

**THE QUALITY OF LIFE OF PARENTS
OF CHILDREN WITH EPILEPSY**

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DECLARATION OF AUTHENTICITY

I, the undersigned, hereby declare that the work contained in this assignment is my own original work, and that I have not previously in its entirety or in part submitted it at any university for a degree.

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ABSTRACT

The focus of the present review is the quality of life (QOL) of parents caring for a child with epilepsy. The review is informed by published books and articles available on the Psychlit and Medline databases. The paper provides an overview of epilepsy and the problems patients, particularly children, are confronted with. The important roles that parents fulfil in their child's life is followed by a discussion of the stress and burden experienced by parents caring for a child with epilepsy. Descriptions and definitions of the construct QOL are followed by reported research findings on the QOL of patients with epilepsy. The importance of the QOL of parents caring for a child with epilepsy is emphasized and this leads to an examination of existing research on the QOL of these parents. Research on the QOL of parents of children with epilepsy is limited despite the important roles parents fulfil in the life of their child with epilepsy and the potentially negative consequences of these additional roles for the child, the parents and the remainder of the family. Identification and an understanding of the dimensions of QOL of parents that are impacted upon by a child's epilepsy may produce improved treatment outcomes and QOL for children diagnosed and living with epilepsy. Recommendations for future research are included in the present review.

OPSOMMING

Die fokus van hierdie oorsig is die lewenskwaliteit van ouers wat 'n epileptiese kind versorg. Die oorsig is gebaseer op gepubliseerde boeke en artikels wat beskikbaar is op Psychlit en Medline databasisse. Die oorsig voorsien 'n omskrywing van epilepsie asook van die probleme wat pasiënte, veral kinders, ondervind. Die belangrike rolle wat ouers in hul kinders se lewe speel word bespreek en dit word gevolg deur 'n bespreking van die stres en druk wat ouers wat epileptiese kinders versorg, ondervind. Beskrywings en definisies van die konstruk lewenskwaliteit word aangebied, gevolg deur 'n opgawe van navorsingsbevindinge oor die lewenskwaliteit van epileptiese pasiënte. Die belangrikheid van die lewenskwaliteit van ouers van 'n epileptiese kind word beklemtoon en dit lei tot 'n oorsig van huidige navorsing oor die lewenskwaliteit van hierdie ouers. Ten spyte van die belangrike rolle wat ouers in die lewe van hul epileptiese kind speel en die moontlike negatiewe gevolge van hierdie bykomende rolle vir die kind, die ouers en die ander familielede, is navorsing oor die lewenskwaliteit van ouers met epileptiese kinders beperk. Identifisering van en insig in die faktore wat 'n impak het op die lewenskwaliteit van ouers met 'n epileptiese kind, kan lei tot verbeterde behandelingresultate en hoër lewenskwaliteit vir kinders wat gediagnoseer word en wat met epilepsie saamleef. Aanbevelings vir toekomstige navorsing word ook in hierdie oorsig gemaak.

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THE QUALITY OF LIFE OF PARENTS OF CHILDREN WITH EPILEPSY

1. INTRODUCTION

Epilepsy, according to Bhigjee (2000) “has been recognised since antiquity and is the commonest neurological condition” (p. 588). The oldest account of this neurological condition can be found on a Babylonian tablet in the British museum dating as far back as at least 2000 BC. Epilepsy was originally called “The Sacred Disease” until the time of Hippocrates, who believed that it was not sacred, but a disorder of the brain. Epilepsy knows no discrimination and can affect an individual’s entire life (Sanders, 2000). It is an episodic disorder rather than a state. Although seizures account for brief periods during the course of a month or year, anticipation and prevention of seizures, recovery from seizures, adaptation of lifestyle to restrictions related to seizures, and a variety of other issues impinge on the daily life of an individual with epilepsy. Restrictions are placed on many activities for both adults and children with epilepsy, because of the possibility that a seizure might result in an accident or self-harm. The restrictions can be imposed either by law or by self-imposed concerns. In addition to these restrictions, epilepsy is a condition with much stigma attached to it (Cramer, 1993). According to Dunn and Austin (2000) epilepsy is a pervasive disorder that can disrupt many areas of functioning and it is therefore essential to consider the overall quality of life (QOL) as an outcome measure in the treatment of patients with epilepsy.

QOL in relation to epilepsy forms the basis of this review. The focus is not on the QOL of the individual suffering from epilepsy but rather on the parents of the epileptic child. Elder (cited in Moen, Robison & Dempster-McClain, 1995) introduces the term “social interdependence” which means that the actions and experiences of significant others impinge on an individual’s life. It is argued that if epilepsy impacts on the child’s QOL, then it also impacts on the parents’ QOL. The impact of the condition on the parents’ QOL will impact on the child’s QOL considering the important role parents play in their child’s life. The present review focuses on the QOL of both parents of children with epilepsy and not exclusively on either the mother or the father. According to Bristol et al., Milgram and Atzil, and Timko, Stovel and Moos (cited in Dyson, 1997) it is a common conception that mothers experience greater stress than do fathers when the family has a child with a disability or chronic illness. Lamb, Schilling, Shinke and Kirkham (cited in Dyson, 1997) argue that the above assumption is understandable because traditionally more mothers stayed at home and assumed greater responsibility

for overall child care. In recent years, however, more mothers have been employed outside the home and researchers have found that fathers with employed wives spend significantly more time interacting with their children and take on more child care tasks than do fathers of non-employed wives (Barnett & Baruch, cited in Dyson, 1997). Due to the rise in maternal employment and the associated increase in child care responsibilities for fathers, it is argued that fathers may experience the same amount of stress as mothers of children with chronic illnesses (Dyson, 1997). The impact on QOL may be as significant for fathers as it is assumed to be for mothers. In order to understand and explore the impact of epilepsy on the parents' QOL, it is necessary to understand the condition itself.

The first section of this review thus consists of an exploration of the diagnosis, management and treatment options of epilepsy. Problems associated with the condition will be focused on, for example, the uncertainty and the difficulty of controlling seizures as well as the stigma associated with epilepsy. Special mention will be made of children who are mentally retarded and have co-morbid epilepsy. A significant number of mentally retarded children also suffer from epilepsy (Betts, 1998). According to Freeman, Vining and Pillas (1997) parents of these children carry a greater amount of guilt, anger, frustration, sorrow and burden. Espie and Kerr (2000) reported that the carers (parents) of children with both mental retardation and epilepsy experience more anxiety and than the patients themselves do. Thus it can be concluded that a child with epilepsy has more needs than a healthy child and may require more than the usual support from his/her parents. Parents play a significant role in the child's life. The second section consists of an exploration of the important roles parents fulfil in the life of their epileptic child. Parents play a significant role in helping the child adjust to his/her condition as well as helping others, for example, grandparents, teachers and the child's siblings to adjust to and accept the child's epilepsy. Because of the many additional roles parents have to play, as well as the nature of epilepsy, parents may experience an increase in their levels of stress and burden. In childhood illnesses the family and particularly the parents may face a considerable burden because of the stresses associated with the illness (Juniper et al., 1996). Factors that may contribute to increase the burden and stress in the life of the parent of the child with epilepsy is explored in the third section. The burden of caregiving impacts on the parents' QOL and hence the fourth section of this review is an exploration of the concept QOL. The fifth section focuses on recent literature exploring the QOL of children and adolescents with epilepsy. Attention will be paid to the factors that impact negatively on the child/adolescent's QOL, as well as the factors which have been reported to improve their QOL. The QOL of adults with epilepsy has received a significant amount of attention and much research has been completed in this area. According to Austin, Smith, Risinger and McNelis (1994) research on the QOL

of children with epilepsy and their families is lacking. QOL studies in children with epilepsy are important because they are at risk for a reduced QOL (Austin, 2000). The importance of the QOL of parents of epileptic children has not been given enough recognition. The sixth section of the present review explores and emphasizes the importance of the QOL of the parents of children with epilepsy and leads to the seventh section, which focuses on the studies that have been published on the QOL of these parents. The review concludes with a section on recommendations for future research.

