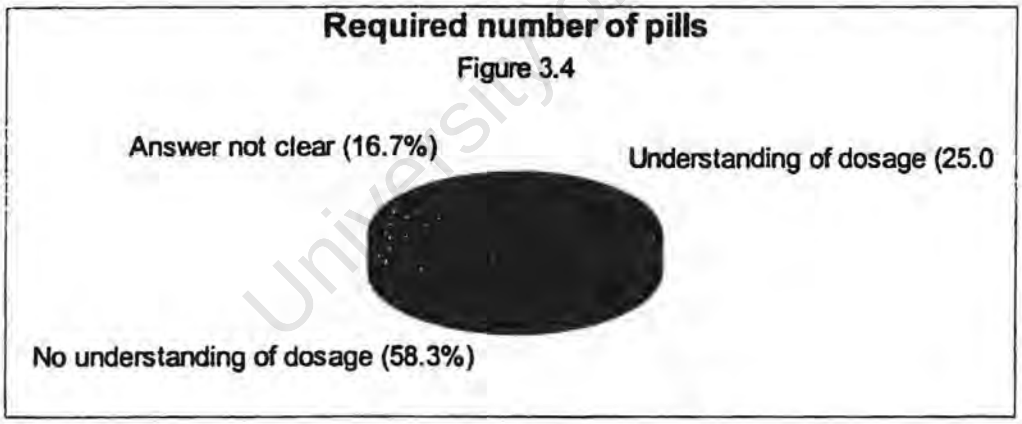
3.4 MANAGEMENT OF MEDICATION

3.4.1 REQUIRED NUMBER OF PILLS

Table 3.8 and Figure3.4 describe the respondents understanding of the prescribed amount of pills to be taken by child. 58.3% of the respondents had no understanding of the prescribed dose of their childrens' medication.

Table 3.8 Respondents' understanding of the required number of pills

Required Dose	n	%
Answer not clear	2	17
Understanding of dosage	3	25
No understanding	7	58



3.4.2 WHEN PILLS NEED TO BE TAKEN

Table 3.9 and Figure 3.5 describe the respondents understanding of when the child has to take pills. 50 % of the respondents had a clear understanding of when their children had to take their medication, while 50% were not specific or did not know.

Table 3.9 Respondents' understanding of when the child has to take pills

When pills need to be taken	n	%
Sure	6	50
Not specific	3	25
Do not know	3	25

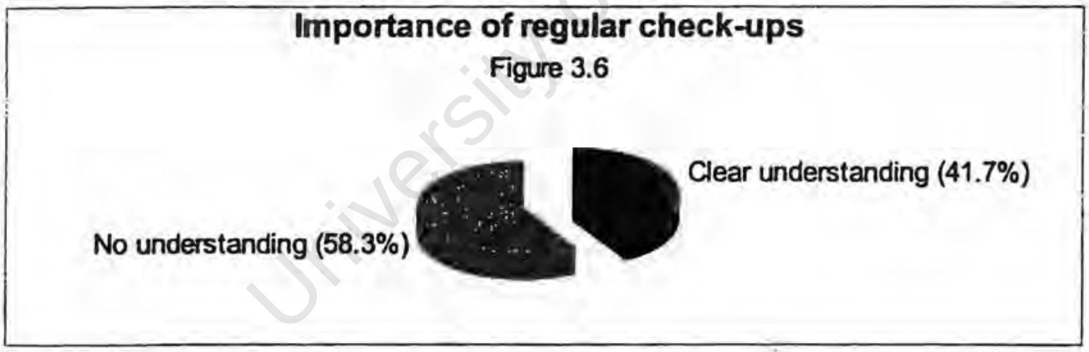
3.5 MANAGEMENT OF CHILDS' EPILEPTIC CHARACTERISTICS

3.5.1 REGULAR CHECK UPS

Table 3.10 and Figure 3.6 describe the respondents understanding of the importance of regular check ups. 58.3% of the respondents had no understanding of the importance of regular check up.

Table 3.10 Respondents' understanding of the importance of regular check - ups

Importance of regular check- ups	n	%
No understanding	7	58
Clear understanding	5	42



3.5.2 RESPONDENTS' UNDERSTANDING OF KEEPING RECORD OF CHILDS' EPILEPTIC ATTACKS

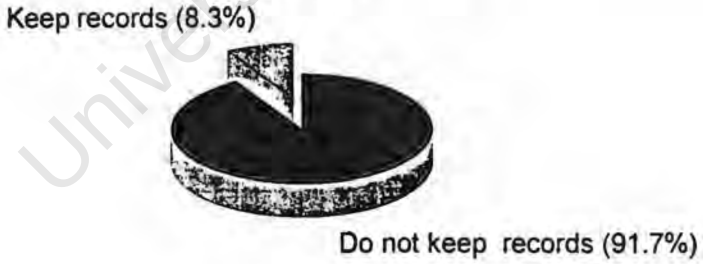
Table 3.11 and Figure 3.7 describe the respondents understanding of the importance of keeping a record of their childrens' epileptic attacks. 92% of respondents do not keep records.

Table 3.11 Respondents' understanding of the importance of keeping record of their childrens' epileptic attacks

Importance of keeping records	n	%
Do keep records	1	8
Do not keep records	11	92

Records of childs' epileptic attacks

Figure 3.7



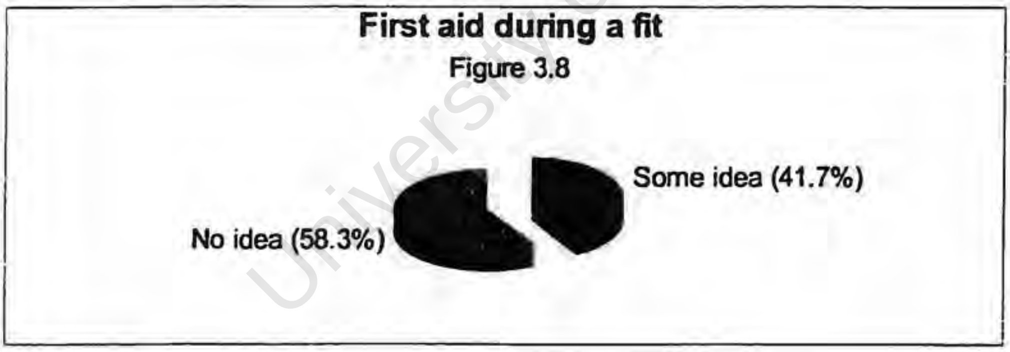
3.6 FIRST AID MANAGEMENT OF FITS

3.6.1 FIRST AID DURING A FIT

Table 3.12 and Figure 3.8 describe the respondents understanding of appropriate management when the child has a fit. 58 % of respondents had no understanding of what to do during a fit.

Table 3.12 Respondents' understanding of appropriate management when child has a fit

Understanding of first aid during a fit	n	%
No idea	7	58
Some idea	5	42

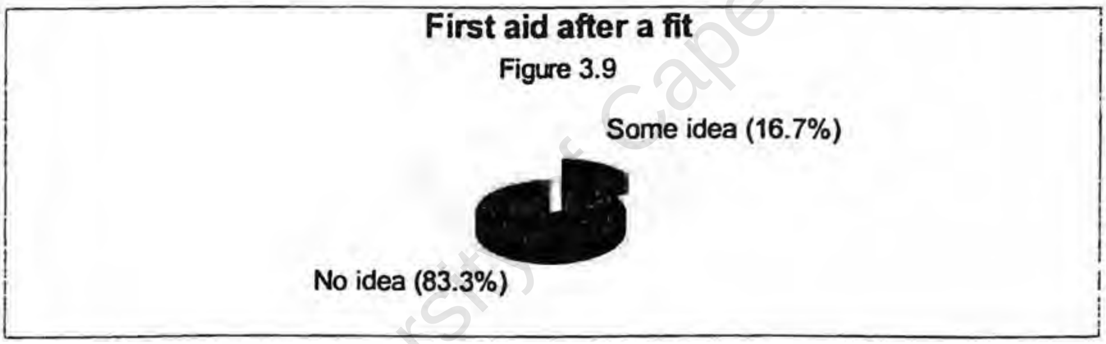


3.6.2 FIRST AID AFTER A FIT

Table 3.13 and Figure 3.9 describe the respondents understanding of appropriate management after the child had a fit. 83.3 % of respondents had no idea of what to do after the child had a fit.

Table 3.13 Respondents' understanding of appropriate management after the child had a fit

Understanding of first aid after a fit	n	%
No idea	10	83
Some idea	2	17

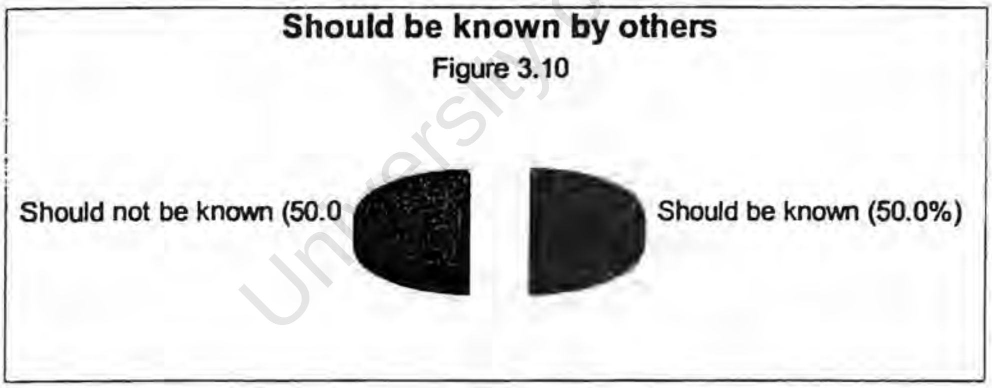


3.7 IMPORTANCE OF CHILDS' CONDITIONS TO BE KNOWN BY OTHERS

Table 3.14 and Figure 3.10 describe the respondents views of whether others should know about their childs' epileptic condition. 50% of the respondents were of the view that others should not know about their childrens epileptic condition, and 50% were of the view that others should know about their childrens epileptic condition.

Table 3.14 Respondents' views of whether others should know about their childs' epileptic condition

Whether condition should be known by others	n	%
Should be known	6	50
Should not be known	6	50



CHAPTER : 4. DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

This study explored what parents understood as the cause of their childrens' epilepsy, and how they managed it. This was done through conducting interviews, analysing and comparing findings. Discussion of findings will be done according to the themes developed from data, and supported by reviewed literature. Examples of some of the respondents answers are included to illustrate the themes. Full transcripts are attached for further reference if necessary (Appendix D).

4.1. DISCUSSION

4.1.1. Causes of epilepsy

From the Anthropological point of view, the ability to rècognise the condition, its name and cause, as well as the reasons for its occurrence is critical in the understanding and management of illness (Sindzingre & Zempleni, 1992).The lack of knowledge about the cause of epilepsy by most respondents in this study, could be suggestive of poor understanding of their childrens' epilepsy. The known causes that were mentioned by four respondents, were similar to findings from the literature that has been reviewed.

Results revealed that most respondents, (67%), did not know the cause of their childrens epilepsy (see figure 3.1 and Table 3.5).

<u>Excerpts of answers of respondents' who did not know the cause of their childrens epilepsy :</u>

Researcher : Mama, I will now start with my questions. The first question Mama, is what causes your childs' epilepsy ?

N: ... , I do not know the cause of her epileptic condition ...

M:I do not know, he only started now when he is older, he did not have it before.

B: What causes her epilepsy ... ... she just started to fit ... without anything - that, that, that caused her fits. She just started to fit like that.

4.1.2. Factors triggering epilepsy

Literature revealed that there are several environmental factors that may trigger the onset of seizures (Middleton, et al., 1981; Kisker, 1985; Lishman, 1987; Fenwick & Fenwick, 1996). These factors are critical in the understanding of management of epilepsy. From the eco-systemic point of view, context in which problems occur is critical in addressing problems as a whole.

Most respondents, (67%), did not know the factors that triggered the onset of their childrens' epilepsy (see Figure 3.2 and Table 3.6). Only four respondents mentioned the following as factors that trigger their childrens' epilepsy : when child is upset; when child has fear; evil spirits and when child sees a bewitched parent.

Two respondents mentioned that evil spirits and bewitchment as the factors that trigger the onset of their childrens' seizures. This is unusual. The literature reviewed on African beliefs usually stresses bewitchment as a cause, and not as a triggering factor.

Excerpts of respondents' answers regarding the factors triggering their childrens epilepsy.

Researcher : What triggers your childs' epileptic attacks ?

K: I do not know.

Q: I do not have any knowledge. I only see my child having fits, even during the night when she is sleeping.

E: ... I do not know. I only see him fitting.

4.1.3. Kind of treatment received by respondents' children

Various studies revealed that epilepsy is a problem that is clouded by beliefs which have some similarity throughout the southern African continent (Jilek - All, et al., 1997). Most African people first consult traditional healers for the purpose of understanding the cause of illness, and to deal with acts of sorcery.

Western practitioners are usually sought as the second option when seizures are uncontrollable (Pefile, 1993 : 54) Findings from this study revealed that most respondents' children received western medication (see figure 3.3 and Table 3.7) Although most respondents mentioned that their children received western medication, most of them had consulted either traditional or faith healers before seeking western treatment. This fact is critical for all western trained practitioners to understand and acknowledge that a holistic paradigm for management of problems is important in addressing the person as a whole (Bodibe, 1992).

Excerpts of respondents' answers indicating that they had consulted traditional healers.

Researcher : Thank you Mama. What kind of treatment does your epileptic child take ?

E: I have been using both treatments. I took him to spiritual healers only, then I ...

N: I once took her to traditional healers, but she could not be helped.

K: I tried to take her to traditional healers -

4.2. Management of Medication

4.2.1. Required number of pills

Literature revealed that lack of information about medication has a great influence in the general poor management of epilepsy (Pefile, 1993 : 51; Ngubane, 1992; Blumer, 1982).

It is reported that most clients with epilepsy do not receive thorough explanation about their prescribed medication. Much emphasis is only on " take the pill, 2 or 3 times a day, do not forget them " (Blumer, 1982).

Although results in (figure 3.3) revealed that most respondents children were on prescribed medication, 58.3% of respondents had no understanding of the required number of pills to be taken by their children. 16.7% of the respondents did not clearly answer the question. Only 33.3% had correct understanding of dosage (See figure 3.4 and Table 3.8).

Exerpts of respondents' answers on required number of pills taken by their children.

Researcher: OK Mama. How many pills does your child take ?

K: ... [unsure]

M: Those pills ... he takes them continuously ... he fetches them.

A: ... [unsure].

4.2.2. When pills need to be taken

Medical practice has been reported to be lacking in giving thorough information and explanations regarding the taking of prescribed medication (Craig, 1983). Much emphasis on seizure control has been on compliance, rather than involving the client. Information has been reported to be very selective, and not addressing the whole issues like, side effects of epileptic medication, or that sudden omission of epileptic treatment can trigger the onset of seizures, and that regular medication prevents further damage to the brain that can occur as a result of uncontrolled fits (Burden & Schurr, 1980: 41-44; Middleton, et al., 1981 : 31-38; Loveday, 1992 : 196).