2. THE NATURE OF EPILEPSY AND ASSOCIATED PROBLEMS

Epilepsy can affect anyone at any age. At any given time there are at least 40 million people with epilepsy in the world (<http://www.epilepsy.org.za>). According to Roux and Shah (2000) epilepsy affects approximately 120 000 South Africans. September (2002) reported that one in every 100 South Africans has epilepsy. It is estimated that in South Africa, as in many developing countries, the incidence of epilepsy is higher than in developed countries, owing to the high incidence of trauma and the occurrence of infectious diseases associated with epilepsy (Bill, 2000). Epilepsy is the most chronic neurological condition in childhood and affects an estimated 60 000 children in the United Kingdom (Camfield, Breau & Camfield, 2001; Hoare & Kerley, 1991; Hoare, 1993; Hoare & Russell, 1995; Kwong, Wong & So, 2000). Approximately half of the patients who develop epilepsy do so before the age of 15 (Simister & Duncan, 2002). Prevalence rates of epilepsy in South African children could not be located at the time the present review was written; however, a recent study on the prevalence of epilepsy in rural South African children estimated that the prevalence in this population is high and that many children do not receive adequate treatment (Christianson et al., 2000). The aforementioned researchers also stated that epilepsy is underreported because of the stigma associated with the condition. Epilepsy is both a medical disorder and a psychosocial disease (Freeman et al., 1997). The medical side of the condition will be focused on first, followed by a discussion of the psychosocial impact of the condition on the lives of patients, with special reference to children.

Epilepsy is not a single disease, but a manifestation of underlying brain dysfunction arising from many different possible causes (Simister & Duncan, 2002). Epilepsy is defined as “a chronic condition of various etiologies characterised by a predisposition to recurrent, usually spontaneous, epileptic seizures”. An epileptic seizure is defined as “an abnormal and excessive discharge of brain neurons involving hypersynchrony accompanied by some behavioural change” (Guberman & Bruni, 1999, p. 1). Epileptic seizures are classified into two groups: partial seizures and generalised seizures. If the

abnormal neuronal discharge remains confined to one part of the brain, the resultant seizure is described as a partial seizure. Partial seizures are further categorised into simple partial seizures, complex partial seizures and partial seizures that secondarily generalise. Simple partial seizures are generally short-lived. The patient does not experience an alteration in consciousness and is able to describe the event. There are four types of simple partial seizures: motor, somatosensory, autonomic and psychic. Complex partial seizures typically consist of three components: the aura, a period of altered consciousness and automatisms (Bill, 2000; Scrambler, 1989; Whitefield, 1999). An aura is defined as “the forewarning of an attack” (Martin, 1980). There are many different types of auras, including cognitive and affective symptoms as well as structured hallucinations. Altered consciousness takes the form of an absence and motor arrest. The patient is motionless and inaccessible and often presents with a stare. Automatisms occur during or after the impairment of consciousness and presents as repetitive and purposeless face or hand movements. These actions can present as swallowing, kissing motions or lip smacking and are usually followed by amnesia for the event (Bill, 2000; Gastraut, cited in Whitefield, 1999). Following a complex partial seizure patients typically feel tired and are confused for a variable period of time. The duration of complex partial seizures is variable, usually between 5 seconds and 15 minutes (Bill, 2000). Partial seizures that secondarily generalise can be described as partial or complex partial seizures that secondarily generalise into a generalised seizure, i. e. the abnormal neuronal discharge may generalise throughout the brain (Bill, 2000; Simister & Duncan, 2002; Whitefield, 1999).

In generalised seizures wide areas of both cerebral hemispheres are involved simultaneously from the onset of the attack and consciousness is impaired from the outset. Generalised seizures are divided into typical absence seizures or petit mal seizures, tonic-clonic seizures or grand mal seizures, myoclonic seizures, clonic seizures, tonic seizures and atonic seizures. Typical absence seizures most often develop in childhood or adolescence. The seizures are characterized by abrupt loss of consciousness and cessation of motor activity. The patient does not fall down because tone is preserved. The patient stares straight ahead and his/her eyes appear glazed. The attack ends abruptly, having lasted less than 10 seconds, and there is no confusion (Bill, 2000). Tonic-clonic seizures start with loss of consciousness and the patient usually falls. During the tonic stage the spine and limbs are held stiffly in extension, the patient’s eyes are rolled up and his/her jaws are clamped shut. Respiration ceases and cyanosis is common. The tonic stage lasts 10 to 30 seconds and is followed by the clonic stage, which is characterized by violent jerks of the limbs that persist for a few minutes. Tongue biting and frothing of saliva may occur (Bill, 2000; Whitefield, 1999). On recovering consciousness the patient is likely to

be confused, usually for 20 minutes to an hour, and may complain of headaches, nausea or drowsiness (Scrambler, 1989). Tonic-clonic seizures occur at any age, may be associated with many varieties of epilepsy and are the most frequently encountered of the generalized seizures (Bill, 2000; Simister & Duncan, 2002). Myoclonic seizures are characterized by sudden jerks of the limbs, head or trunk, which occur intermittently and unpredictably. It can precede a tonic-clonic seizure (Bill, 2000; Whitefield, 1999). Clonic seizures consist of generalized clonic movements without a preceding tonic phase. The jerking is often asymmetrical and irregular. Clonic seizures are most frequent in neonates, infants and young children (Bill, 2000). Tonic seizures are characterized by rigid muscular contractions and altered consciousness as well as the absence of a clonic phase. They are usually brief, lasting no longer than 60 seconds, and occur at all ages. Atonic seizures cause a sudden loss of postural tone, causing the patient to fall to the ground. They may sustain injuries because of their inability to protect themselves (Bill, 2000; Whitefield, 1999). It can be concluded that there are many types of epileptic seizures and according to Scrambler (1989) there are a variety of causes of which only a few have been identified.

The causes of epilepsy can be classified into three groups. The first is remote symptomatic which means the cause is due to a known or identifiable previously acquired brain lesion. The second is cryptogenic, due to an acquired brain lesion that has not been identified or is of unknown cause. The third group is idiopathic or of unknown cause and a genetic basis is presumed. It is estimated that 60% of all epilepsies are idiopathic or cryptogenic (Guberman & Bruni, 1999). All grey matter conditions can cause epilepsy and the range of causes is strongly age-dependent (Bill, 2000). In the neonatal and infant group causes of epilepsy include birth injury, anoxia, metabolic disorders and infantile spasms. During childhood infections, metabolic disorders, trauma and thrombosis of cerebral arteries or veins are cited as common causes of epilepsy. Idiopathic epilepsy is also common in this age group. During adolescence and early adulthood idiopathic epilepsy is common. Trauma and withdrawal from alcohol or other sedative hypnotic drugs are also known causes of epilepsy in these age groups. During middle age and late life trauma, vascular disease, alcohol or drug withdrawal, tumors and degenerative diseases are known causes of epilepsy (Adams & Victor, cited in Whitefield, 1999). According to Bill (2000) trauma and infection are common causes of epilepsy in the South African population due to deficient sanitation, poverty and illiteracy. The example of infection cited by Bill (2000) is that of neurocysticercosis, which is common in many parts of South Africa. It may lead to long-term neurological sequelae, the most common of which is epilepsy. The many causes of epilepsy, as well as

the grave social and economic implications of the condition for the patient and his/her family, must be taken into consideration by the clinician diagnosing and treating the patient (Van der Meyden, 2000).

Diagnosing epilepsy is complicated by the fact that patients are often unable to describe the events surrounding a seizure to the clinician because of the loss of consciousness which often accompanies epileptic seizures. According to Van der Meyden (2000) the diagnosis of epilepsy is primarily a clinical one. It should be based on a good history and examination and supplemented by adequate collateral information on the events concerned. A detailed description of the events experienced by the patient before, during and after the attack is essential for the clinician to obtain. Special attention should be given to possible alcohol and drug withdrawal, exposure to environmental toxins and a review of all currently used medications (Bill, 2000). Parents play an important role in the clinical interview as they are often the ones who witness the child's seizures and then seek treatment. Parents, significant others and friends may provide valuable information concerning the seizures of adult epileptics. According to Van der Meyden (2000) good collateral information on the events surrounding the seizure may be more valuable than all the available special investigations combined.

The special investigations include various clinical tests that aid in the diagnosing of seizures. The electroencephalogram (EEG) is a sensitive clinical test that records the electrical activity of the brain. It may add weight to the clinical diagnosis and help in the classification of the seizures and epilepsy syndromes (Van der Meyden, 2000; Whitefield, 1999). The four methods of neuroimaging used in the diagnosis of epilepsy are: computed tomography (CT), magnetic resonance imaging (MRI), position emission tomography (PET) and single photon emission computed tomography (SPECT) (Simister & Duncan, 2002; Van der Meyden, 2000; Whitefield, 1999). The CT scanning and MR imaging aid in the diagnosis of epilepsy by identifying structural abnormalities such as tumors and lesions. PET and SPECT examine changes in the cellular metabolism of the brain. Metabolic activity is reduced in damaged brain tissue and these areas are more easily detected by using PET and SPECT (Van der Meyden, 2000). The identification of the area of the brain with damaged tissue may provide information on the origin of the seizure in the brain. A neuropsychological assessment can be performed to assist with the diagnosis of epilepsy. The Neuropsychological Battery for Epilepsy (NBE) which consists of a range of cognitive tests has been shown to be sensitive to the effects of structural and functional abnormalities in the brain (Dodrill & Wilkus, cited in Whitefield, 1999). The special investigations mentioned above are invaluable to the clinician having to make the diagnosis. Seizures are associated with increased mortality and morbidity and patients with epilepsy have

mortality rates two- to threefold higher than the general population. Treatment is therefore essential once epilepsy has been diagnosed (Hennessy et al., 1999; Simister & Duncan, 2002).

According to Bhigjee (2000) various modalities of treatment have been tried over the centuries, including potions, ointments, exorcisms, dietary changes and behavioural therapy. The aim of treatment is to prevent seizures without causing side effects (Simister & Duncan, 2002). The two types of treatment of epilepsy which will be discussed are the medical treatment involving the regular use of anti-epileptic drugs (AED) and surgical treatment. There is no cure for epilepsy and the above-mentioned treatments serve only to control the frequency and severity of epileptic seizures (Wagner & Vickrey, 1995). The standard treatment is the use of AED. During the mid and late 1990's a flurry of new AED entered the market; however, many of these new drugs are not yet available in South Africa (Bhigjee, 2000; Scrambler, 1989). AED circulate in the bloodstream at optimal and steady levels to provide maximum seizure control. The levels vary from patient to patient and must be adjusted over time to achieve optimal seizure control and few side effects (Porter, cited in Whitefield, 1999). Clinicians may either decide on monotherapy, which involves using one drug to achieve control, or they may decide on polytherapy, using a combined medication regime. Monotherapy is believed to be safer because of fewer cognitive and physical side effects. The side effects experienced depend on the individual patient, the AED used and the dosage. Side effects include worsening of seizures, sedation, agitation and irritability, weight gain or loss, vomiting and motor dysfunction (Bhigjee, 2000; Ketter, Post & Theodore, 1999; Whitefield, 1999).

In addition to the many side effects produced by AED it is also associated with a number of chronic toxicity syndromes. It has also been estimated that 25 to 30 % of patients remain unsuccessfully controlled on AED (Roux & Shah, 2000; Schwartz, Cole, Vickrey & Gelber, 1995). Intractable epilepsy refers to an unacceptable degree of epilepsy control after an adequate trial of AED. For patients whose seizures are intractable other treatments such as epilepsy surgery should be considered (Baker & Jacoby, unpublished; Helmstaedter & Elger, 1994; Roux & Shah, 2000). Surgical treatment is an expensive option and the evaluation for surgery is lengthy and invasive. The types of surgical procedures include anterior temporal lobectomy, which is the most frequently performed procedure, as well as corpus callosotomy, amygdalohippocampectomy, lesionectomy and multilobar resections (Roux & Shah, 2000; Simister & Duncan, 2002; Whitefield, 1999). Surgical treatment has been used to treat medically intractable epilepsy in childhood for several decades and many researchers have suggested that surgery be offered to more children at younger ages (Gilliam et al., 1997; Roux & Shah, 2000).

Surgical treatment has been recognized to render many patients seizure free and may have a positive influence on psychosocial functioning and QOL (Baker & Jacoby, unpublished; Roux & Shah, 2000). Surgical treatment is contra-indicated for patients who have persisting psychosis and other psychiatric illnesses, a poorly supportive environment as well as those with comorbid mental retardation (Baker & Jacoby, unpublished; Roux & Shah, 2000). The treatment of epilepsy is challenging for both the clinician and the patient. There are several risks and no guarantee that a seizure free state will be achieved. The treatment of epilepsy in childhood is complex and should be undertaken by paediatricians or paediatric neurologists. Children with mental retardation and comorbid epilepsy present the clinician with unique challenges (Simister & Duncan, 2002).