Comparing results, only 33% of respondents had a clear understanding of the required dosage of pills taken by their children (Figure 3.4), whilst 50% of respondents were sure of when their children had to take their epileptic medication (see figure 3.5). These findings suggest a lack of clear understanding in the general management of epileptic medication. This could be an indicative factor for poor seizure control.

Exerpts of respondents' answers on when pills need to be taken

Researcher : When does your child take her pills ?

Q: That day when she had a fi - , when she had it.

E: As written on the bottle.

B: I am not sure ... it was once a day.

4.3. Management of childs' epileptic characteristics

4.3.1. Regular check-up

A regular check-up for clients with epilepsy includes the management of the psychological and social aspects, life skills training and treating any psychiatric complications.

Epileptic medication is used over a long period of life, and can have side effects like : drowsiness, restlessness, irritability, agitation and behavioural problems (Kapp, 1991: 266). The client need to have regular check up to determine whether the client responds to treatment by checking the drug plasma level.

The clients weight need to be monitored to adjust the medication dose, and to determine and control factors that might precipitate seizures, (Plein, et al., 1992 : 215 - 216). Literature revealed that uncontrolled seizures may occur as a result of clients being on other drugs, and conditions like inflammation of the stomach (gastritis), might cause poor absorption of epileptic medication (ibid).

Supportive mechanisms like counselling should be provided to give the client more information about the nature of epilepsy; to understand the clients problems and to give support; to assess the severity of fits and to discuss future management. This way of management provides a basis for good client - doctor relationship. It also creates a conducive environment for exploring attitudes and misconceptions (Lishman, 1987; Plein, et al., 1992).

Results from this study revealed that most respondents (58.3%), had a general lack of understanding of the importance of regular check up of their childrens condition (see figure 3.6 and Table 3.10).

Exerpts of respondents answers on regular check up

Researcher : Thank you Mama. How often do you take your child for check-up ?

N: ... for check-up ... ... she is never checked, she is only given pills, then she is asked whether she is still having fits, how often, you see -

L: I take him Mama when they have called him at hospital.

B: Ever since she was turned back I never took her back.

4.3.2. Keeping record of childs' epileptic attacks

Management of epilepsy includes the importance of keeping what other authors refer to as a " seizure diary ". Recording of the frequency of epileptic attacks is a critical aspect of the management of epilepsy. It involves clients with epilepsy to take part in caring for themselves, and being able to control their seizures. Keeping of a seizure diary assist the client in identifying the factors that might trigger the onset of fits, and the client can know what happened before a fit. This form of management increases the clients interest in their own condition (Plein, et al., 1992 : 214).

Findings revealed that most respondents (92%), do not keep a record of their childrens epileptic attacks (see figure 3.7 and Table 3.11), and did not understand the importance of keeping their childrens' seizure record.

Exerpts of respondents' answers on the importance of keeping a seizure record

Researcher : Thank you Mama. Do you keep a record of your childs' epileptic attacks ?

E: I never thought that it is important to keep a record

M: No. That is one thing that I have never thought of.

A: No. That thing was not yet in my mind.

4.4. FIRST AID MANAGEMENT OF FITS

4.4.1. First aid management during a fit.

Epileptic attacks can be very frightening to onlookers as well as to people rendering first aid during a fit. Literature on management of first aid during a fit reveals that a person with epilepsy should be attended with minimal interference. Some people tend to stop the movements, and forcefully put something in the mouth to stop injuries to the tongue.

First aid management during a fit entails the following : keeping the person calm; removing dangerous objects around the person; supporting the head and loosening any tight clothing. The duration and frequency of fits should be noted, including the parts affected. Nothing should be given orally whilst the person is fitting. The person may be referred if fitting frequently (WHO, 1989 : 1-10; Sands & Minters, 1979 : 25 - 26; Burden & Schurr, 1980 : 41 - 44; Loveday, 1990 : 196 - 197; Evian, Orlek & Scholtz, 1993 : 21).

Results from this study revealed that 58.3% of respondents had no idea of what to do during a fit (see figure 3.8 and Table 3.12).

Exerpts of respondents' answers on first aid management during a fit.

Researcher : Thank you Mama. What do you do when your child has a fit ?

N: We sometimes hold her -

T: Mh - there is nothing that I do, besides taking her and massaging her and ... and massage her whole body.

B: ... I do not do anything. I leave her to fit until her fits are over.

4.4.2. First aid management after a fit.

After the fits have stopped, it is important to check whether the person with epilepsy has not suffered any injuries. Small cuts can be washed with clean soapy water and dressed with a clean cloth. It is important to take history of what happened, and if the person was fitting for the first time, a referral would be necessary for thorough examination. The person should be allowed to rest, and any behaviour change should be noted (WHO, 1989 : 1-10; Evian, et al., 1993 : 21).

A personal account from an author who was also suffering from epilepsy revealed the frustrations she encountered through lack of explanation of what actually happened when she had a fit. According to Blumer (1982), it is important for a person with epilepsy to know what actually happened during a fit and the reasons for the occurrence of fits. The author emphasised the need for reassurance and support (67 - 70).

Findings from this study revealed that 83.3% of respondents had no idea of how to manage first aid after their children had a fit (see figure 3.9 and Table 3.13).

Exerpts of respondents' answers on first aid management after a fit

Researcher : OK. What do you do after she has had a fit ?

N: We just hold her, we never know what to do except giving pills only. We do not know what to do.

T: I ... I give her those pills, I give her those pills when she has had a fit. I give her a pill ... I give her those pills and massage her until she falls asleep.

B: I do not do anything. She just become all right on her own. Then she wakes up and care for herself.

4.5. IMPORTANCE OF CHILDS' CONDITION TO BE KNOWN BY OTHERS

Epilepsy is an important community problem. Literature revealed that psychological and social trauma experienced by people with epilepsy, stems from the negative societal attitudes towards the condition. Previous studies on epilepsy revealed that parents of children with epilepsy preferred to keep their childrens' condition a secret (Kisker, 1985). Disclosure about the condition assist in rendering a holistic approach to management of epilepsy - i.e. focusing on preventive, promotive and curative interventions and taking into account the context in which the problem occurs.

Findings from this study revealed that only 50% of respondents are of the view that their childrens' condition should be known by others, and that there is a reluctance to disclose the condition (see figure 3.10 and Table 3.14).

Exerpts of respondents' views about the importance of their childrens' condition to be known by others.

Researcher : Thanks Mama. Is it important that others should know about your childs' condition ?

T: Your childs' condition - (mq) shou----, shou ---, ... it is important that it must be known by you as a parent.

B: ... No. Even though it is not known by others, if it is only known by the family.

E: ... it is a laughter here in our area.

4.6. CONCLUSIONS AND RECOMMENDATIONS

The data presented here were obtained from reports of a group of parents of children with epilepsy in Khayelitsha. The sample consisted of 12 parents of children with epilepsy that were known by Zibonele Community Health workers who work in the areas of Town 2 and Silvertown, in Khayelitsha. Findings of this study cannot be generalised as they might not be representative of the whole population of Khayelitsha, and future research is necessary.

Generally, most respondents had no understanding of the causes and factors that might trigger the onset of their childrens' seizures. Although most respondents' children received western medication, the majority did not understand the management of the different aspects of epilepsy, namely, medication; the importance of regular check-ups and keeping of seizure records; first aid during and after a fit. Respondents had a general reluctance to disclose their childrens' epileptic condition. These results are indicative to poor seizure control due to lack of information about the condition as a whole.

The study highlights the need for an integrated approach to develop appropriate interventions that can bring a contextual understanding of the condition. Interventions should aim at the following : addressing the needs of parents; the special needs of children with epilepsy; improving relationships; collaborating resources; increasing participation; improving communication and sharing information; life skill development; understanding cultural aspects and traditional practices involved with epilepsy.

Future research should be directed to investigating the problems encountered by teachers, children with epilepsy and their peers at school, and how such problems are dealt with.

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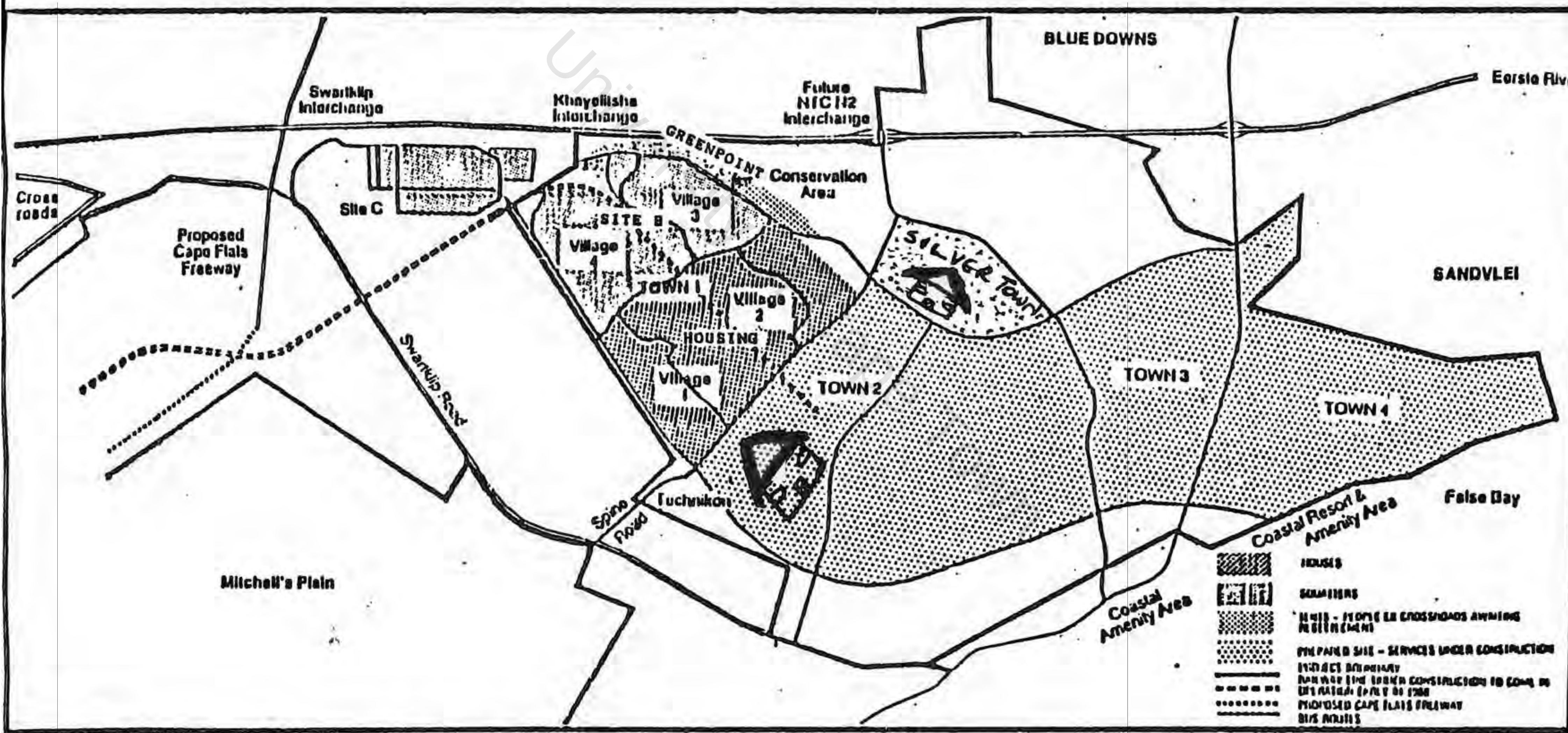
Khayelitsha

APPENDIX A



→ AREAS WHERE THE SAMPLE WAS

APPENDIX B

INTERVIEW SCHEDULE (ENGLISH).

Name:......................................Date:.....................

Age:...Sex:......................

Address:....................................Educational status:............

Number of children:....................Occupation:..................

Marital status:........................

A. CAUSES OF EPILEPSY.

1. What causes your childs' epilepsy ?

B. FACTORS TRIGGERING EPILEPSY

1. What factors trigger your childs' epilepsy ?

C. KIND OF TREATMENT RECEIVED BY CHILD

1. What kind of treatment does your epileptic child take ?

D. MANAGEMENT OF WESTERN MEDICATION

1. How many pills does your child take ?
2. When does your child take pills ?
3. How do you know when your child has taken too many pills ?
4. Does the pills control your childs' fits ? If yes, how ?
5. Is there any difference between curing and controlling your childs' epilepsy ?
6. Is it important to know your childs' epileptic condition ? Why ?

E. MANAGEMENT OF CHILDS' EPILEPTIC CHARACTERISTICS

1. Does your child have frequent epileptic attacks ?
2. How often do you take your child for check- up ?
3. Do you keep a record of your childs' epileptic attacks ? If yes, how ?

F. MANAGEMENT OF FIRST AID

1. What do you when your child has a fit ?
2. What do you do after your child has had a fit ?

G. IMPORTANCE OF CHILDS' EPILEPTIC CONDITION TO BE KNOWN BY OTHERS

1. Is it important that others should know about your childs' condition ? Why ?

APPENDIX C

INTERVIEW SCHEDULE (XHOSA)

Igama : ....Umhla :.......................................
Iminyaka :...........................Ubuni :.......................................
Idilesi :...............................Ibanga lemfundo:.........................
Inani labantwana :................Umsebenzi :................................
Uhlobo Lomtshato:...............

A. CAUSES OF EPILEPSY

1. Zesiphi izinto ezibangela ukuxhuzula komtwana wakho ?

B.FACTORS TRIGGERING EPILEPSY

1. Zeziphi izinto ezichukumisa ukuxhuzula komtwana wakho ?

C. KIND OF TREATMENT RECEIVED BY CHILD

1. Luhlobo luni lonyango umtwana wakho aluthathayo ?

D. MANAGEMENT OF WESTERN MEDICATION

1. Umtwana wakho uthatha ipilisi ezingakanani ?

2. Uzithatha nini umtwana wakho ipilisi zakhe ?

3. Uyazi njani xa umtwana wakho athathe ipilisi zezindlula umlinganiselo ?

4. Ingaba ziyamnceda umtwana wakho ipilisi zokuxhuzula ? Ukuba ewee, njani ?

5. Ingaba kukho amahluko phakathi kokunyanga nokuthomalalisa ukuxhuzula komtwana wakho ?
6. Kubhalulekile na ukuiyazi imeko yomtwana wakho ? Ngoba ?

E.MANAGEMENT OF CHILDS' EPILEPTIC ATTACKS

1. Uxhuzula rhoqo na umtwana wakho ?

2. Umsa kangakanani na umtwana wakho ukuba a xilongwe ?

3. Ingaba kukhona indawo ubhala kuyo xa ethe wa xhuzula umtwana wakho ? Ukuba ewee, ubhala phi ?

E. MANGEMENT OF FIRST AID

1. Wenza ntoni xa umtwana wakho axhuzula ?

2. Wenza ntoni emva kwakuthi umtwana wakho abexhuzule ?

G. IMPORTANCE OF CHILDS' EPILEPTIC CONDITION TO BE KNOWN BY OTHERS

1. Ingaba kubhalulekile na ukuthi imeko yomtwana wakho iyaziwe ngabanye abantu ? Ngoba ?

Z O1

Pseudonym for interviewee: N
Address described in the interview will be changed for confidentiality and protection of identity of the interviewee.
Name of interviewer : Johannah (J)
Date of interview : 6/11/97
Time : 10h30 - 11h00
Place : Khayelitsha

N is a mother of a 16 year old child with epilepsy. The child attended school until standard five, and could not continue with her education due to her condition. N is unemployed because she has to look after her child.