Epilepsy is the most frequent additional handicap in children with mental retardation. It has been estimated that in the profoundly mentally retarded nearly 50% will also have epilepsy, while in those with mild mental retardation 5% will have epilepsy. Mental retardation never causes epilepsy and epilepsy seldom causes mental retardation (Betts, 1998; Coulter, 1993; Eriksson, Erila, Kivimaki & Koivikko, 1998; Freeman et al., 1997). Epilepsy is over-diagnosed in patients with mental retardation; this is partly due to the lack of subjective verbal description and because acting out behaviour is particularly likely to be paroxysmal and thus mistaken for epilepsy (Betts, 1998). The treatment of patients who have both mental retardation and epilepsy is challenging. Surgical intervention is contra-indicated for these patients and their seizures are often drug resistant (Donohoe & Hauser et al., cited in Eriksson et al., 1998). Alvarez (cited in Eriksson et al., 1998) reported that there is a higher recurrence of seizures after withdrawal of AED in individuals with a lower intelligence quotient (IQ). AED may lead to further impairment of cognitive functioning in already compromised brains.

The diagnosis and treatment of epilepsy affects many areas of the patient's life with many negative consequences. The negative consequences of epilepsy are often related to the stigma associated with epilepsy (Collings, 1990; Conrad, cited in Faircloth, 1999; Gil-Nagel & Garcia-Damberre, 2001; Whitefield, 1999). According to Scrambler and Hopkins (cited in Scrambler, 1989) there are two different kinds of stigma: enacted stigma and felt stigma. Enacted stigma refers to episodes of discrimination against people with epilepsy based on stigma. Enacted stigma is fuelled by negative attitudes and misperceptions about people with epilepsy. Research on lay attitudes towards people with epilepsy has tended to present a negative picture. People with epilepsy are described as sexual deviants, antisocial, excitable, aggressive, potentially violent, mentally ill and unattractive (Bishop & Hermann, 2000; Follet, 2000; Jacoby & Baker, 2000; Schachter, 2001). Felt stigma refers to the feeling of shame

often associated with being labelled epileptic and the fear of encountering enacted stigma. It is further argued that felt stigma tends to be more disruptive in patients' lives than enacted stigma. Felt stigma may cause the patient to become anxious, depressed, have a low self esteem and may lead to maladaptive behaviours such as dependency, rigidity, anger and aggression (Bishop & Hermann, 2000). In children enacted stigma, in the form of being teased by their peers, can be painful and humiliating and may leave deep emotional scars that interfere with the child's social and emotional development (Gibson, 2001).

Epilepsy is not only a condition that carries a great deal of stigma; it is also characterized by uncertainty. Most of the time, the majority of patients with epilepsy are "normal". They take their medication and continue with their lives. However, without warning, some of these individuals with controlled epilepsy experience a seizure (Freeman et al., 1997). The nature and uncertainty of seizures, as well as the stigma associated with the condition, affects many areas of the patient's life. Studies completed on adult patients with epilepsy identified areas patients felt to have been negatively affected by their epilepsy. Patients reported that their careers have been limited, their schooling reduced and their social life restricted (Camfield, cited in Ettinger & Kanner, 2001; Dodrill, Breyer, Diamond, Dubinsky & Geary, 1984; Edwards, cited in Gil-Nagel & Garcia-Damberre, 2001; Hanson & Taylor, cited in Whitefield, 1999). Epilepsy seems to have a major impact on employment. It has been estimated that 79.6% of people with epilepsy living in the Western Cape are unemployed and those who are employed occupy positions that are below their potential (Epinews, 1999). Patients with epilepsy are restricted from employment that may expose them to injuring themselves or others in the event of a seizure. Restrictions imposed by their condition, as well as enacted stigma in the workplace, may be the cause of the high unemployment rate among epileptic patients. Employers often perceive patients as less efficient and therefore a poor investment. Employers also anticipate high absenteeism and perceive patients as less competitive and less productive (Freeman et al., 1997; Mielke, Sebit & Adamolekun, 2000; Scrambler, 1989; Whitefield, 1999). Enacted stigma and felt stigma are highly interrelated. Many patients may be reluctant to seek employment for fear of enacted stigma and a belief that they will not be employed because of their epilepsy (Gil-Nagel & Garcia-Damberre, 2001; Levin, Banks & Berg, 1988; Scrambler, 1989).

Many patients are forced to remain dependent on others for financial security because of the increased rates of unemployment and underemployment associated with epilepsy (Levin et al., 1988). Patients may also not be able to live independently because of having uncontrollable seizures as well as

additional handicaps. Epilepsy is reported to be an expensive disorder to have. Special investigations, medication and visits to the neurologist contribute to the direct costs of having the condition (Cramer, 1999; Gibson, 2001; Van Hout et al., 1997). It is argued that a better socio-economic status may alleviate certain difficulties in the life of a person with seizures, but this does not mean that the person is exempt from other stresses associated with epilepsy (Dodrill et al., 1984). Patients with epilepsy are restricted from driving because of the increased accident risk among these patients. The restriction of driving privileges impacts on independence as well as self-esteem, especially in adolescence (Devinsky et al., 1995; Gibson, 2001; Guberman & Bruni, 1999). Epilepsy is also associated with repeated disabling and distressing episodes of loss of consciousness which often results in personal embarrassment and loss of dignity as well as further decrease in self-esteem (Robertson et al., cited in Hermann & Wyler, 1989). Low self-esteem is common among patients with epilepsy and increased rates of depression and anxiety have also been reported. Depression and anxiety are the commonest forms of psychiatric morbidity among people with epilepsy (Cramer, 1999; Dodrill et al., 1984; Jacoby, Baker, Steen, Potts & Chadwick, 1996). Researchers have also reported that there is an increased risk of suicide among patients with epilepsy. Suicide attempts are reported at a fourfold higher frequency in patients with epilepsy as compared to the general population (Ettinger & Kanner, 2001; Guberman & Bruni, 1999; Kanner & Nieto, 1999). It has been reported that marriage rates among patients with epilepsy are low when compared to the rates of marriage in the general population. Males with epilepsy are less likely to marry than females with epilepsy (Batzel & Dodrill, 1984; Dansky, Andermann & Andermann, 1980; Jacoby et al., 1996; Scrambler, 1989). Social withdrawal and isolation are commonly reported among epileptics and this has been argued to be a major contributing factor to the reduced rates of marriage (Baker & Jacoby, unpublished; Seidman-Ripley et al., 1993). It seems that for patients with chronic, uncontrolled epilepsy the impact on their lives is significantly worse than for patients with well controlled epilepsy.

The findings of the negative impact of epilepsy reported above are based on studies done on adult patients. Findings based on research done on children and adolescents have revealed a high incidence of psychiatric, psychological and behavioural difficulties in this population group (Batzel et al., 1991). Austin (2001) reported that mental health problems are more than four times higher in these children than in children in the general population. Children with epilepsy are often overwhelmed by feelings of embarrassment, frustration and helplessness as well as often displaying a great deal of fearfulness, dependence and demandingness (Hoare & Kerley, 1991; Hughes & Jabbour; Bridge, cited in Matthews et al., 1982). Anxiety, depression and social withdrawal are also high in epileptic children (Bax, 1999).

Academic underachievement has been reported to be high in these children and boys have been found to be at increased risk for academic problems. Reasons cited for this include the cognitive side effects of AED as well as lowered expectations from parents and teachers (Austin 2001; Brown, 1994; Dunn & Austin, 2000; Kwong et al., 2000; Matthews et al., 1982, Ward & Bower, 1978). Both parents and teachers place restrictions on the child's activities. Often they are common sense restrictions such as not bicycling on busy roads and swimming (Gordon & Sillanpaa, 1997; Carpay et al., 1997). According to Brown (1994) restrictions can become discriminatory, for example, when they are excluded from organized games at school and are never allowed to participate in swimming activities.

Epilepsy is both a medical diagnosis and a social label (Arnston et al., cited in Jacoby, 1992). An iceberg has been used as an analogy for epilepsy, emphasizing the large amount of 'ice' beneath the surface (Aicardi, cited in Bax, 1999). This has been demonstrated in the above section of the present review. The focus thus far has been on the patients and the impact that epilepsy has on their lives. Epilepsy appears to have a particularly negative impact on children. In addition to the normal developmental tasks of childhood, epileptic children are confronted with other psychosocial stressors linked to their illness. Children and their families, specifically their parents, need to make a successful adaptation to epilepsy to facilitate the optimal development of the child (Austin, 2001). Parents play a significant role in helping their child adapt to his/her condition.

3. THE IMPORTANT ROLE OF PARENTS IN THE LIFE OF A CHILD WITH EPILEPSY

The word role is defined as "any pattern of behaviour involving certain rights, obligations and duties which an individual is expected, trained and, indeed, encouraged to perform in a given social situation – a person's role is precisely what is expected of him or her by others" (Reber, 1985, p. 673). The most basic role of the parent is to provide a safe environment for their child from which, he/she can explore the world and develop normally. The child with epilepsy is faced with both direct and indirect stressors linked to his/her condition and these stressors make "normal" development an increasingly difficult task for them. The unsuccessful negotiation of these stressors prevents the child from adapting successfully to his/her condition and this may lead to psychosocial adjustment problems throughout childhood, continuing into adulthood (Austin, 2001). A variety of environmental stimuli, internal or external, may also induce seizures and one of these stimuli is stress (Cull, Fowler & Brown, 1996).

According to Gibson (2001) it is the family, specifically the parents, that manages the disorder and sets the stage for adjustment.

Long term follow-up studies of epileptic children showed an increased risk of unemployment, a significantly greater risk of completing only six years of school, social isolation, financial dependence, and that they were less likely to be married than those in a matched control sample (Camfield, cited in Ettinger & Kanner, 2001; Silanpaa, cited in Guberman & Bruni, 1999; Dunn & Austin, 2000). It seems that parents have important roles to play in the life of their epileptic child and that the nature of their roles changes as the child develops. During infancy and childhood children need an environment where they can develop autonomy and initiative. If parents' response to the epilepsy involves overprotection and overindulgence, the child could be deprived of experiencing feelings of competence. Overprotection could lead to the parents placing too many restrictions on the child's activities and this could hinder his/her development of life skills (Austin, 2001). The developmental tasks of middle childhood include becoming more independent of parents and more attached to peers. It is crucial to the child's psychosocial development that he/she is actively involved in peer groups and that he/she achieves success in the school environment. Epilepsy can interfere with these tasks. Negative feelings about their epilepsy could lead to feeling different from peers, withdrawing from peer groups and poor self-esteem. These negative feelings may be incorporated by the child into his/her self-concept and as a result the child experiences negative feelings about him/herself (Austin, 2001; Jan et al., 1983; Ziegler, Erba, Holden & Dennison, 2000). Adolescence is a time to consolidate one's identity so that one emerges into adulthood with a strong sense of identity. Achievement of independence from parents, establishment of intimate relationships outside the family and identification of a vocation are added tasks of adolescence. The presence of epilepsy can interfere with the achievement of these tasks in different ways. Overprotection may lead to failure on the part of the adolescent to develop a sense of self-competence which in turn leads to poor self-esteem and feelings of being different from others. Seizures and having to take AED can lead to a reduced sense of physical competence while the stigma associated with epilepsy can have a negative impact on his/her self-perception. In each of the three stages described above parental response to the child's diagnosis is crucial to the successful achievement of the developmental tasks.

According to Scrambler (1989) most parents are extremely upset when their child is diagnosed as epileptic, mainly because of the stigma associated with the condition. Parents tend to view epilepsy as something "bad" and are not willing to discuss it with their children, family and friends. Typical

parental responses are reported to be shock, devastation, anger, frustration, sorrow and depression. Other reactions include horror, disbelief, guilt, embarrassment, avoidance and confusion (Appelton & Chappel, 1997; Levin et al., 1988; Scrambler, 1989; The David Lewis Centre, 1994). In addition to the response to the diagnosis, the witnessing of a seizure in a young child, especially a tonic-clonic seizure, can be one of the most frightening experiences for a parent (Gibson, 2001). It may lead to feelings of helplessness and fear and often results in overprotection or overindulgence of the epileptic child. The parents' attitude may also influence the child's attitude to his/her condition. If parents are frightened the child may become frightened even if he is unable to understand why. The most important role parents therefore have is instilling positive feelings about the condition in the child. It is a common occurrence for parents who have a child with a chronic illness to neglect their other healthy children; as a result siblings have difficulty adapting and sibling rivalry may be exacerbated (Freeman et al., 1997; Jan et al., 1983; The David Lewis Centre, 1994). It has been reported that siblings in families with a chronic epileptic child are more disturbed than siblings in a control group (Ellis, Upton & Thompson, 2000; Levin et al., 1988). In the home parents play an important role in helping the epileptic child and his/her siblings to adapt and cope with the condition. At the same time they have to negotiate and come to terms with their own feelings and attitudes.

Parents have an equally important role to play outside the home. Children and adolescents spend a great deal of time in the school setting and it is essential for development that children view it as a safe environment. The attitude of the parents as well as those of the teachers is an important factor that can either add to or detract from the child's development in the school environment. Parents and teachers may perceive the epileptic child as fragile and expect him/her to have poor concentration, low performance and to be less active. These children may not be encouraged to work hard and try their best. A teacher's response to a child having a seizure may influence how the other children view seizures. If the teacher reacts calmly, the children may accept that there is nothing to be frightened of (Austin 2001; Brown, 1994; Dunn & Austin, 2000; Gordon & Sillanpaa, 1997; Kwong et al., 2000; Matthews et al., 1982, Ward & Bower, 1978). Parents play an important role in changing the attitudes some teachers may have towards children with epilepsy. In addition, parents may have to make the decision as to whether or not their children should remain in a mainstream school or be transferred to a school for children with special needs. It has been reported that parents of children who attend special schools experienced greater satisfaction than those with children in mainstream schools (Stewart, Matthews, Foley & Aszkenasy, 1998). Because of the stigma attached to epilepsy parents may be

reluctant to inform teachers about their child's condition, fearing that the child may be discriminated against.