J: Hello Mama
N: Hello
J: How are you Mama ?
N: I am all right, there is nothing special, and how are you ?
J: I am all right Mama.
J: Mama, I am Sis J.
N: Yes.
J: I work at Zibonele.
N: Yes.
J: I am also a student at UCT.
N: Yes.
J: I will now ask you Mama to introduce yourself to me.
N: I am N.
J: OK
N: I live here in ═══, at ═══.
J: OK.
N: I am not working.
J: OK Mama.
N: Yes, mh.
J: I am happy that you have allowed me to talk to you -
N: Yes.
J: about your childs' condition.
N: Yes, mh.
J: I am requesting your permission to use a recorder -
N: Yes.
J: this tape-recorder (pointing), sothat I can be able to use the information -
N: Yes.
J: information will be confidential.
N: Yes.
J: I do not know whether you are allowing me.
N: You are allowed.
J: Mama, I will begin by asking questions.

N: Yes.
J: I will be thankful for your input regarding the questions that I will ask.
N: Yes.
J: The first question, Mama is, what causes your childs' epilepsy ?
N: ... , I do not know the cause of her epileptic condition ...
J: OK Mama. You do not know the cause of her epilepsy ?
N: I do not know anything about epilepsy... but, what she is using now is pills.
J: Pills.
N: Yes.
J: Have you never been told about the cause of your childs' epilepsy ?
N: NO.
J: OK. In your own view, what causes your childs' epilepsy ?
N: I do not know what causes her epilepsy ... ... We took her to Day hospital -
J: OK.
N: She got pills there.
J: OK Mama, thanks. I will now ask about what triggers your childs' epilepsy ?
N: mh, ... mh... triggers... my child says that she often experience fear.
J: OK. She experiences fear ...
N: ER... she becomes fearful and shivers, thereafter, she gets a fit.
J: OK. Is there anything else at home -
N: mh
J: that triggers -
N: mh
J: Is it only fear ?
N: Yes, only fear ...
J: OK Mama.
N: Thereafter she fits.
J: Thank you Mama. What kind of treatment does your epileptic child take ?
N: ... I do not know the name ... I forget - but she takes pills.
J: OK.
N: ER -
J: So, she take pills.
N: Yes.
J: OK Mama, it does not matter when you do not know the name, but she takes pills.
N: Yes.
J: How many pills does your child take ?
N: She takes monthly supply of pills.
J: OK. When does she take her pills ?
N: In the morning -
J: In the morning.
N: She only takes them in the morning, then after a month, she goes for a resupply - It all depends as to when the pills are completed. Sometimes, she is given an appointment date for resupply before they are finished -
J: OK.
N: then she goes again.

J: OK. How do you know when your child has taken too many pills ?
N: Too many pills ?
J: Yes.
N: ... I know that when she has taken them, taken them, taken them, -
J: OK.
N: It is important that she must go again before they are finished.
J: So, your child never takes too many pills. By too many pills I mean not giving according to what has been stated.
N: [Laughing]. She was taking one pill, now she takes two pills -
J: OK.
N: She was taking pills at Day hospital, then she left and she now takes them at Harare -
J: At Harare.
N: At Harare, she was given pills, and she takes one in the morning and one late -
J: So she takes one pill in the morning and one late.
N: mh... everyday.
J: Thank you Mama. How often do you take your child for check-up ?
N: ... for check-up ... ... she is never checked, she is only given pills, then she is asked whether she is still having fits, how often, you see -
J: OK. She is never checked.
N: mh. They only ask about how often she had fits.
J: OK. Does the pills control your childs' fits ?
N: ER... pills do control her fits.
J: How Mama ?
N: She stops to fit - mh.
J: Thank you Mama. Whom do you consult for your childs' epilepsy ?
N: ... I bring her here, sometimes at clinics and at Nomsa Mapongwana, or Day hospital - mh.
J: You do not consult with traditional healers.
N: NO. She does not take traditional medicines.
J: You have never consulted with traditional healers.
N: I once took her to traditional healers, but she could not be helped.
J: She was never helped, Thank you Mama. Does your child have frequent epileptic attacks ?
N: NO. She does not have frequent fits.
J: She does not have frequent fits. Do you keep a record of your childs' epileptic attacks ?
N: ... , I do not write -
J: OK.
N: I know the frequency of her fits, you see -
J: OK.
N: So it is important to report how she fits even when she is on pills.
J: OK. So, how do you keep record of her fits ?
N: I only write somewhere when requested there.

J: OK, all right Mama.
N: mh.
J: What do you do when your child has a fit ?
N: We sometimes hold her -
J: OK.
N: ... we just hold her ... mh ...
J: And what do you do after holding her ?
N: We hold her until she has completed to fit.
J: OK. What do you do after she has had a fit ?
N: fitting and fitting again -
J: After your child has had a fit, what do you do ?
N: She sleeps for a long time, ofcourse -
J: She sleeps for a long time.
N: Yes. She sleeps until in the morning because she often have fits during the night.
J: OK. You do not do anything after she has had a fit.
N: We just hold her, we never know what to do except giving pills only. We do not know what to do.
J: OK, all right Mama.
N: mh.
J: Is there any difference between curing and controlling your childs' epilepsy ?
N: Yes there is a difference - by control you only lay fits to rest for a while, you see, fits are not completely cured. So when you have cured epilepsy, it will not recur.
J: OK. So is epilepsy controlled or cured ?
N: Epilepsy is curable because you do not get fits when you use pills.
J: OK. Is it important to know your childs' epileptic condition ?
N: mh, it is important.
J: Why Mama ?
N: To know the problem that you have - ...
J : Is there anything that you would like to add ?
N: NO. I have nothing to add.
J: Is it important that your childs' condition should be known by others ?
N: It is important, because sometimes one may need advice and there can be somebody to give advice.
J: Mama, thank you very much for your time. I have now come to the end of our conversation. I am very much thankful for your input.
N: mh.
J: I will now give you the opportunity to say something pertaining to our conversation.
N: Laughing, I do not have anything to say.
J: OK, Mama, we have now come to the end of our conversation. Thank you once again for your time.

Pseudonym for interviewee: T
Address described in the interview will be changed for confidentiality and protection of identity of the interviewee
Name of interviewer : Johannah (J)
Date of interview : 6 / 11 / 97
Time : 12h30 - 13h00
Place : Khayelitsha

T is a mother of 2 children. She lives with NT, her grand child who is a 7 year old twin that has epilepsy.

J: Hello Mama
T:Hello
J: How are you Mama ?
T: I am all right -
J: Yes.
T: There is nothing special, and how are you ?
J: I am all right, thanks Mama.
T: mh (nodding her head)
J: Mama, I am Sis J.
T: Yes.
J: I work at Zibonele.
T: Mh.
J: ER, I am also a student at UCT.
T: Mh.
J: I will now ask Mama to introduce yourself
T: I am T.
J: Yes.
T: I am not working. I was working before at ===
J: Yes.
T: I then lost my job.
J: OK Mama. I am very much pleased that you could afford me your time to be able to talk to you.
T: Yes.
J: I am doing an investigation about children with epilepsy. I will appreciate your input regarding this issue.
T: Mh.
J: OK. Mama, another thing is that I will use a tape recorder.
T: Mh.
J: So, I do not know whether Mama will allow me to use it.
T: Oh.
J: I do not know whether that will be all right.
T: OK, you may use it. I really do not see any... I do not see any... I do not know ofcourse... that ... I do not see any problem to your request.

Z 02

J: OK Mama.
T: Yes.
J: Our conversation will be confidential.
T: OK.
J: That is this conversation between ourselves.
T: Mh.
J: I am recording for the purpose of being able to revise, grasp and understand all that we have talked about. I am happy that you have allowed me.
T: Mh.
J: Mama, I will now start with my questions. The first question Mama, is what causes your childs' epilepsy ?
T: ... that causes her epilepsy ?
J: Yes.
T: What I am not able to know then, is what is the cause.
J: Yes.
T: Yes. I ofcourse see her when she is already having a fit.
J: Yes.
T: I know already what she does when she is about to have a fit.
J: Yes.
T: Mh.
J: Now, in your view Mama, what do you think is the cause of her epilepsy ?
T: I do not know what causes her epilepsy.
J: OK.
T: Mh.
J: So you were never told about the cause of her epilepsy.
T:Yes.
J: OK Mama.
T: This child was born like this - she cannot walk, she cannot sit. She always lies flat.
J: OK.
T: Mh.
J: OK. thank you Mama. What triggers your childs' epilepsy ?
T: ... that she fits ?
J: Yes.
T: ... this child (mq,) the time she started to fit -
J: Yes.
T: she started here - she cried the whole night, she cried, and cried, and cried and cried until in the morning - I was still working then.
J: Yes.
T: So, very early in the morning I said - Hey, we never slept - then I said to the mother lets take her to Redcross -
J: Yes.

T: Ofcourse yes, we took her to Redcross. The child was admitted.
J: Yes.
T: After her discharge from Redcross - she was just a floppy child (mother showing me how the child was floppy) -
J: Mh.
T: She was taken to Philani -
J: Yes.
T: She was just a floppy child and was unable to flex her joints -
J: OK.
T: Mh - We tried her and treated her and used warm water to massage her so that she can be able to flex -
J: Yes.
T: Then she was able to flex - her neck was not stiff - therefore she cannot sit -
J: OK.
T: Then I stayed with her in that condition - then after a long time I saw her eyes doing like this (mother winking and rolling her eyes)-
J: OK.
T:Then I took her to another Doctor -
J: Mh.
T: When she is just about to fit, she does like this (mother winking and rolling eyes) -
J: OK.
T: ER, I took her again to another Doctor - Yes, that Doctor told me that ... because the Doctor did not take note that the child is epileptic - when I actually told him that my child is having epilepsy -
J: Yes.
T: So one time I was at this Doctor, then she started to fit -
J: Mh.
T: The Doctor said, NO, she does... she does... this child is not epileptic- and I was actually showing the Doctor in the same way that I am showing you.
J: Mh.
T: He said, NO, man, she is not epileptic - it is just that she is not all right mentally -
J: Mh.
T: Then I said I do not know when he actually wanted to tell me.
J: Mh.
T: I could see that he was trying a way of telling me, shame, he said I do not know how to tell you.
J: Mh.
T: Then I said - tell me (emphasising) ... he said I do not know how to tell you, anyway, this child ... i——s, her mental state is not all right - that is - she is having ment——al retardation -
J: OK.
T: You see now.
J: mh.

T: Now that I am also a person ... ever since I was told about that -
J: Mh.
T: I was worried, but he told me that he did not know how to tell me , shame, poor person, so I then insisted that he tell me that painful issue.
J: Mh.
T: So, he told me in that way, but I was troubled -
J: You were troubled.
T: I remained troubled and did not even pay him, I left and I went straight home and I realised that my heart was sore -
J: OK.
T: Even though my heart was sore, my conscience told me that he told me -
J: Mh.
T: He said he does not know how to tell me, but then I insisted to be told. So he told me , now I am troubled now and yet I was told in the manner that I insisted
J: OK.
T: Yes, thats about all -
J: Thank you Mama. What triggers your childs' epilepsy ?
T: I think this child - because we are traditional Xhosa people. I think it is spirits that triggers my childs fits...
J: OK.
T: I also took her to Faith healers -
J: OK.
T: And because one of the healers said he has never come across such a condition. He said that he usually treats others, but this one, this child, I am unable to treat, she cannot be healed.
J: OK.
T: Then I took her to hospital - and she goes and get help there.
J: Now what kind of treatment does your child take?
T: There at hospital ?
J: Yes.
T: She goes for treatment there now.
J: What kind of treatment does she take ?
T: She takes pills.
J: Pills. When does she take her pills ?
T: I take them now and at the end of the month - when the month ends, I am supposed to fetch another supply.
J: OK. Now how many pills does your child take ?
T: Daily ?
J: Yes.
T: She takes 2 in the morning.
J: 2 in the morning.
T: Yes.
J: How do you know when you have given too many pills ?

T: NO. I do not, because I was told that when I ... ... but when I give her pills she does not fit when I have given her, but when I have missed a day without giving her pills -
J: mh.
T: Then the next day I will know that she did miss taking her pills, and I can see when she has not taken her pills.
J: Thank you Mama. Now, how often do you take your child for check -up ?
T: For check-up -, She goes after 2 months - the 3rd month she has a check - up.
J: Where ?
T: At Site B.
J: Thank you Mama. Does the pills control your childs' fits ?
T: I wont say that pills do control her fits -
J: Mh.
T: I wont say they do control fits, she only stops when I have given her pills.
J: Yes.
T: My only problem is that fits are not cured completely -
J: OK. Thank you Mama. Now regarding traditional treatment //
T: I have never taken such a long time to treat a person with no response -
J: So, traditional treatment did not help.
T: NO. It did not help.
J: Does your child have frequent epileptic attacks ?
T: When she did not take her treatment, she fits frequently.
J: When she did not take treatment.
T: Mh.
J: How often does she fit ?
T: during the day..., sh——e (unsure) when she is about to - I normally do this
J: Yes.
T: Because I already know her -
J; Yes.
T: I give her those pills even during the day when she did not take them - because she has a distinct cry -
J: OK.
T: When she is about to fit.
J: OK.
T: Then I give her.
J: OK.
T: But if I have given her pills, then she stops.
J: She stops.
T: Mh.
J: Do you keep a record of your childs' epileptic attacks ?
T: Keep a record ?
J: Yes.
T: NO. I do not have any record.
J: Where do you record ?

T: In my mind.
J: In your mind.
T: Mh. I monitor the interval between when last she had a fit and I keep this in my mind.
J: OK. What do you do when your child has a fit ?
T: When she fits ?
J: Yes.
T: Mh - there is nothing that I do, besides taking her and massaging her and ... and massage her whole body.
J: What do you do after she has had a fit ?
T: I ... I give her those pills, I give her those pills when she has had a fit. I give her a pill ... I give her those pills and massage her until she falls asleep.
J: OK. Is there any difference between control and curing your childs' epilepsy ?
T: Control ?
J: Yes.
T: And curing epilepsy ?
J: Mh.
T: To cure is that a person will live.
J: Mh.
T: There is a difference because control does not mean cure, that thing is not completely cured in someone's blood -
J: OK.
T: To cure means to treat that condition until it is completely cured and will never recur again.
J: Mh.
T: To control means that when she is fitting, I give her a pill, then she stops, but when she has not taken a pill, fits will recur -
J: OK.
T: There is a difference.
J: OK. Is it important to know your childs' epileptic condition ?
T: To know your childs' epileptic condition is important -
J: mh.
T: Because if it is not known by you as a parent -
J: mh.
T: Living with that child who else will know about it ?
J: OK. Is it important that your childs' condition should be known by others ?
T: Your childs' condition - (mq) shou—, shou —, ... it is important that it must be known by you as a parent.
J: OK.
T: It is important also that there are other people, when you are a person, that you can inform them about your problem. There are those that you cannot tell.
J: OK.
T: When you are a person.