Not only do parents fear divulging their child's epilepsy to teachers; they also fear telling their friends and family while some even have difficulty telling the grandparents. Parents feel shame and fear blame and rejection from the afore-mentioned groups and may withdraw from their family and social circle. This only leads to further isolation. It is the parents' responsibility to educate themselves about their child's epilepsy as this may not only reduce their fears but better equip them to answer questions posed by their friends and family. People often fear the seizures but they also fear that they may not know what to do should a seizure occur. A positive attitude in parents may influence a positive reaction in friends and family (Ellis et al., 2000; Freeman et al., 1997; Jan et al., 1983; Scrambler, 1989). Parents therefore have the very important role of ensuring that the child's epilepsy has a minimal impact on his/her life, the lives of their siblings as well as the lives of the parents. Parents take responsibility for educating and changing the attitudes of those involved in their child's life and ensuring that the child has a secure and safe environment from which to explore the world.

One of the most important roles still to be discussed is the parents' role in the medical side of the illness. According to Strauss and Glaser (1975) the child's family is part and parcel of the medical situation. The parents accompany the child to the doctor, provide details of the events surrounding seizures and ensure that the child remains compliant with his/her treatment. Parents are relied on to provide feedback to the clinicians about the number and severity of seizures as well as the negative side effects of medication. Together with the clinician, parents negotiate appropriate restrictions that need to be placed on their child's activities. Parents are also often placed in the difficult situation of having to decide whether new treatment options, which to them may seem terrifying and increase their burden, should be explored - an example of this being surgical treatment (Bairstow, 2000; Carpay et al., 1997; Lang, Neil-Dwyer & Garfield, 1999; Strauss & Glaser, 1975).

From the above it seems that parents act as agents with a variety of tasks such as protecting, negotiating and assisting their epileptic child (Strauss & Glaser, 1975). Parents have many tasks, including making sense of their child's condition, mastering treatments, creating a normal life for their child, adapting the family's routine to the condition, and negotiating with school and health-care professionals (Austin, 2001; Gibson, 2001, Hoare & Kerley, 1991). They also have to continue with their everyday tasks of raising their other children and working outside the home. The additional roles of caring for a child

with epilepsy may cause an increase in stress for parents and possibly a decrease in their QOL. This has particular relevance if it is coupled with what Abbey and Andrews (1986) refer to as 'role ambiguity' which refers to the extent to which a person is unsure about how to carry out a particular role. The various factors that contribute to an increase in stress for parents with an epileptic child will follow.

4. THE FACTORS THAT CONTRIBUTE TO INCREASED STRESS AND BURDEN AMONG PARENTS CARING FOR A CHILD WITH EPILEPSY

In addition to the many roles parents have to fulfill there are other stressors that parents with epileptic children are faced with. Stressors are defined as "conditions, experiences, and activities that are problematic for people, threatening them, thwarting their efforts, fatiguing them and defeating their dreams" (Aneshensal, Pearlin, Mullan, Zarit & Whitlatch, 1995, p. 65). In parents of children with epilepsy, stressors can be divided into two groups: primary and secondary stressors. Primary stressors are stressors that flow directly from the needs of the child with epilepsy, while secondary stresses are arguably those that parents share with other parents who do not have an epileptic child. Stressors can lead to an increase in burden for parents. Burden is defined as "the extent to which the caregiver perceives that his/her physical, social, mental and spiritual status is suffering as a result of caring for a sick family member" (Tebb, 1995, p. 88). Burden can be divided into two groups: subjective and objective burden. Subjective burden involves the psychological consequences of the individual's illness for the family and the individual while objective burden refers to the disruption of the family/household due to the individual's illness. Objective burden is observable, for example, finances, routines and relationships (Heru, 2000; Lieberman & Fisher, 1995; Magaqa, 1999; Martens & Addington, 2001; Thompson & Gallagher-Thompson, 1996).

Lipman-Blumen (cited in Danielson, Hamel-Bissell & Winstead-Fry, 1993) argues that there are ten dimensions of an illness that have the ability to cause stress, strain and crisis in a family with a child suffering from a chronic illness. The ten dimensions, proposed by Lipman-Blumen, are used as a framework to explore the factors that may lead to an increase in the burden and stress of parents with an epileptic child. Despite the fact that each family and each illness is unique, it is argued that illness stressors fall into common groupings. Parents of children with a chronic illness experience the most stress because of the many roles they have to play. Therefore, even though mention is made of the impact of the illness on the family, it is argued that parents experience the majority of the stress and their stress filters down into the rest of the family (Dyson, 1993).

The first of Lipman-Blumen's ten dimensions (cited in Danielson et al., 1993) is the origin of the illness. Incorporated in this dimension is whether the illness involves an actual family member as well as whether the cause is directly linked to the family. If a family member is diagnosed with a chronic illness, the burden and stress is greater than if a distant relative is diagnosed. The diagnosis of a chronic illness in a child may be particularly stressful for parents as their hopes and dreams are often embedded in the child (Jan et al., 1983). According to Ziegler et al. (2000) the issue of loss is prominent in the minds of parents when their child is diagnosed with a medical condition and the severity of the parents' reactions increases in relation to the severity of the condition, poor prognosis and the suggestion that there may be additional developmental handicaps. Parents may grieve the loss of a "normal" child and a bereavement process takes place that can take many forms. Parents may also experience feelings of guilt and responsibility and this may be linked to the cause of the illness. It is argued that if the cause is hereditary, special problems arise. Parents often fear that some failure on their part precipitated the child's epilepsy. Feelings of guilt may result in parents who devote all their time and energy to the epileptic child and consequently neglect the siblings. Parents may also overprotect and/or overindulge the child (Bairstow, 2000; Ellis et al., 2000; Freeman et al., 1997; Jan et al., 1983; Ward & Bower, 1978).

The second dimension that can cause an increase in stress in families is if the illness impacts on the entire family as opposed to only a few members, because the demands for change and the use of family resources increase. This may lead to an increase in family tension and disruption (Danielson et al., 1993). The burden of care may fall more heavily on one member, which may lead to resentment and increased family tension. Childhood epilepsy affects the entire family. Plans for the future are placed on hold and the family may spend less time enjoying activities outside the home, fearing that the child may have a seizure. Siblings may miss out on school activities and face many disappointments. Activities that the epileptic child may not participate in may also be stopped, for example, viewing fireworks displays, swimming and horse riding (Ellis et al., 2000; Kuhn, Allen & Shriver, 1995; Levin et al., 1988; Stewart et al., 1998; The David Lewis Centre, 1994; Ward & Bower, 1978). One parent may have to end his/her employment outside the home, which may lead to a reduced income for the family and therefore the reduction of certain activities.

The third dimension involves the severity of the illness. The more severe the illness, the greater the demands will be on family time, energy and finances (Danielson et al., 1993). According to Jan et al.

(1983) the more severe the epilepsy, the greater the parents' emotional stress and strain as a result of feelings of guilt and anger. The relationship between the severity and frequency of the child's seizures and the amount of stress parents will experience is argued to be directly proportional (Danielson et al., 1993). The more frequent and severe the seizures are, the more frequent visits to the doctor may become. AED may have to be increased, which may lead to cognitive impairment as well as behavioural difficulties. One parent may have to stay home from work often and risk loss of employment (Bairstow, 2000; The David Lewis Centre, 1994).