J: OK Mama. Thank you very much for your input. I have now come to the end of our conversation. I am now going to give you the chance to say something regarding our conversation.
T: Mh. What I will like to add is this - when you are a person and having children, it is important to know their condition -
J: Mh.
T: It is also important that one should not go about telling people about ones problem, because there are those who after telling them about your problem, then they make a joke about it.
J: OK.
T: That is one important thing that a person should be careful about.
J: Mh. OK. All right Mama. Thank you very much for your input regarding this issue. I am still saying thank you very much Mama for your time.
T: Mh, It is all right. Thank you.
J: Thank you Mama.
T: OK.

Pseudonym for interviewee : K
Address described in the interview will be changed for confidentiality and protection of identity of interviewee
Name of interviewer : Johannah (J)
Date of interview : 7 / 11 / 97
Time : 15h30 - 15h45
Place : Khayelitsha

K is a single mother, unemployed and having 2 children. MK is her 17 year old child who left school at Sub B due to her condition.

J: Hello Mama.
K: Hello.
J: How are you Mama ?
K: I am all right, and how are you ?
J: I am all right. Mama, I am Sis Johannah.
K: Yes.
J: I work here at Zibonele. I am also a student at UCT.
K: Yes.
J: So, I am doing an investigation about children with epilepsy.
K: Yes.
J: I will now give Mama the chance to introduce yourself
K: I am K====M====
J: Where do you live Mama ?
K: I live here at No ====.
J: Thank you. Mama I am going to use a tape recorder to record our conversation. I am therefore requesting your permission to use it. The information pertaining to our conversation will be confidential.
K: Yes.
J: I do not know whether you do allow me.
K: Yes, you are allowed.
J: Thank you Mama. I will start by asking the first question What causes your childs' epilepsy ?
K: ... ... (amazed, frowned, unsure)
J: I was asking Mama about what causes your childs' epilepsy ?
K: ... ... that causes epilepsy ?
J: Yes.
K: ... ...
J: When you think about your childs' condition, in your view, what could be the cause of her condition ?
K: My child was born without this condition ...
J: Born without this condition.
K: She started having this condition in 1987 -
J : In 1987.
K: Yes. She became weak, and weaker and weaker -

J: Becoming weaker.
K: She was taken to hospital at ====, because that is where I come from. Doctors could not see what the condition is all about.
J: OK.
K: Child continued, and continued and continued - until i—n 1990 -
J: In 1990
K: I saw my sister bringing my child to me and saying that the child is no more weak, but now she also has fits.
J: So she has fits now.
K: Yes - then it happened, happened, happened when she is here with me -
J: Yes.
K: I tried to take her to traditional healers -
J: Yes.
K: Because other people said that I must also take her to traditional healers -
J: OK.
K: Yes - I then took her there -
J: mh.
K: They said that she is bewitched -
J: She is bewitched.
K: Yes. With chicken meat ... and now she does not eat chicken anymore. When she eats it, she fits.
J: OK.
K: But she eats other types of meat.
J: OK.
K: Now I realised that they... she cannot be helped by traditional treatment -
J: Mh.
K: I then took her to hospital - and there I ... she was given pills and she was also seen by the Doctor - Then every time I must go and fetch her treatment, everytime I must fetch her treatment every month.
J: OK.
K: Mh.
J: So Mama, in your view is bewitchment the cause of your childs' epilepsy ?
K: ... ... I do not know
J: OK.
K: From consulting with traditional healers I did not see anything - I only saw improvement at hospital - because when she takes pills - she stays a long time -
J: OK. You mentioned earlier that your child takes pills.
K: Yes. She takes them. I almost forget.
J: What triggers your childs' epileptic attacks ?
K: I do not know.
J: OK Mama. How many pills does your child take ?
K: ... [unsure]
J: OK. When does she take her pills ?
K: She does not take them in the morning - she takes them at night after meals.

J: OK. How often do you take your child for check -up ?
K: ... ... I have taken her now ... now I will again take her to be seen by the Doctor in December -
J: Mh, OK.
K: On the 30th.
J: How do you know when your child has taken too many pills ?
K: She never misses her time, whether two or three when she has to be seen by the Doctor.
J: OK. Does the pills control your childs' epilepsy?
K: Yes - pills help her -
J: How Mama ?
K: Because ever since she has been on them she is much better compared to the first time.
J: OK. Does your child have frequent epileptic attacks ?
K: When the month ends, she fits maybe once or twice or thrice at night -
J: OK. Do you keep a record of your childs' epileptic attacks ?
K:... where I go ?
J: Where you write when your child has had a fit at night or during the day. Do you perhaps keep such a record ?
K: I do not write. I keep it in my mind -
J: OK.
K: When I go there then Doctors ask me and I tell them.
J: OK. What do you do when your child has a fit ?
K: I hold her -
J: You hold her.
K: Then I put something in the mouth so that she should not bite herself -
J: OK. Then what do you do after she has had a fit ?
K: I leave her to sleep, and sleep until ... then she sleeps, then after her sleep is over, I then realise that her mind is not all right ... I do not know what to do...
J: Her mind is not all right.
K: Yes... I do not know what to do
J: What you do then when you see that her mind is not all right ?
K: I stay with her the whole day sothat she should not go outside ...
J: OK.
K: Until I have seen how she is.
J: OK. Thank you Mama. Is there any difference between curing and controlling your childs' fits ?
K: ... ...
J: To cure and control ?
K: ... control ...
J: Is there any difference when we say epilepsy can be cured or controlled ?
K: There is a difference.
J: How Mama ?
K: In curing the illness she becomes completely cured.
J: OK.

K: Control means that the illness is not completely cured, then after sometime the illness comes back again.
J: OK. Is it important Mama to know your childs' condition ?
K: Yes It is important.
J: Why ?
K: That is an important thing for me to know as a parent ... what is wrong with my child
J: OK Mama. Is it important that your childs' condition should be known by others ?
K: ... ... NO. It is not important.
J: Why Mama ?
K: ... ... other people make a joke about peoples illnesses
J: They make a joke.
K: Yes as if one has called for that sickness somewhere.
J: OK.
K: It is important that I should inform only those people who can be of help to me -
J: So you do not think other people should know.
K: NO - because they make a joke out of this illness.
J : OK Mama. I have now come to the end of our conversation. I am very much thankful for your input and your time.
K: Yes.
J: Now I will give you the chance to say something regarding our conversation.
K: I am asking for advice as to how can she go back to school because she does not want to stay at home doing nothing ...
J: And what else Mama, I can see you still want to say something.
K: Like a grant, I am not working and I am having no husband. Every thing is dependent on me and sometimes there is no food at home and these pills ...
... ...
J: OK Mama, I have listened to all that you have said. I am very much thankful for your input and your time. Thank you once again.

Z 04

Pseudonym for interviewee: E
Address described in the interview will be changed for confidentiality and protection of the interviewee
Name of interviewer: Johannah (J)
Date of interview: 10 / 11 / 97
Time: 11h30 - 11h50
Place: Khayelitsha

E is a grand mother of BM aged two and half months, and has epilepsy. E's daughter left BM with her grand mother to look for her boyfriend who deserted her. E has been looking after BM since she was 2 months old. E is 46 years of age and has 6 children.

J: Hello Mama.
E: Hello.
J: How are you Mama ?
E: Thank you very much, I am all right.
J: I am all right. Thanks. Mama I am Sis J.
E: Yes.
J: I work at Zibonele. I am also a student at UCT.
E: Yes.
J: I am doing an investigation about children with epilepsy.
E: Yes.
J: I will now give Mama a chance to introduce herself.
E: I am E==== I live at =====
J: You live at =====
E: Yes.
J: Mama I am going to use a tape recorder during our conversation.
E: Yes.
J: I do not know whether Mama will allow me to use it.
E: Yes.
J: Our conversation will be confidential.
E: Yes.
J: Thank you very much for allowing me.
E: Yes.
J: I will now start to ask the first question.
E: Yes.
J: What causes your childs' epilepsy ?
E:I do not know the cause. The child start by being feverish. Then she cries and thereafter she fits.
J: OK. Thank you Mama. So in your view what causes your childs' epilepsy?
E: I do not know. But there is something that was said at hospital when she was born.
J: OK.

E: The child remained for 10 days in hospital and they did not want to discharge her because they said that the child appeared to be born before the time.

J: OK.

E: They said the child appeared to be too small, even though it was full term.

J: OK.

E: But she was kept at hospital.

J: OK.

E: She was then discharged as if she is all right. Then after a month when she was now at home, she started to fit.

J: OK.

E: I took her to the Doctor -

J: Yes.

E: Then it appeared as if she is becoming better. But she was not all right mentally.

J: She is not all right mentally.

E: Yes ... ...

J: OK.

E: She has poor eye sight ... and then sh—e cannot eat properly ... she cannot remain by herself. You always have to look after her. She cannot play with other children.

J: OK.

E: She does things that are not for her age ...

J: OK.

E: Even when you have given her food, she cannot see that this is food, she takes time before she can eat.

J: OK.

E: So I have to remain home and look after her ... if I want to work, I must find somebody to look after her.

J: OK Mama. So in your view what do you think is the cause of her epilepsy ?

E: Mama, I do not want to lie. I do not know the cause. I think this child was born with a problem according to the explanation given at hospita—l... I was told that I must wait, the child is not right.

J: So they did not inform you of what was it that the child was born with ?

E: NO. They only said that the child cannot feed from her mothers breast, nor from the bottle ... and she cannot... she has poor co-ordination of actions ... she looks like a child who is born before the time. That is what they explained to me ... the nurses when I wanted to understand the problem with the child.

J: Thank you Mama. I will now ask what kind of treatment does your child take?

E: Because she was taken by her mother at first, I would not know. I do not want to lie.

J: Now what does she take at present Mama ?

E: How Mama ?

J: That is what does she take for her epileptic condition.

E: Like somebody who is not literate, please do not be troubled. I do not know what they are because I sometimes take her to a special Doctor, you see. Then he makes a card for me and tell me when to come back with the child.
J: OK Mama. What kind of treatment does your child take ? Is she taking a pill or any other form of treatment ?
E: They give her medicine in a bottle.
J: How much medicine do you give her ?
E: According to the way it is explained to me.
J: When does she take her medicine ?
E: As written on the bottle.
J: How do you know when you have given too much medicine ?
E: I give her according to the time.
J: Does the medicine control your childs' fits ?
E: I can see that the medicine helps— because she has a long time —almost a year without having fits. Now the main problem is that she is not all right mentally.
J: So medicines control her fits.
E: Yes medicines help because she does not fit anymore. She sometimes has cramps but no fits.
J:OK. How often do you take her for check up ?
E: When the medicine is finished.
J: OK.
E: She is not all right mentally ... she does things that are below her age ... has poor eyesight. She cannot play well with other children. You can notice that she is not like other children.
J: OK.
E: mh... She is also aggressive towards other children, she cries even though you have given her a toy thinking that she will be happy, she will cry, throw herself on the floor. And you can see that she wants attention from an older person.
J; Thank you Mama. I hear you say that she is aggressive, she cries. Are there any factors that trigger your childs' epilepsy ?
E:I do not know ... I really do not know ...
J: There is nothing in your view that you think may trigger her to fit ?
E: NO ... I do not know anything that may trigger her to fit.
J: Thank you Mama. Whom do you consult for your childs' epileptic condition ?
E: I took her to Site C ... because my other daughter is not working ... and whilst I was working I use to leave her with her so that she can take her to the clinic because I live here.
J: Thank you Mama. Does your child have frequent epileptic attacks ?
E: NO. She does not have frequent fits because it is already a year that she has not had an attack. But the main problem is that she is not all right mentally.
J: Thank you Mama. Do you keep a record of your childs' epileptic attacks ?
E: Where I write ?
J: Mh.
E: I never thought that it is important to keep a record.

J: What do you do when your child has a fit ?
E: I undress her to reduce fever. I also put a wet washing rug on her forehead, because she normally start by being feverish ... then she fits thereafter. Then I remove things that might hurt her. Then I put a pillow to allow free flow of saliva and I ... ... I do like that.
J: What do you do after she has had a fit ?
E: I normally try and take her to the Doctor.
J: Thank You Mama. Is there a difference between curing and controlling your childs' epilepsy ?
E: NO. I do not know how to respond now.
J: My question was that is there any difference between curing and controlling your childs' epileptic attacks ?
E: I have hope that epilepsy can be cured ... because I do hear that there are some people who have been cured, those that had epilepsy ... and I also think that when fits recur, it means that they are still not yet cured.
J: So according to you epilepsy can be cured.
E: According to me, epilepsy can be cured.
J: Thank you Mama. Is it important to know your childs' epileptic condition ?
E: It is important Mama.
J: Why ?
E: Because that is when you will know the condition. When you know you are able to live with the child, and know how to care for her, and to know about the condition.
J: Thanks Mama. Is it important that others should know about your childs' condition ?
E: Which people then ?
J: May be members of the family, neighbours, and at school, that is generally other people.
E: It is not important that your childs' condition should be known by people who cannot be of assistance to you. I think people who should know are those that can be of help to you towards your childs' condition.
J: So other people like family members, at school, neighbours, are not important to know.
E: I do not think it is important because there is nothing that they can help you with. People like Social Workers and our Doctors and many others, those are the people that help me when I have problems.
J: Thank you very much for your input Mama. We have now come to the end of our conversation. I am going to give you the chance in case you have something to add to our conversation regarding this issue.
E: Mama please do not be troubled when I was unable to respond to all questions. I am very much thankful that you have accepted me with the problem that I have. Accept me and assist me to know more about this condition.
J: Thank you Mama for your time and important input towards my study.
E: I also say thank you very much.

Pseudonym for interviewee: L
Address described in the interview will be changed for confidentiality and protection of identity of interviewee.
Name of interviewer: Johannah (J)
Date of interview: 10 / 11 / 97
Time: 14h00 - 14h15
Place: Khayelitsha

L aged 24 is a mother of 2 children. US is her 5 year old child.with epilepsy and is not attending pre-school due to his condition.

J: Hello Mama.
L: Hello.
J: How are you Mama ?
L: There is nothing special Mama and how are you ?
J: I am all right too thanks. Mama I am Sis J. I work at Zibonele.
L: OK.
J: I am also a student at UCT.
L: OK.
J: I am doing an investigation about children with epilepsy.
L: OK Mama.
J: I will now ask you Mama to also introduce yourself.
L: I am L====
J: Where do you stay Mama ?
L: I stay at ====
J: Thanks. Mama I am going to record our conversation.
L: OK Mama.
J: I will request Mama to allow me to use the tape recorder.
L: OK Mama.
J: Our conversation will be confidential.
L: OK Mama.
J: Thanks. I will start by first asking what causes your childs' epilepsy ?
L: What causes his epilepsy ... I do not know what the cause is.
J: You do not know what the cause is.
L: Yes.
J: In your view what do you think is the cause of your childs' epilepsy ?
L: NO. I do not know.
J: Thanks Mama. What triggers your childs' epilepsy ?
L: He uses his head only.
J: Mama says he uses his head.
L: Yes. Only his head moves during a fit ... the rest of body remains still.
J: So you do not know anything that may trigger his fits.
L: I do not know my dear.
J: OK Mama.
L.: Yes.