The fourth dimension involves the duration of the illness. The longer an illness persists, the greater is the impact on the parents and hence on the family. The average duration of symptoms among people with epilepsy is approximately twelve years and in 70% of cases the epilepsy goes into remission over a period of years (Scrambler, 1989; Simister & Duncan, 2002). Even among parents who have a child that has been rendered seizure free, there may be considerable stress and strain because they cannot be sure that seizures will not recur (Baker, 1995). The longer the time period before the child's seizures go into remission, the greater is the length of time parents have to fulfil the increased roles specific to having an epileptic child.

The fifth dimension of an illness that can prove stressful for parents is whether the onset of the illness is sudden or gradual. If the onset is sudden, the parents have little time to investigate, gather information and develop appropriate coping strategies. Feelings of disruption and disorganization may result and may culminate in a sense of loss of control and family crisis (Danielson et al., 1993). The onset of epilepsy is sudden and this increases stress in parents ((Bairstow, 2000; Jan et al., 1983; Lane, Dede, Chandra & Gilmore, 1998; The David Lewis Centre, 1994).

The sixth dimension proposed by Lipman-Blumen (cited in Danielson et al., 1993) is the manageability of the illness. An illness that is perceived as unmanageable may impact negatively on the parents and family. Parents may feel that they have no control and as a result spend all their energies trying to gain control. Their failure to achieve the desired control and management of the illness may lead to loss of self-esteem, anxiety and depression (Danielson et al., 1993). Seizures often contribute to a sense of loss of control. During a seizure very little can be done to help the child and nothing can be done to stop the seizure. Parents have to wait until it is over (Scrambler, 1989; Ward & Bower, 1978). The loss of control may be further exacerbated if the epilepsy is uncontrolled, either because the optimal treatment

level has not been reached or the child is not compliant with his/her medication (Freeman et al., 1997; Jan et al., 1983).

Linked to the origin of the illness mentioned earlier is the seventh dimension, which involves the cause of the illness. It is argued that an illness of unknown cause is more stressful than if the cause were natural (bacterial or viral infections) or man-made (car accidents) (Danielson et al., 1993). There are many causes of epilepsy but few have been identified (Scrambler, 1989). Parents may worry that they are responsible for the child's seizures. They may also worry that their other children may develop epilepsy. Parents may also fear that others will blame them and believe the child's epilepsy is due to failure on their part. Mothers may fear that the child's epilepsy is due to neglect during pregnancy. Feelings of inadequacy may develop, which may lead to further loss of self-esteem. As a result parents may withdraw from others and risk increasing isolation (Jan et al., 1983; Ward & Bower, 1978).

The uncertainty of an illness is the eighth dimension proposed by Lipman-Blumen (cited in Danielson et al., 1993). Uncertainty makes it difficult for parents to plan and prepare for the illness in different situations. Uncertainty increases feelings of loss of control and helplessness, which may lead to an increase in anxiety and stress. Epilepsy is an episodic condition that is unpredictable. A child may be continuing with his/her daily activities when a seizure may occur. Parents will then have to help the child deal with the seizure and its after-effects, not knowing when the next one will occur (Austin, 2001; Freeman et al., 1997; Jan et al., 1983; Ward & Bower, 1978). It is argued that a chronic illness with unpredictable characteristics like epilepsy puts a family at risk for poor communication, poor cohesiveness, and poor integration (Ferrari, Matthews & Barabas, cited in Danielson et al., 1993). Uncertainty is also linked to the cause as well as to the treatment of epilepsy and, as mentioned above, this can be stressful for parents.

The ninth dimension incorporates the resources available to and employed by the family of a child with a chronic illness. Families with many resources are often more capable of handling the strain caused by illness than the family with few resources (Danielson et al., 1993; Fink, 1995). Resources include effective coping strategies and skills of caring for a child with epilepsy, money and social support. It has been reported that parents who feel able to handle their child's illness and who feel they have the necessary skills to deal effectively with seizures will experience less burden and stress (Chou, Montagne & Hepworth, 1999; Schumacher, Stewart, Archbold, Dodd & Dibble, 2000). It has already been established that epilepsy can be an expensive condition to have (Cramer, 1999; Lane et al., 1998;

Gibson, 2001; Van Hout et al., 1997). Specialists, medication and special investigations are costly, as well as transport to and from the hospital and the cost of child care for the children left at home. It is argued that when parents start caring for a child with a chronic illness, they engage in fewer social activities resulting in social isolation and loss of social support (Barnett & Boyce, 1995). Social isolation has been shown to be almost inevitable and to increase distress among those caring for the chronically ill (Logiudice et al., 1999; Schofield et al., 1997). It has been reported that individuals caring for an individual with a chronic illness need to associate with those who are experiencing the same stressful situation as they are. It provides them with the opportunity to share feelings that are causing them distress without having to fear rejection (Kahn, 1994; Pillemer & Suitor, 1996). Supportive others may impart valuable advice and suggestions to parents. Parents may call on supportive others to care for their child while they enjoy time alone together or complete necessary errands. The more social support parents experience, the less stressed they report feeling (Dyson, 1997). Because of felt and enacted stigma associated with epilepsy, parents may experience a decrease in social support.

The tenth and final dimension concerns the stigma associated with the illness. The greater the stigma attached to the illness the more negative is the impact on the life of the family (Danielson et al., 1993). Parents may experience a sense of shame and this can lead to feelings of anxiety and guilt. Parents may react on felt stigma which is argued to apply not only to the patient with epilepsy, but also to parents and siblings and often the extended family. Felt stigma may lead parents to withdraw from relationships outside the family, increasing the family's sense of isolation and decreasing their social support. Activities outside the home may come and inviting outsiders into the home may end. Parents may be secretive about their child's epilepsy, which could lead to significant anxiety. Having to disclose the child's epilepsy to the child's teachers may also be stressful, especially if teachers have their own prejudice. Family members and friends may withdraw from the parents and family of a child with epilepsy. Individuals may react on their own prejudice and misconceptions of the illness. They may also feel inadequate to cope with the seizures and fear being left alone with the child in case he/she has a seizure. Parents may find it difficult to find child care assistance and as a result may have very little free time away from the child (Appleton et al., 1997; Ellis et al., 2000; Freeman et al., 1997; Scrambler, 1989; Ward & Bower, 1978).

In addition to the ten factors described above it is argued that parental stress is likely to increase over time as the child grows older due to management difficulties, financial demands and an increased

concern about the child's future. As a child grows older, increased contact with the larger community is a threat to the secrecy of epilepsy. An adolescent may withdraw, become depressed or employ acting out behaviours in response to his/her epilepsy and parental overprotection (Dyson, 1993; Ziegler et al., 2000). The addition of behavioural problems, a common occurrence in children with epilepsy, may increase the amount of stress and burden experienced by parents (Byrne & Cunningham, 1988; Dunn & Austin, 2000; Hoare & Kerley, 1991; Sokol et al., 1996). Behavioural problems may be related to the side effects of AED (Dunn & Austin, 2000). With regard to restrictions on their child's activities, parents may find themselves in a stressful position having to find a balance between overprotection and negligence (Carpay et al., 1997). According to Freeman et al. (1997) parents of children who have both epilepsy and mental retardation experience a greater amount of burden. It is argued that these parents often come to accept the child's mental retardation, but the seizures cause them a significant amount of distress. The presence of epilepsy and mental retardation increases the risk of injuries and parents may experience a great deal of anxiety and distress if they have to constantly monitor their children (Coulter, 1993; Espie & Kerr, 2000). Parents may be exhausted physically and psychologically, having to provide almost constant care and pay for repeated medical visits, hospitalization, and AED (Yang et al., 1996).