J: OK. Thanks. What kind of treatment does your epileptic child take ?
L: He takes treatment.
J: He takes treatment. You said treatment. What kind ?
L: He takes pills.
J: Where does he take his treatment ?
L: At Site B.
J: He takes them at Site B. How many pills does your child take ?
L:The small pills ... white ones.
J: When does he take his pills ?
L: He takes them regularly after a month.
J: Thanks Mama. How do you know when your child has taken too many pills ?
L: When they are too many he can become ill. Because I remember when he was taking treatment at Site B ... He was given pills that were not for his age. He was swollen and was admitted at Redcross. At Redcross they said that he was given pills that were not for his age. They gave me a letter sothat he can be given the right pills. He then got the white small pills that he is taking now. So I never give too many pills.
J: Thanks Mama. How often do you take your child for check - up ?
L: I take him Mama when they have called him at hospital.
J: You only take him when they have called him. Now when they have not called him what do you do.
L: They give him a date sothat I must regularly bring him to the Doctor.
J: Thanks Mama. Does the pills control your childs' fits ?
L: Ever since he has been on pills I have not seen anything.
J: There is nothing that you have noticed.
L: Yes.
J: So do you think that pills control his fits.
L: If I can be patient, pills do control his fits.
J: Whom do you consult for your childs' epilepsy ?
L: Do you mean ... at hospital ?
J : I mean consultation for treatment any where.
L: NO. I am still concentrating on hospital treatment because it is along time that he has been treated there.
J: Thanks Mama. Does your child have frequent epileptic attacks ?
L: NO ... only at some times ... some--- times.
J: Thanks. Do you keep a record of your childs' epileptic attacks ?
L: NO.
J: How do you know when last your child had a fit ?
L: I can see that he can feel that he is going to have a fit because he does not become trapped like that ... ... he comes back and fall at the door ... I can see that there is a sign that he feels ... It is just that he is still small, he is therefore unable to say what he feels.
J: Thanks Mama. You never keep a record of when he had a fit.
L: NO. Mama, I do not keep a record.

J: What do you do when your child has a fit ?
L: When he fits, I put a cloth sothat he should not bite himself.
J: You say you put a cloth. Where do you put it.
L: In his mouth sothat he cannot bite himself.
J: OK. What do you do after he has had a fit ?
L: After he has had a fit I bath him because he is usually exhausted. Therafter I give him his pill and leave him to sleep.
J: Is there a difference between curing and controlling your childs' epilepsy ?
L: NO. There is n—o There is a difference because he is not like before he started taking pills.
J: In your view, is there a difference between controlling and curing epilepsy ?
L: Pills cure epilepsy.
J: Thanks. Is it important to know your childs' epileptic condition ?
L: It is important.
J: Why ?
L: ... ... It is important to know your childs' condition because you live with him. So you must know all the problems that he has.
J:Thanks. Is it important that others should know about your childs' condition ?
L: ... It is important my dear, because others may give you advice.
J: Thank you Mama. We have now come to the end of our conversation.
L: OK.
J: I am happy for the time that you have given me.
L: OK Mama.
J: I am going to give you chance to add something pertaining to our conversation.
L: I have nothing special.
J: You have nothing special. Mama thank you once more for your input and your time.
L: Thanks.

Pseudonym for interviewee:Q
Address described in the interview will be changed for confidentiality and protection of identity of interviewee.
Name of interviewer: Johannah (J)
Date of interview: 12 / 11 / 97
Time: 14h30 - 14h45
Place: Khayelitsha

Q is a 41 year old mother of 3 children. She has a 21 year old epileptic child who is now not attending school.

J: Hello Mama.
Q: Hello.
J: How are you Mama ?
Q: I am all right, Nurse. How are you ?
J: I am all right thanks. Mama, I am Sis J.
Q: I am M====='s mother.
J: Thank you Mama. I work at Zibonele.
Q: I live here at =====
J: Thank you Mama. I am a student at UCT.
Q: I am resident here =====
J: OK. I am doing an investigation about children with epilepsy.
Q: Yes. I do have a child with epilepsy.
J: Thank you Mama. I would like to express my greatest appreciation for having agreed to talk about this issue.
Q: I am also thankful. Maybe I can be able to get help.
J: Thank you Mama. I am going to use a tape recorder. I will therefore request your permission to do so. The information will be confidential. I do not know whether you permit me or not.
Q: Yes. I do accept.
J: Thank you very much Mama. My first question is, what causes your childs' epilepsy ?
Q: I have no knowledge. I have only realised that she fits.
J: OK Mama. You have only realised that she fits.
Q: Yes.
J: You do not actually know what causes your childs' epilepsy.
Q: I do not know, but I did take her to hospital.
J: You took her to hospital.
Q: Yes.
J: At hospital, what did they say the cause of your childs' epilepsy is ?
Q: Doctors said that thing is in the head, a growth in the head ...
J: What kind of a growth is that Mama ?
Q: From Xray, they said it is a growth
J: A growth.
Q: mh.

J: So they explained to you that it is the cause of your childs' epilepsy.
Q: The Doctor said like that.
J: The Doctor said like that. Thank you Mama. Now what triggers your childs' epilepsy ?
Q: What sort of trigger ?
J: By trigger, it means maybe those things that may cause your child to fit, perhaps at home.
Q: I do not have any knowledge. I only see my child having fits, even during the night when she is sleeping.
J: You only see her having fits.
Q: mh.
J: You do not know any factors that triggers her epilepsy.
Q: NO.
J: OK. Thank you Mama. What kind of treatment does your epileptic child take?
Q: I use traditional Xhosa treatment because the Doctor wanted to operate her, and I refused.
J: You refused the operation.
Q: mh.
J: What kind of treatment does your child take now ?
Q: She is taking pills, Xray, and clinic, every time she has an attack. She does not fit everyday.
J: OK.
Q: [] Once a year, 3 , and during the year. She does not fit quiet often during the year. That particular day that she has epileptic attacks, she goes quickly to hospital to get Xray, and to get pills and pump (inhaler).
J: OK. How many pills does your child take ?
Q: [coughing]. My child is big. She is 21 years old. She continues to take her pills.
J: She takes her pills.
Q: Yes.
J: When does your child take her pills ?
Q: That day when she has a fi - , when she had it.
J: She does not take them regularly.
Q: [] NO.
J:Pills for epilepsy.
Q: Yes. She takes them. In packets.
J: Where does she take them ?
Q: At Harare and at Site B.
J: OK. How do you know when your child has taken too many pills ?
Q: She takes them. It is written here. I can see her when she takes them.
J: She does not take too many pills.
Q: NO.

J: OK. Mama. How often do you take your child for check - up ?
Q: She goes when ... when it started with Asthma ... we then take her to the clinic for Xray things like that.
J: I hear you talk about Asthma. Does your child has Asthma and epilepsy ?
Q: It started with Asthma ... this thing.
J: It started like (( )) could you please explain.
Q: It starts like being chesty.
J: Yes.
Q: She blocks and coughs.
J: Yes.
Q: Then during the night she fits. Things like that.
J: She fits.
Q: It starts like a cough with her.
J: OK. Thank you Mama. Does the pills control your childs' fits ?
Q: I can say because she takes a long time before she can fit again.
J: She takes a long time before //
Q: Fitting and being chesty.
J: Whom do you consult for your childs' epilepsy ?
Q: At Harare, and again at Site B where there is Xray.
J: OK. You mentioned before that you refused that your child be operated. Did you consult with traditional healers. Kindly explain further.
Q: Yes. I refused the operation, because the Doctor said to me that the thing that my child is having is that she is bewitched.
J: It is bewitchment.
Q: Yes.
J: Was this being said by a traditional healer ?
Q: A white Doctor, a female at ═══
J: So, does this mean that you now use both traditional and western treatment ?
Q: When she has an attack, I take her to hospital, and thereafter, I treat her with traditional treatment.
J: So you use both.
Q: Yes. I use both kinds of treatment.
J: OK. Thank you Mama. Does your child have frequent epileptic attacks ?
Q: She does not fit frequently. Once a year or once, not frequently, that day.
J: That day. Do you keep a record of your childs' epileptic attacks ?
Q: I did not hear.
J: Do you keep a record of your childs' epileptic attacks ?
Q: I do not understand what you are saying.
J: To keep a record, to write somewhere ...
Q: She.
J: NO. When she fits, do you write down to say she had a fit on this day, at this time.
Q: NO. I do not do like that.
J: How do you keep a record.

Q: I only remember the day she had a fit. Now what confuses me is that she only fits once a year, then once. That is the thing that beats me. She does not fit all the time.

J: OK. So you do not keep a record.

Q: NO. I do not keep a record.

J: OK Mama. What do you do when your child has a fit ?

Q: I call my brother. Then they undress her. Then they put a wooden spatula in the mouth.

J: They put a wooden spatula in the mouth.

Q: mh.

J: OK.

Q: // So that she cannot bite her tongue.

J: OK. What do you do after your child had a fit ?

Q: I wait ... if she had a fit at night, I wait till in the morning to take her to the clinic.

J: You take her to the clinic. Thank you Mama. Is there any difference between curing and controlling your childs' epilepsy ?

Q: What do you mean ?

J: In your view, do you think epilepsy can be cured or controlled ?

Q: I have hope as if it can be cured ... because now they are absent ... they do not occur the way they occurred before.

J: Mh.

Q: I do not see her having fits now.

J: So, do you think that pills cure or control epilepsy ?

Q: I can say pills control fits, but at the same time I am not sure because I also use traditional treatment. But I have hope that epilepsy can be cured.

J: OK Mama. Is it important to know your childs' epileptic condition ?

Q: Yes it is important.

J: Why ?

Q: Because it is my child and it is painful to me.

J: OK. Is it important that others should know about your childs' condition ?

Q: Yes, others should know about it.

J: Why ?

Q: Because they can also find help, and it should not be a secret.

J: So, in your view it should not be a secret.

Q: Yes.

J: Mama, I have now come to the end of our conversation.

Q:Yes, thank you.

J: I am now giving you the chance to say something regarding what we have been talking about.

Q: mh.

J: That is you might want to say something.

Q: Yes. I would like to have information regarding epilepsy... because I have hope that she can be cured ... I also use both traditional and western treatment... Is there nothing wrong in what I am doing .

J: NO. There is nothing wrong in using both treatments.when you believe that they are helpful. When both treatments help your child, there is nothing wrong.
Q: It is like that.
J: OK Mama. I am very thankful about the information you shared with me, as well as your time.
Q: Yes. Thank you very much.
J: Thanks.

Pseudonymn: R
Address described in the interview changed for confidentiality and protection of identity of the interviewee.
Name of interviewer: Johannah (J)
Date of interview: 13 / 11 / 97
Time: 09h00 - 09h20
Place : Khayelitsha

R is a mother of 4 children. Her youngest child P, is 14 years old, disabled and has epilepsy. She attends a local school for the disabled.

J: Hello Mama.

R:Hello Mama.

J: How are you Mama?

R:I am all right, thanks and how are you Mama ?

J: I am all right thanks. Mama, I am Sis J. I work at Zibonele. I am also a student at UCT.

R: I live here at ═══ No═══

J: Thank you Mama. I am doing an investigation about about children with epilepsy. I am happy that you afforded me the time to have a conversation with you about this issue.

R:Thanks Mama.

J: Another thing Mama is that I am going to use a tape to record our conversation which will be confidential. I am asking your permission to do so.

R:Thanks Mama.

J: I do not know whether Mama agrees to that.

R:I do agree Mama.

J:Thanks Mama. I am now going to ask the first question. What causes your childs' epilepsy ?

R:What causes my childs' epilepsy , is that my child had an illness called meningitis. I truly did not know that she had meningitis ... my child. She was a child that happened to have constant running stomach like that, that could not stop. That was the child that I took to the Doctor.

J: mh.

R:Then one time I realised that she wanted to vomit.

J: OK.

R:I took her to Redcross.

J: mh.

R:Whilst I was still waiting at Redcross, I saw my child ha—d, had a part that appeared to be shaking.

J: OK.

R: But she is not fitting and there are no foams.

J: OK.

R:I do not know, I did not know at that time that she is fitting. I only thought that she is having cramps.

J: OK.

R: But as I was still waiting to be called by the Doctor at Redcross -
J: OK.
R:I saw a Nurse arriving and quickly taking her to a room that I saw was , was, was , a room that had lights, a theatre, I do not know.
J: OK.
R:When I followed, I was not allowed to enter.
J: OK.
R:Then I said to myself, let me wait. I waited. But I was not allowed to enter. It was said that I should come back tomorrow.
J: OK.
R:When I came back the following day, I found my child in drips.
J: OK.
R:When I asked what happened [emphasising]. It was said that sh—e, this child has Meningitis.
J: OK. Thank you Mama for the explanation that you gave me regarding the cause of your childs' epilepsy. So according to your knowledge the cause of your childs' epilepsy is Meningitis.
R:I am sure it is because she was not born with fits.
J: Thank you Mama. Now what triggers your childs' epilepsy ?
R: At home, sh—e, sh—e, she stopped fittin—g that time. She stopped fitting from that time she was treated -
J: Yes.
R:At Redcross.
J: OK.
R:It was a long time that she did not fit.
J: OK.
R:She started fitting again this year.
J: OK.
R:Yes.
J: What kind of treatment did they give her at Redcross ?
R:At Redcross they gave her treatment ... th—e, th—e, th—e, physiotherapy, she did no—t, I do not know what they gave her now for her fits because she never had fits again [emphasising] ... from the time she was 11months old until she started again when she is now 14 years old.
J: You mentioned earlier that your child was taken to theatre. Now could you kindly tell me Mama what operation did they actually do?
R: ... they made an operation ... on her head -
J: OK.
R: Two operations.
J: Did they explain to you what they actually did ?
R:[sigh] ... they ... they never explained - they only said that her brain has shifted ...
J: OK.
R: It shifted.
J: OK.

R: That is what they explained to me that she has Meningitis.
J: OK.
R: Meningitis.
J: Meningitis.
R:mh.
J: Thank You Mama. So they never gave her any treatment.
R:They did not give her at that time -
J: mh.
R:All these years -
J: OK.
R:I was then surprised when her fits recurred now when she is older.
J: OK.
R:But when I went to the Doctor, they said that if she can fit again, it could be that she was given something strong at that time.
J: OK.
R:They said then that even though she is now older, that thing does normally recur ... fits.
J: Fits.
R:mh.
J: Now that she started to fit again when she is 14 years old, what did you do ?
R:When she started to fit again, I took her to the Doctor. The Doctor refused and said I must take her to the clinic.
J: OK.
R:Doctor ==== refused and said I must take her to the clinic to get pills.
J: Pills. So that she can get pills.
R:I got pills. She is taking them now.
J: Thanks. How many pills does your child take ?
R:She takes 2 pills.
J: When does she take her pills ?
R: Only in the evening when she is about to sleep.
J: OK. How often do you take your child for her for check up ?
R:I am given an appointment. Sometimes at hospital. I am normally given pills that would last 2 months or 1 month. Then I am told when to come.
J: Thank You Mama. Does the pills control your childs' epilepsy?
R:I praise them a lot Mama, because she does not fit when I have given her - unless I have been careless myself, not giving her, then she fits.
J: I hear Mama say that you become careless. What do you mean by becoming careless ?
R:By being careless is when I— I— I— forget to give her.
J: OK.
R:Sometimes.
J: Thank You Mama. How do you know when your child has taken too many pills ?

R: ... What are you saying Mama [softly].
J: When you give your child her pills, how do you know when you have given too many pills?
R:I do not give too many pills. I only give her 2 pills in the evening when she is about to sleep, according to the way it is written.
J: OK. Thank you Mama. Whom do you consult for your childs' epilepsy ?
R: ... [taking deep breath]. I take her to the clinic at Harare.
J: At Harare.
R:Yes.
J: You only take her to the clinic. No other place perhaps.
R:I do not ... I do not have any ... I have been taking her to Harare. She has been actually attending a clinic. I believe in the clinic.
J: You believe in the clinic.
R:Yes.
J: OK. Thank you Mama. Does your child have frequent epileptic attacks ?
R: ... She does not have frequent epileptic attacks. Sh—e Sh—e Sh—e only fits during the night. Her fits occur only at night when we are asleep. But I can hear her when she is about to start fitting ... sh—–e but she only fits sometimes.
J: OK.
R:But I do hear her when she starts.
J: How do you hear her when she starts ?
R: ... Sh—e sh—e breathes loudly when she starts.
J: OK.
R:She breathes loudly. Then I am aware. I can see that she is starting to have a fit.
J: OK.
R:Yes.
J: OK. Thanks Mama. Do you keep a record of your childs' epileptic attacks ?
R: ... ... Yes Mama.
J: How do you keep a record that your child had a fit on this day.
R: ... [sighing]. I do keep a record Mama because it is important to keep it. At the clinic I am being asked how often did she fit. It is important that I must give information.
J: OK. Where do you record ?
R:I keep it like when she has a fit, I do not leave her. I quickly take her to the clinic.
J: How do you keep a record?
R:I do write on a piece of paper and place it in her clinic card, stating how often she had a fit ... because it is important for me to know whether foams did appear during a fit ... I am usually asked all those things.
J: OK.
R:Then I can say, NO, there are no foams that appear when my child has a fit.
J: OK.
R:She fits in a funny manner, like, she just fits.
J: OK Mama. What do you do then when your child has a fit ?

R:When my child has a fit, when I do not have pills ... I usually take water ... not knowing ofcourse that I am doing the write thing.
J: mh.
R:Cold water. Then I take off her blankets -
J: Yes.
R:Then I wrap her with a wet cloth.
J: OK. Then what do you do after your child has had a fit ?
R:[looking puzzled]
J: After she had a fit, when she has stopped.
R: ... [doubtful]. I—I— I— check her ... and I try to wake her up. Then I can see that she is exhausted and limp. Then I remain with her and until she has stopped, because when she fits she breathes loudly sometimes ... and this makes me to be shameful ... that is why I take water.
J: OK.
R:T—o t—o t—o to let her ... because after she had a fit, sh—e sh—e sh—e takes a long time before she can breathe.
J: OK.
R:Yes.
J:Thank You Mama. Is there any difference between curing and controlling your childs' epilepsy ?
R: ... ... there is a difference.
J: Why ?
R:Because if there are no pills - it means I must ... she fits.
J: So does that it mean that it is cured or controlled.
R:In my own view, it seems as if it is controlled.
J: OK. Is it important to know your childs' epileptic condition ?
R: ... It is very important Mama.
J: Why ?
R:Because it is important to know her condition sothat you should not stay with her without knowing her condition - because when she has a fit - when you do not have her pill—s, what will happen of you after that.
J: OK.
R:You become shameful.
J: OK.
R:Yes.
J: Is it important Mama, that others should know about your childs' condition ?
R: ... I myself I do not see i—t, I do not see the reason for not telling others about your childs' condition, because you may get help from others.
J: OK. So, in your view, it is important that others should know about your childs' condition.
R:Yes Mama.
J: OK.
R: // because even when your child is sick, you can share with another person. You see ... I had this child - I learnt things about sharing with others.
J: OK.

R:My disabled child.
J: OK.
R:Yes.
J: Mama, thank You very much for your input. I am now going to give You the chance to say something regarding what we have been talking about.
R:To all, al—l, thank you Mama. To all people who have epileptic children, please people, let us not hide our childrens' condition. Let us seek help...let us come up with our children because when we hide them -
J: mh.
R:I take epilepsy like somebody having an attack, and thereafter, when the attack is over, she wakes up.
J: mh.
R:A person may also fit and not wake up.
J: OK.
R:The child may fit whilst walking alone -
J: OK.
R: In the street -
J: mh.
R:And may not wake up, because you may not have cared about her, you as a parent.
J: OK.
R:Come with your child and get advice - do not take epilepsy very simple.
J: OK.
R:Pills are very helpful to me.
J: OK.
R: // I will very much be thankful if all people can take my advice.
J: OK.
R:Because I did not know that I have an epileptic child, but now I do have such a child -
J: mh.
R:I am not shameful.
J: mh.
R:Because I now know when pills are finished, how many days I can stay without them. I know then that on a particular day she will have a fit.
J: OK.
R:Thanks.
J: Mama I am very much thankful for your input. I am also thankful for your time despite your commitments. I am thankful that we could be able to discuss about this issue. Your input will be helpful towards my study.
R:[smiling]. I am also thankful Mama.
J: Thank you very much.

Pseudonym for interviewee: M
Address described in the interview will be changed for confidentiality and protection of identity of the interviewee.
Name of interviewer: Johannah (J)
Date of interview: 14 / 11 / 97
Time: 10h00 - 10h15
Place: Khayelitsha

M is a mother of a 20 year old child with epilepsy.The child never attended school due to his condition. He is not working and now drinks alcohol excessively.

J: Hello Mama.
M:Hello.
J: How are you Mama ?
M:I am all right, and how are you ?
J: I am all right. Mama I am Sis J. I work at Zibonele. I am doing an investigation about children with epilepsy.
M:I do have a child who is also having fits - [hesitant to speak].
J: OK.
M:This is the fourth year that he is having fits.
J: OK.
M:He cannot be cured totally _ _ [tu, emphasising].
J: He cannot be cured.
M:NO. [shaking her head]
J: Mama, I am very much thankful that you agreed to talk to me about your epileptic child.
M: ... NO. There is no problem.
J: OK. Another thing that I will ask Mama, is to use a recorder sothat I can be able to have all the information that we shall be talking about. The information will be confidential.
M:OK. [softly]
J: OK, Mama. I am thankful that you have allowed me. I will therefore start by asking the first question. What causes your childs' epilepsy ?
M:I do not know, he only started now when he is older, he did not have it before.
J: OK.
M:It started now, this thing, i—n -
J: OK. It started when.
M:It started ... it is the fourth year now...
J: Yes.
M:That he is having fits.
J: Yes. When Mama says he started when he was older, how old was he ?
M:H—e, it is the fourth year now that he is an adolescent.
J: What was his age then.

M:// He is now 20 years old.
J: 20 years old.
M:Yes. 20 years.
J: OK thanks Mama. So you do not know what causes your childs' epilepsy.
M:Exactly. [tu]. I have long been trying t—o trying, even now I am still trying, but in vain.
J: OK.
M:He does not stop to fit _ _ [emphasising].
J: He does not stop. What kind of treatment does he take ?
M:What I do now is just to continue fetching pills.
J: Yes.
M:At the clinic there at that place, at Site B.
J: Yes.
M:That is where we fetch pills.
J: OK.
M:Now regarding traditional medicines, I have now stopped using them.
J: You have stopped to use traditional medicines now.
M:Yes. I only use western medicines now.
J: You use western medicines now. Thank you Mama. So you do not know what causes your childs' epilepsy.
M:- [hesitant]. exactly.
J: You do not know.
M:Exactly.
J: OK Mama. What triggers your childs' epilepsy ?
M: ... I am not sure.
J: You are not sure.
M:Because if you do not know you become unsure.
J: Yes. So is there nothing at home that sometimes may trigger him to fit ?
M:That thing happens when I come from Transkei - it is as if I am bewitched and when he sees me, he fits.
J: When you come from Transkei.
M:Yes.
J: So what does this mean Mama ?
M:What traditional healers say, they say " the thing is at home ".
J: The thing is at home.So bewitchment triggers his epilepsy.
M:Yes.
J: I do understand Mama. I heard you say earlier on that he is now taking pills.
M:Yes.
J: How many pills does your child take ?
M:Those pills ... he takes them continuously ... he fetches them.
J: OK.
M:Now recently last month, they gave him an injection.
J: OK.

M:It was clear that at that time he had frequent fits -
J: OK.
M:They said his blood i-------s, his heart was beating fast.
J: Yes.
M:Yes.
J: OK. When does your child take his pills?
M:[puzzled] ... ...
J: May be during the day.
M:He takes them late.
J: Late.
M:He does not take them during the day.
J: OK.
M:He does not take them during the day. You see it was said that he must stop them, but he does not.
J: Yes.
M:It was said that when he takes pills he should not drink alcohol.
J: OK.
M:He does not stop to drink alcohol.
J: He does not stop drinking alcohol.
M:NO... _ _ [emphasising].
J: He drinks alcohol.
M:He drinks too much.
J: But he takes one pill.
M: // NO. At night. He takes a pill at night.
J: OK. How often do you take him for check up ?
M: ... to take him therefor----e.
J: Yes.
M:He has records there.
J: He has records there.
M:records there -
J: OK.
M:I do take him with his records. They give him a date of when to come back.
J: OK.
M:Yes.
J: OK Mama. How do you know when your child has taken too many pills ?
M:He is being told that he must take one pill only.
J: OK.
M:Yes.
J: So you he does not take too many pills.
M:NO. He does not.
J: OK. Does the pills control your childs' fits ?
M:NO. I do not see that they do control his fits because he does not stop. He stops only for a short period.
J: OK.
M:Then that thing comes again.

J: OK. Whom do you consult for your childs' epilepsy ?
M:I now take him here, at hospital.
J: At hospital.
M:Yes.
J: You said before that you did consult with traditional healers.
M:I did take him there ...
J: Yes.
M:I did not see any improvement.
J: OK.
M:What I have seen is that my pocket was becoming empty.
J: Your pocket.
M:Yes.
J: What do you mean by a pocket ?
M:I mean money.
J: Money.
M:Money.
J: OK.
M:Because traditional healers ask a lot of money even though they are unable to help.
J: OK.
M:Yes.
J: Thank you Mama. Does your child have frequent epileptic attacks ?
M:He fits frequently. Last month they gave him an injection.
J: OK.
M:Then, the—n, he fits and fits, that is all.
J: mh.
M:When he has started on Monday,Tuesday, Wednesday -
J: mh.
M:He will become better on Thursday.
J: OK.
M:At night and during the day.
J: At night and during the day.
M:Yes.
J: OK. Do you keep a record of your childs' epileptic attacks ?
M:NO. That is one thing that I have never thought of.
J: How do you keep a record of his frequent attacks ?
M:I keep it in my heart, my sister. I do not want to lie.
J: You keep it in your heart.
M:Yes.
J: OK Mama. What do you do when your child has a fit ?
[end of tape].
J: OK Mama. Let me repeat the question. What do you do when your child has a fit ?

M:I do nothing, my sister.
J: OK.
M:I just wait for him... when he recovers I give him a pill.
J: Yes.
M:There is nothing else that I do.
J: You do absolutely nothing.
M:Yes.
J: OK. What do you do after he has had a fit ?
M:I give him those pills.
J: Yes.
M:Then I leave him to recover his senses.
J:You say you leave him to recover his senses. Please explain.
M:I mean he must stop to fit at that time -
J: Stop to fit.
M:Then he sle—, he sleeps, whilst he is sleeping, it comes again that thing.
J: OK. Thanks.
M:When he is about to fit, he will start by saying that his whole body is not well.
J: He says his body is not well.
M:Yes.
J: OK.
M:He says it is as if he is not having enough blood.
J:OK.
M:Then I know that that thing might start again.
J: OK.
M:Yes. Before he fits he usually senses it -
J:That his body is not well.
M:That his body is not well.
J: Yes.
M:Then I know that there is something that will happen.
J: OK Mama. Thank you. Is there any difference between curing and controlling your childs' epilepsy ?
M:There is none.
J: There is no difference.
M:NO. There is no difference. There is nothing that I choose.
J: Yes.
M:Even there with pills even with medicines, there is no treatment that I choose.
J: OK.
M:NO.
J: So, in your view, epilepsy can be cured or controlled ?
M:It cannot be cured ... what is being done is ju—st to contr—, to, to do this, so that he— ... may appear to be a little better.
J: OK.
M:Because he had suffered burns.
J: OK. He had burns.
M:He had burns. We were from Transkei.

J: Yes.
M:We went home.
J: OK.
M:Then we went to buy what was needed ... he had burns.
J: He had burns.
M:Yes.
J: What was the cause of his burns ?
M:He had fits in the absence of elderly people.
J:OK.
M:He had burns.
J: OK.
M:People arrived whilst he was still having burns.
J:Thank you very much Mama. Is it important to know your childs' epileptic condition ?
M:It is important to know -
J: Yes.
M:It is ofcourse up to you.
J: Yes.
M:Because you would not know how to deal with it ... it might be all right to hear from someone.
J: OK. Is it important that others should know about your childs' condition ?
M: ... NO my sister.
J: Yes.
M:You can get advice from a traditional healer.
J: Yes.
M:Because you may not keep a thing to yourself.
J: Yes.
M: To be asking from others what will help ?
J: OK.
M:It does not help that thing.
J: So according to you, is it important that others should know about your childs' condition ?
M:It is not important.
J: It is not important.
M:Yes. Ofcourse when you have forgotten ...
J: Yes.
M:You have to do like this ...
J: Yes.
M:That you may get medicine from anybody.
J: OK.
M:Somebody who has knowledge.
J: OK.
M:Because when he fits, I do not have hope that he will wake up. I can only see that God made him to wake up.
J: So, according to you it is not important.

M: ... ... [facing downwards]
J: Why ?
M:What is not important is this. With this condition, I can hardly eat, I just become dull.
J: OK. All right. Mama thank you very much for your input on this issue. We have now come to the end of our conversation. I will now give you the chance to say something regarding this issue.
M:To say something.
J:Yes.
M:Because I take away a lot of money consulting with traditional healers.
J: Yes.
M:That is what I want to say.
J: OK.
M:Because I am not working.
J: OK.
M:He is also not working.
J: I only do my small business. Sothat when I am told there is somebody who can help, I can go there.
J: OK.
M:And he become unable to help me.
J: mh.
M:Then he has taken all my money.
J: mh.
M:I took him to five people, that is traditional healers.
J: Traditional healers. So they did not help you.
M:NO.
J: So what does that mean.
M:It means they could no—t cure him.
J: OK. Now regarding this issue, can you briefly say something.
M:My input is that I have given him medicines that could not help him. I have wasted a lot of money without any help. Sometimes we have been without food ... and the money we have given to traditional healers. We cannot stay without food at home.
J: Mama. Thank you very much for what you have said.
M:Thanks.
J: I am very much thankful for your time as well as for the information you have given me. It is going to be very helpful for my study.
M:Thanks.
J:Thank you very much Mama.
M:Thanks.
J: Thank you.

Pseudonym for interviewee: B
Address described in the interview will be changed for confidentiality and for protection of identity of the interviewee.
Name of interviewer: Johannah (J)
Date of interview: 14 / 11 / 97
Time: 13h00 - 13h10
Place: Khayelitsha

B is a mother of 5 children. N is her 21 year old child with epilepsy. She never attended school due to her condition.

J: Hello Mama.
B: Hello.
J: How are you Mama ?
B: I am all right. We are still protected. How are you ?
J: I am all right thanks.
B: Yes.
J: Mama, I am Sis J.
B: OK. I am Mama B═══ N═══
J: Thank you Mama B. I work at Zibonele. I am also a student at UCT.
B: Yes.
J: I am doing an investigation about children with epilepsy.
B: OK.
J: So I will ask Mama if it is all right to use a tape during our conversation. The recorded information will be confidential.
B: OK. It is all right then.
J: I am also thankful that you could afford me your time, that I should be able to talk to you.
B: Yes. It is all right.
J: I will now start by asking the first question. My first question is, what causes your childs' epilepsy ?
B: What causes her epilepsy ... ... she just started to fit ... without anything - that, that, that caused her fits. She just started to fit like that.
J: She just started to fit like that. You do not know what caused her epilepsy.
B: NO. I do not know what causes her epilepsy.
J: What trigger your childs' epilepsy ?
B: Hey, I do not know what causes her epilepsy ... because _ _ [emphasising], there is no—thing ... may be that was not ... may be she was not taken to the Doctor -
J:Yes.
B: When she was still young.
J: Yes.
B: So, I do not know what causes her epilepsy.
J: I heard Mama say earlier that she was taken to the Doctor. Was she taken to a traditional or a medical Doctor ?

B: When she was still small, ofcourse, she was taken to the clinic -
J: OK.
B: Yes.
J: OK. What did they give her at the clinic ?
B: Er. Let me say like this, she wa---s, she was not taken because she was doing like tha---t that is ... she was not taken because of her epilepsy... she was taken because she was still a baby - taken to the clinic.
J: OK.
B: Yes.
J: Then when did she start to have fits ?
B: When she started to fit , like she was born in '76.
J: Yes.
B: She star—, started in '79.
J: OK. She started in '79.
B: Yes.
J: What factors trigger your childs' epilepsy?
B: NO. I do not know ... [looking at me as if she wanted to say something].
J: OK. OK. Mama. Is there something that you wanted to say ?
B: NO. There is nothing ... that I want to say ... [thinking, doubtful].
J: Yes.
B: NO. I do not know what I wanted to say. Presently we do not know what to do about her.
J: OK.
B: Yes.
J: OK. Thank you Mama. What kind of treatment does your child take ?
B: She was always taken to traditional healers like that ... now that she is having fits.
J: Yes.
B: Yes -
J: Yes.
B: She was never helped.
J: She was never helped.
B:NO.
J: Whom did you consult after realising that traditional medicines did not help her ?
B: She was taken no where ... she was taken like ... now when she is older.
J: Yes.
B: She was taken to- to- to- to- to the clinic -
J: OK.
B: A— t, here at ... at Site B.
J: OK.
B: Then she was given pills.
J: Yes.
B: Now when she was supposed t——o, they said she must come back.
J: OK.

B: When she was supposed to go, she was taken.
J: mh.
B:Then it was said that she did not get them.
J: mh.
B: They said she was supp—-, she was supp, it was said ... Er ... mh ...
J: OK.
B: I—t i—-t i—t, it is not, there is nothing written on the card that she must come and fetch pills _ _ [emphasising and nodding her head].
J: mh.
B: Yes -
J: OK.
B: She did not get them then.
J: She did not get pills.
B: Yes.
J: OK Mama. How many pills did she take before she stopped ?
B: She ... she ... it was sai—-d that she has epilepsy.
J: Yes.
B: She was then given those pills.
J: Yes.
B: It was said that she must return again ... that is when she did not get them.
J: OK. Now how many pills did your child take?
B: She was taking one pill.
J: One pill. When did she take the pill ?
B: I am not sure ... it was once a day.
J: How do you know when your child has taken too many pills ?
B:What are you saying ? [surprised]
J: When your child has taken too many pills.
B:How do I know.
J: Yes. How do you know.
B: ... ... [no response]
J: How do you know when you have given too many pills.
B: I ... [emphasising]. I give her according to the way it is explained to me.
J: OK. How often do you take her for check up ?
B: Ever since she was turned back I never took her back.
J: OK. Thanks Mama. Does the pills control your childs' epilepsy ?
B: I will not say they help...she had a fit after sh—-e she had them.
J: Yes.
B: But no——w NO. She does not fit now.
J: She does not fit now.
B: // Yes, she has stopped now.
J: OK.
B: Yes.
J: So, when she has stopped, do you continue to give her pills ?
B: ... Yes I wanted t—-o, if they are available, because she ... sometimes I can see that she ... sh——e is exhausted as if she ca- , it can recur again that thing.

J: OK.
B: Yes.
J: OK. My question was whether you are still continuing to give her pills. Or does it mean that you stop treatment when her fits have stopped.
B: ... NO ... she was taking them now ...
J: OK.
B: Yes.
J: OK.
B: Now that they were not finished.
J: OK.
B: Yes.
J: When they are finished what do you do ?
B: NO, even now that I am sitting here, they are finished.
J: OK. Does it mean you did not take her to the clinic ?
B: NO. I do not take her to the clinic.
J: When would you fetch them ?
B: NO. She is not taking them now ever since she was turned away that time when she was supposed to get them ... she did not get them.
J: OK.
B: Now she is no more going.
J: Thank you Mama. Does your child has frequent epileptic attacks ?
B: NO ... she does not fit frequently.
J: OK.
B: Yes.
J: Do you keep a record of your childs' epileptic attacks ?
B: What are you saying ?
J: Do you keep a record ?
B: // keep a record of how often she had fits ?
J: Yes.
B: Er ... NO. I ... I ... do like this, I .... can se—e, because she fits in my presence.
J: OK.
B: Yes... How often she has a fit -
J: OK.
B: Because sometimes sh—e fits during the night.
J: Yes.
B: She fits ... but now she had frequent fits.
J: Yes.
B: She had fits almost thrice.
J: OK.
B: Yes.
J: Now how do you keep a record of how many attacks she had ?
B: NO. I do keep a record of how often she had fits.
J: OK. How do you keep a record of her fits ?

B: NO. I keep it in my mind.
J: In your mind.
B: Yes.
J: Thank you Mama. What do you do when your child has a fit ?
B: ... I do not do anything. I leave her to fit until her fits are over.
J: OK.
B: Yes.
J: Now, what do you do after she has had a fit ?
B: I do not do anything. She just become all right on her own. Then she wakes up and care for herself.
J: OK.
B: Yes.
J: Is there any difference between curing and controlling your childs' epilepsy ?
B: What are you saying now ?
J: Is there any difference.
B: It cannot be cured.
J: Yes.
B: There could be a difference if it could be cured.
J: Yes.
B: If it can be cured.
J: Yes.
B: There should be a difference.
J: Yes.
B: She must be seen to be healed.
J: OK.
B: When it is indeed cured.
J: OK.
B: Yes.
J: When we say control what do we mean ?
B: To control is that it is lying silently ...
J: Yes.
B: Yes ... We know it can recur again sometime.
J: OK.
B: Yes.
J: So in your view, is epilepsy controlled or cured ?
B: Hey, I do not know anything about epilepsy, but in my view it seems as if i—t , cannot be cured.
J: OK.
B: It is controlled.
J: OK.
B: Because I do have one of my relatives who is also epileptic.
J: OK.
B: It cannot stop, the only thing is that ... it seems as if he is not all right mentally.

J: OK.

B: Yes.

J: Thank you Mama. Is it important to know your childs' epileptic condition ?

B: Yes. It is important.

J: Why ?

B: Because I want to know about it.

J: OK.

B: Yes.

J: Is it important that others should know about your childs' condition ?

B: ... NO. Even though it is not known by others, if it is only known by the family.

J: OK.

B: Yes.

J: So, according to you it is important that it must be known by the family.

B: Yes.

J: Why ?

B: Because they must know about the childs' condition here at home when she is not all right.

J: Thank you Mama. I have now come to the end of our conversation.

B: Yes.

J: I am very much thankful for your input regarding this issue.

B: Yes it is OK.

J: So I will now give you the chance to say something regarding what we have discussed.

B: NO. There is nothing that I want to say. I am only happy that you were able to come here at my home.

J: Yes.

B: Yes. For you to come and get more information regarding my epileptic child.

J: Yes.

B: Yes, I am very happy.

J: Thank you very much Mama. I still repeat to say thank you very much for your time.

B: Yes. Thanks.

J: Thanks.

Pseudonym for interviewee: E
Address described in the interview will be changed for confidentiality and protection of identity of interviewee.
Name of interviewer: Johannah (J)
Date of interview: 14 / 11 / 97
Time: 15h00 - 15h30
Place: Khayelitsha

E is a mother of 4. She is also suffering from epilepsy. Amongst her four children, the eldest died from epilepsy. N who is 14 years old attended school until Standard 2. He could not continue with school due to his condition. N who is 6 years old had epilepsy once and was treated at Redcross. She is now on no treatment. P is the youngest and is 5 years old. He has not had any fits.

J: Hello Mama.
E: Hello.
J: How are you Mama ?
E: I am all right, and how are you ?
J: I am also all right, thanks.
E: mh.
J: Mama, I am Sis J.
E: Yes.
J: And what is Mama's name ?
E: I am E ═══
J: Mama's name is E.
E: Yes.
J: OK Mama. I am working at Zibonele.
E: OK.
J: Yes. I am also a student at UCT.
E: OK.
J: I am doing an investigation about children with epilepsy.
E: OK.
J: Mama I am also going to use a tape.
E: OK.
J: So, I will ask Mama to allow me to record our conversation.
E: OK.
J: The information will be confidential.
E: OK.
J: I am thankful that Mama has agreed.
E: Yes.
J: Mama I will now start to ask questions.
E: Yes, you may start.
J: My first question is , what causes your childs' epilepsy ?
E: They were just born like that, the two of them.

J: OK. Can you explain further.
E: Yes. They were born like that.
J: OK.
E: It was said that they got it from me.
J: It was said that they got it from you.
E: Yes.
J: So what does that mean, Mama ?
E: They got it from me.Traditional healers said so.
J: OK. It was said that they both got it from you.
E: Yes. Because I also have epilepsy.
J: Traditional healers said that they got it from you.
E: Yes.
J: OK. What triggers their epilepsy ?
E: ... triggers ... how ?
J: What makes them to fit, perhaps here at home.
E: ... I do not know. I only see him fitting.
J: You do not know. You only see him having fits.
E: Yes. I only see him having fits.
J: OK. Whom do you consult for your childs' epilepsy ?
E: Here. [pointing]. At that clinic.
J: At that clinic.
E: mh. // There at that clinic.
J: So, what kind of treatment does your child take ?
E: [Bring them, asking the child] ... He will show you Ma.
J: Is he taking pills ?
E: Yes. Let him bring them sothat you can see.
J: [Looking at them]. How many pills does he take ?
E: Regularly at the end of each month.
J: OK. He takes them regularly at the end of the month.
E: Yes.
J: When does he take his pills ?
E: He takes them daily, at night, 3 pills.
J: He takes //
E: At night 3 pills.
J: OK.
E: He does not take them during the day. He takes them at night.
J: He takes them at night.
E: mh.
J: OK Mama. How do you know when your child has taken too many pills ?
E: ... How ?
J: When he has taken too many pills.
E: ... He does that thing. I know him. He does not take them the right way. He doe—s no——t ta—k——
J: So he does sometimes take too many pills.
E: Yes.

J: OK. All right Mama. How often do you take him for check up ?
E: I take him every month.
J: You take him every month.
E: Yes, I take him every month.
J: OK.
E: Here [pointing]. We have a clinic here.
J: OK.
E: mh.
J: Does the pills control your childs' epilepsy ?
E: They do not control it.
J: How Mama ?
E: He fits, he drinks alcohol.
J: So they do not control it.
E: Yes.
J: Does your child have frequent epileptic attacks ?
E: Yes. Every month he does have a fit.
J: How often ?
E: Quite a lot ... he fits quite a lot now.
J: He fits a lot now.
E: Yes.
J: OK Mama. What kind of treatment does your child take ?
E: I have been using both treatments. I took him to spiritual healers only, then I ...
J: mh.
E: Then I also took him to the Doctor ... the spiritual healers gave him spiritual water.
J: They gave him spiritual water. Did that help ?
E: NO. He was never cured.
J: Thank you Mama. Do you keep a record of your childs' epileptic attacks ?
E: NO.
J: You said earlier that he fits frequently. How do you know ?
E: I am always there. He fits in my presence.
J: He fits in your presence.
E: Yes.
J: Now where do you record that he had frequent fits ?
E: He fits frequently.
J: You do not write somewhere.
E: NO.
J: You do not keep a record.
E: I can only notice.
J: What do you do when your child has a fit ?
E: I hold him.
J: You hold him and what do you do.
E: I take his shoes off.
J: And what do you do next.

E: Then I let him lie down ... look how he is [showing marks on the face due to injuries].
J: OK.
E: When he fits, he usually gets injured.
J: OK.
E: He fits for 2 days , then we take him to the Doctor.
J: What do you do after your child has had a fit ?
E: I take him to the doctor.
J: You take him to the Doctor.
E: mh.
J: OK.
E: Because he fits frequently.
J: OK. Is there any difference between curing and controlling your childs' epilepsy ?
E: For curing ?
J: Yes.
E: How ?
J: In your view is there a difference between curing and controlling epilepsy ?
E NO. It cannot be cured ... ever since ... it cannot be cured.
J: It cannot be cured.
E: Yes.
J: Is it important to know your childs' epileptic condition ?
E: ... What ?
J: Is it important to know your childs' epileptic condition ?
E: Yes.
J: Why ?
E: Because I will be remaining with him.
J: OK. Is it important that others should know about your childs' condition ?
E:NO.
J: Why ?
E: ... it is a laughter here in our area.
J: OK.
E: mh. People talk badly.
J: So you do not think it is important that others should know about your childs' condition.
E: Yes.
J: OK Mama. I have know come to the end of our conversation.
E: Yes.
J: I am now going to give you the chance to say something regarding what we have been talking about.
E: What should I do ?
J: Perhaps there is something that you will like to say from what we have been talking about.
E: NO.
J: There is nothing that you will like to say.

E: Yes.
J: Mama, thank you very much for affording me your time to talk to you about this issue.
E: mh.
J: I am very much thankful for your input. This is going to help me very much towards my study.
E: Yes.
J: Thank you very much indeed for your valuable information.
E: Yes.
J: I still repeat to say thank you very much Mama.
E: Thanks.
J: Thanks.

Pseudonym for interviewee: O
Address described in the interview will be changed for confidentiality and protection of identity of interviewee.
Name of interviewer: Johannah (J)
Date of interview: 15 / 11 / 97
Time: 09h30 - 09h45
Place: Khayelitsha.

O is a mother of 2 children. Z is 16 years old and has epilepsy. She is in standard 7. She suffered extensive burns from a paraffin stove and was alone in her home whilst she had fits. She is now in hospital.

J: Hello Mama.
O: Hello Mama.
J: How are you Mama ?
O: I am all right thanks, and how are you ?
J: I am all right thanks. Mama I am Sis J.
O:mh.
J: I work at Zibonele.
O:mh.
J: I am also a student at UCT.
O:OK.
J: I am doing an investigation about children with epilepsy.
O:mh.
J: I will now ask Mama to introduce herself.
O: I am O═══ and I live at ═══
J: OK.
O:mh.
J: OK. Thank you very much Mama. Many thanks for the time that you have given me.
O:OK.
J: To talk to you about your child who is having epilepsy.
O:OK.
J: I am going to use a tape.
O:Yes.
J: I am now asking Mama to allow me to record our conversation. The information will be confidential.
O:OK.
J: I do not know whether I am allowed.
O:You are allowed.
J: Thanks Mama. My first question is what causes your childs' epilepsy ?
O: ... Hey, I do not know ... because ... I did not see what she has eaten ... I only saw her having fits.
J: Mama does not know what causes her epilepsy.

O:mh NO ... mh NO. I do not know.

J: You do not know.

O:Yes.

J: What triggers your childs' epilepsy ?

O:That triggers ? [puzzled]

J: Yes.

O:How then ?

J: Factors triggering her epilepsy perhaps at home when you are with her.

O:mh ...

J: Maybe something that will make her fit afterwards.

O:NO. I do not know.

J: Mama does not know.

O:Yes.

J: So in your view, you do not know what causes your childs' epilepsy.

O:Yes. I do not know.

J: When did your child start to have fits ?

O:My child started in 1990.

J: 1990.

O:mh.

J: How did she start ?

O:She was not with me. She was with her father in H ═══

J: OK.

O:So I do not know how she started.

J: OK.

O:mh.

J: You were never told about what caused her epilepsy.

O:Yes.

J: OK Mama. What kind of treatment does your epileptic child take ?

O:She takes pills.

J: How many pills does she take ?

O:Tergretol 200mg a day.

J: OK. When does she take her pills ?

0 :She takes one per day.

J: Where does she get them from ?

O:A——a——a——at at this place, at Site B.

J: At site B.

O:At Nolungile.

J: Yes.

J:How do you know when your child has taken too many pills ?

O:NO. I do not give too many pills. I have never given her too many pills.

J: Thanks. How often do you take your child for check up ?

O:How often do I take her ?

J: Yes.

O:O—n ... on her appointment dates.

J: On her appointment dates.

O:Yes.
J: Are you given an appointment ?
O:... [no response, looking down]Y—es... at the end of the month.
J: Does your child has frequent epileptic attacks ?
O: ... I do not know how to answer... [looking down].
J: OK Mama.
O:mh.
J: Do you keep a record of your childs' epileptic attacks ?
O:Do I keep a record ?
J: Yes. Do you keep a record.
O:I do not keep it [laughing].
J:How do you know when your child had fits ?
O:I memorise it.
J: You memorise it.
O:mh.
J: OK.
O:Then I inform the Doctor when he asks me.
J: OK.
O:mh.
J: Does the pills control your childs' epilepsy ?
O:Yes ... they do contro—l, ... the thing is that she forgets them.
J: She forgets them.
O:mh.
J: OK. But according to you they do control it.
O:Yes. They do control it.
J: Whom do you consult for your childs' epilepsy ?
O:My child takes pills.
J: So you do not consult with traditional healers.
O:NO. I do not consult with traditional healers.
J: OK. What do you do when your child has a fit ?
O:I massage her.
J: Yes.
O:Then I wipe her, then I take a wet cloth and clean her mouth.
J: OK.
O:mh. I massage her and take off any stiff clothes and loosen them, and take off her shoes.
J:OK.
O:I loosen all stiff clothes.
J: OK.
O:mh.
J: What do you do after she has had a fit ?
O:After she has stopped ?
J: Yes.
O:I do not know what to do...
J: OK. Is there any difference between curing and controlling your childs' epilepsy ?

O:There is no difference with pills.
J: There is no difference with pills.
O:mh.
J: In your view, do pills control or cure your childs' epilepsy ?
O:Pills do control. That is my view.
J: So, in your view epilepsy can be cured ?
O:It can be cured.
J: Pills do control fits.
O:Pills in my view do control fits.
J: OK. Thanks Mama. Is it important to know your childs' condition ?
O:Yes it is important.
J: Why ?
O:So that she sho—-uld n—ot sta—y nea—r things li—ke—- fire.
J: Yes. Could you please explain more.
O:She must not stay near the primus stove, things like that ... stoves things with open flame.
J: mh.
o:mh. Because when she handles such things she can be burnt. Like falling in front of the heater, she may suffer burns like what happened now.
J: OK.
O:So it is important that I should know her condition.
J: OK. Is it important that others should know about her condition ?
O:So that other people can also help, and when they hear her crying they can assist her when I am personally not there.
J: Mama, I have now come to the end of our conversation. Thank you very much for the time you afforded me, especially on a Saturday when I know you do have engagements.
O:OK.
J: I will now give you the chance to say something regarding our conversation.
O:[laughing]. I am also thankful that you could come and find more information from me about my child.
J: OK.
O:What I want to ask you now is what can I do to find a Social Worker.
J: OK.
O:What can I do.
J: There is a Social Worker that comes to the clinic, you can see her.
O:OK.
J: I still repeat to say thank you very much Mama.
O:I also want to thank you very much.
J: Thanks.
O:Thanks.

Pseudonym for interviewee: A
Address described in the interview will be changed for confidentiality and protection of identity of interviewee.
Name of interviewer: Johannah (J)
Date of interview: 15 / 11 / 97
Time: 11h30-11h50
Place: Khayelitsha

A is a mother of 7 children. N, is her daughter who is having epilepsy and has never attended school.

J: Hello Mama.
A: Hello.
J: How are you Mama ?
A: I am all right. My children are not well at home.
J: OK.
A: My children are 2.
J: OK.
A: The first one was born in 1964.
J: Yes.
A: She had fits when she was 7 years old.
J: When she was 7 years old.
A: She started to fit on this side [showing the arm]
J: Yes.
A: What is happening ? ... I do not know what to do.
J: Yes.
A: NO. ... Leave her ... , hold it, ... Yes. She is having fits.
J: OK.
A: It was when she now really started to fit.
J: OK.
A: Now the second one.
J: Yes.
A: She just wanders about. She does not want to do anything.
J: OK.
A: Go to school - she will hide somewhere.
J: OK.
A: Go to school - she will go and fetch water, leave that water and disappear.
J: OK.
A: She is a wanderer.
J: OK. Thanks Mama.
A: Yes Mama.
J: Mama I am Sis J.
A: Yes Mama.
J: I work at Zibonele.

A: OK.
J: I am also a student at UCT.
A: OK.
J: I am doing an investigation about children with epilepsy.
A: Children with epilepsy.
J: Yes.
A: Yes Mama.
J: I will now ask Mama to introduce yourself.
A: I am A ═══
J: OK.
A: I live here at ═══
J: Thanks Mama.
A: Yes.
J: Mama I will request you to allow me to use a tape recorder.
A:I can, I can be happy.
J: OK. Our conversation will be confidential.
A: OK.
J: I will appreciate your input. I am sure that the information I am going to receive from you is going to assist me towards my study.
A: OK.
J: Mama I will now start to ask questions. My questions will be directed to your child who is having epilepsy.
A: OK.
J: OK. What causes your childs' epilepsy ?
A: [mq] Like I told you before that she started to fit on one side.
J: Yes.
A: She then began by having a cry ... she start crying lie this. Yooh.
J: Yes.
A: Then she will indeed start to fit.
J: OK.
A: Hey - she will fit almost nine times before sunrise.
J: Yes.
A: ... then she will again fit during the day when she is sleeping, ofcourse she likes to sleep.
J: OK.
A: She cannot be reprimanded __ there is absolutely nothing that you can say to them.
J: mh.
A: Because they are the people they are __
J: mh.
A: They are only concerned about their condition ... in which they are.
J: OK.
A: We cannot tell them to do anything __ They are always sleeping in their beds.
J: OK.

A: Even now, at anytime, you will find them sleeping in their beds.
J: Always sleeping in their beds.
A: You will first find this one, this one who is having epilepsy.
J: OK.
A: The one who wanders about ... you can find her sometimes. Sometimes you may not find her. Like she is now not at home this morning.
J: OK.
A: We said to her bath your child, sothat she can be changed and be clean.
J: OK.
A: I wash her blankets _ _ I wash her clothes.
J: mh.
A: I am also sick from Arthritis.
J: OK.
A: Now I am unable to decide to leave work ... because I have to care for them.
J: OK.
A: She will go out as if she is going to the toilet.
J: OK.
A: I am talking about what happened this morning ... it is the usual thing.
J: OK. Thank you very much Mama. Now , in your view, what do you think is the cause of your childs' epilepsy.
A: ... ... Traditionally in Xhosa it is Amafufunyane.
J: Amafufunyane.
A: Even when it said like that, it is not cured, because I do go to such places.
J: OK.
A: The one who is wandering, it is said " u ya thwasa ". I took her to the place where people go to "thwasa ", trying to get help.
J: Yes.
A: Then it was also not helpful.
J: OK.
A: Then I had to go back to hospital.
J: Back to hospital.
A: ... Now at hospital there is a bit of help.
J: OK. Thanks Mama. Now according to you, what is the cause of your childs epilepsy ?
A: ... [mq] [tu]. In al these things ... ... I only see her having fits.
J: You only see her having fits.
A: Because I am not a Traditional healer.
J: OK. All right.
A: So, that is what I cannot understand.
J: So you do not know the cause of her epilepsy.
A: I do not know the cause of her epilepsy ... because I myself _ _ I never had fits.
J: OK.
A: Yes.

J: OK.
A: But when I traced about her epilepsy ...her father, her legitimate father had epilepsy.
J: Her father had epilepsy.
A: Her Grand father, her fathers' father, is also having epilepsy __
J: OK.
A: The whole family of this particular home, has epilepsy. I only talk like this because this is my own view.
J: So what does this mean in your own view.
A: In my view when I trace it, it is " umnombo ", it comes from her family.
J: OK.
A: It does not come from my family.
J: OK. Is "umnombo" similar to "lufuzo" ?
A: ... [listening]
J: I wanted to find out whether " umnombo " is similar to " lufuzo ".
A: Umnombo is [heredity] ukufuza.
J: Heredity [ukufuza].
A: She inherited it from her family __
J: OK.
A: Because this problem is within her family __ such a problem does not exist in my family.
J: OK. Thanks Mama. I can now understand.
A: You do understand now.
J: Yes. Thanks very much. What triggers your childs' epilepsy ?
A: That triggers ?
J: Yes. That triggers, perhaps at home.
A: Let me say, when she is upset, you see.
J: Yes.
A: Sh—e sh—e sh—e she then fits. Then we leave everything and humble ourselves.
J: OK.
A: Sothat she can do as she wants throughout her whole life __ , You see.
J: OK.
A: We then stopped to say do this , do this , do this, do this ... she now does as she likes.
J: What do you mean by do this, do this.
A: When I ask her to do something.
J: OK.
A: You see, to clean, it should be clean, let it be clean here at home, let it be -
J: OK.
A: Then she becomes annoyed. You see. She does not want to work.
J: OK.
A: So we leave her. We pretend as if there is nothing.
J: OK Mama. You said earlier that you consulted with traditional healers as well as western.

A: Yes.
J: What kind of other treatment does your epileptic child take ?
A:// Both treatments. Even at N ==[spiritual healer] she is already from there. She also got pills from hospital.
J: How many pills does your child take ?
A: ... [unsure].
J: When does she take her pills ?
A:She takes them daily in the morning.
J: How do you know when your child has taken too many pills ?
A: When she takes too many pills, she can become confused,... she can become confused.
J: mh.
A: She was once admitted at Groote Schuur.
J: OK.
A: She got into a coma.
J: When she has taken too many pills.
A: We wash our hands ... and can see that she is no more there.
J: So you think she might have taken too many pills.
A: NO, NO, she takes her pills quite well.
J: How often do you take her for check up ?
A: Wooh. 100% to go to the Doctor.
J: OK.
A: She does not miss the date [tu].
J: OK.
A: The one who misses it is this one who is not well mentally.
J: OK.
A: You see 100% ... she.
J: So when does the one who is having epilepsy go for check up ?
A: She goes ... may be she goes a day later or a week later but I do want -
J: Where does she take her pills ?
A: She takes them at Site B.
J: At Site B. OK Mama. Does the pills control your childs' epilepsy ?
A: I can say they do control it.
J: mh.
A: You see, because they make her not to go around.
J: OK.
A: She likes going to church a lot.
J: OK.
A:She attends Father ===s' church. Sometimes she becomes unable due to her condition.
J: OK Mama. Does your child have frequent epileptic attacks ?
A: ... ... Sometimes she stays for about 3 months without seeing nothing.

J: mh.
A: We then hear a cry ... then I wake up so as not to allow her to fall asleep. I myself deep down within me, I do not want her to fall asleep.
J: mh.
A: She stays awake as if it is during the day.
J: OK.
A: Ofcourse this thing makes her to fall asleep.
J: OK. Do you keep a record of your childs' epileptic attacks ?
A: What do you say now ? [amazed]
J: Do you keep a record ?
A: Keep a record ?
J: Yes.
A: NO. That thing was not yet in my mind.
J: In your own way, how do keep a record then.
A: I memorise it.
J: OK. What do you do when your child is having a fit ?
A: When she fits, I take a spoon and put it, and make sure that she does not bite herself, and become injured.
J: OK.
A: So at hospital her bottom teeth were taken out. She is now unable to bite herself.
J: OK. What do you do after she has had a fit ?
A: After she has had a fit ?
J: mh.
A: There is nothing that I do.
J: mh.
A: Then I check how many pills are left.
J: mh.
A: That is what I do ... there is nothing else, I do not want to lie.
J: OK. Is there any difference between curing and controlling epilepsy ?
A: To control. I think it is being controlled.
J: mh.
A: Epilepsy cannot be cured.
J: mh.
A: I have seen from my experience.
J: All right Mama. Is it important to know your childs' epileptic condition ?
A: I can be happy if I can be informed about this condition.
J: mh.
A: Yes.
J: Now as a parent, do you think it is important to know your childs' condition.
A: It is very much important[emphasising].
J: Why ?
A: You have to know ofcourse that this thing started when, where does it come from, what you can do, because as a parent you are always worried.
J: OK. Is it important that others should know about your childs' condition ?
A: ... Very much Mama.

J: mh.
A: I do not hide, I am not shameful to talk about it. I might be able to get advice.
J: OK.
A: You see. When I talk that is when I will get help.
J: Thanks Mama. I have now come to the end of our conversation.
A: Yes.
J: I am very much thankful for the way you explained everything to me.
A: // the way.
J: I am now going to give you the chance to say something regarding what we have been talking about.
A: OK.
J: I am now giving you the chance.
A: This one who is mentally ill, she loves men. She has a naughty child, a clever child. That is why we say the thing is in the family, you see.
J: OK.
A: That is why we hardly know the childs' father. She wanders around, you see.
J:mh.
A: So I would not know where she gets this from.
J: OK.
A: I do not know about her condition. This one with epilepsy, I do know.
J: OK Mama. I am very much thankful for the time that you have given me.
A: Yes [nodding the head, acknowledging].
J: Especially amidst your commitments.
A: Yes Mama.
J: I am thankful that you agreed to talk to me especially on a Saturday when I know that people are very busy and have engagements.
A: Yes Mama.
J: Thank you very much Mama.
A: Thank you Mama.
J: Thanks.