Perceptions play an important role in the levels of stress and burden experienced by those caring for an individual with a chronic illness (Coen, O'Boyle, Swanwick & Coakley, 1999). It is argued that perceptions of problems related to the care of a child with a chronic illness have more influence on a parent's mental health than the actual occurrence of the problem. Perceptions play a role in the outcome of dealing with the problems associated with caring for an ill child and has also been argued to be the link between depression and caregiving experiences (Berg-Weger, Rubio & Tebb, 2000; Ellis et al., 2000; Yates, Tennstedt & Chang, 1999). It is reported in the literature that if caregivers perceive themselves as capable of dealing with the demands and challenges of caregiving and feel they have the resources to cope with the stressors they are confronted with, they will experience a greater sense of well-being, less dysfunction and less life stress (Antonovsky, cited in Svavarsdottir, McCubbin & Kane, 2000). It is further argued that changing parents' perceptions of the caregiving situation and the child with epilepsy may decrease the stress they experience (Danielson et al., 1993). Parents who perceive the child with epilepsy as having more emotional problems, being more unpredictable and highly strung, less able to perform well at school, unable to participate in sport, and as fragile and helpless, may impose greater restrictions on the child and the family because they worry more and experience a greater amount of anxiety and guilt which results in a greater sense of burden (Gibson,

2001; Kwong et al., 2000; Levin et al., 1988; Matthews et al., 1982). Higher divorce rates have been reported among parents of children with epilepsy than among those in the general population, and the siblings of children with epilepsy appear to be at a greater risk of psychiatric disturbance (Gibson, 2001; Hoare & Kerley, 1991; Silanpaa, cited in Baker & Jacoby, unpublished; Silanpaa, cited in Bishop & Hermann, 2000).

The above section explored a few of the many parental stressors resulting from a diagnosis of epilepsy in a child. These stressors can lead to a considerable increase in burden and stress for the parents of a child with epilepsy. These stressors have an impact on many areas of the parents' life, their relationships, psychological functioning as well as employment outside the home, and ultimately leads to a decrease in the parents' QOL. It is the parents' QOL that is the focus of the present review. However, before this area can be explored, attention will be focused on the concept QOL as well as the reported findings of research on the QOL of epileptic patients.

5. QUALITY OF LIFE (QOL): DESCRIPTIONS AND DEFINITIONS

QOL research began in the 1940's and after a modest beginning it has progressed to the point that it is now an important consideration in patient care, health economics, policy development and clinical trials of all types (Kaplan, Bergner & Mosteller, cited in Hermann, 1993). It has its origin in the field of oncology and was used to draw attention to the fact that not only the cure and survival of patients but also their psychological well-being must be considered as important in medical care (Coetzee, 2002; De Haes & Knippenberg, 1987). It has become an important measure in assessing the impact of disease and its treatment on individuals and their families (Abeles, Gift & Ory, 1994). It seems that there is little agreement as to the definition of the term QOL, how it should be measured or whether it should be measured at all. It is argued that researchers from different disciplines have different perspectives on the term and their perspectives reflect the preoccupations of their particular disciplines (Hunt, 1997; Nuamah, Cooley, Fawcett & McCorkle, 1999).

The term QOL has been described in many different ways. It is a hypothetical construct that is impossible to define; however, it elicits much interest and stimulates much research (Andrews, 1986; Szalai, 1980). It is described as vague and ethereal, abstract and complex, an entity that many people talk about but which nobody knows what to do about (Bowling, 1997; Campbell et al., cited in De Haes & Knippenberg, 1987). QOL is also described as changing over time and as a patient-perceived entity –

it is an individual matter; what matters to one person may not matter to another and therefore an outsider cannot judge the quality of another's life (Calman, 1987; Schipper, Clinch & Powell, 1990). It is a concept that refers to an individual's overall life satisfaction and total well-being (Abeles et al., 1994). QOL is described as multidimensional and different researchers emphasize different dimensions (Ward, Carlson-Dakes, Hughes, Kwekkeboom & Donovan, 1998). According to Weisgerber (1991) there are 15 dimensions constituting QOL which include, among others, participation in active recreation, helping and encouraging others, learning and improving one's understanding, and expressing oneself in a creative manner. Schipper et al. (1990) emphasize four domains of QOL: physical and occupational, psychological, social and somatic dimensions. Additional dimensions that are focused on by researchers include: economic status, happiness, cultural, spiritual and philosophical dimensions, personality, support network, life satisfaction and self-esteem (Abeles et al., 1994; Calman, 1987; George & Bearon, 1980; Hughes, 1993; Spilker, 1990).

Just as there are many dimensions that constitute QOL, there are also many definitions of QOL (Spilker, 1990). There are two main types of definitions of QOL. The first pertains to a global measure and the other to health-related QOL (HRQOL) (Nuamah et al., 1999). QOL has been defined as "a subjective evaluation of the overall character of life" (Szalai, cited in De Haes et al., 1987, p. 173). Calman (cited in Schipper et al., 1990, p. 15) defines QOL as "the gap between the patient's expectations and achievements" and argues that the smaller the gap, the higher the QOL. Calman (cited in Cramer, 1993, p. S9) offers his definition of QOL as "the difference between expectations and actual experience". "The possession of resources necessary to the satisfaction of individual needs, wants and desires, participation in activities enabling personal development and self actualization and satisfactory comparison between oneself and others" is yet another definition offered by Shin and Johnson (cited in Bowling, 1997, p. 6). HRQOL refers to the specific impact of an illness or injury, medical treatment or health care policy on an individual's QOL (Levi & Drotar, 1998). HRQOL is defined as "the value assigned to duration of life as modified by the impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment or policy" (Patrick & Erickson, cited in Lindqvist, Carlsson & Sjoden, 2000, p. 1399).

There are many dimensions of QOL, as mentioned earlier, and no consensus among researchers as to a single definition. In the present review it is argued that having to care for a child with epilepsy impacts on many different domains of a parent's life. These domains are the same as those that are argued to constitute QOL. It is argued that the parents' perception of the impact of the child's epilepsy on their

lives is invaluable when examining their QOL. Using Calman's definition of QOL, namely that it is "the difference between expectations and actual experience" (cited in Cramer, 1993, p. S9), it is argued that the parents' perceptions of the impact that having to care for an epileptic child has had on the different domains of their life will determine how they rate their QOL. In other words, an individual's evaluation of overall life satisfaction results from combining evaluations of relevant life domains (Abbey & Andrews, 1986). For example, if parents perceive that the child's epilepsy has resulted in the loss of advancement at work, decrease in leisure activities as well as an increase in anxiety they will rate their QOL of life as low. In addition, if they perceive that if they did not have a child with epilepsy their lives may have turned out differently, for example, advancement at work, increase in social relationships and less anxiety, they may rate their QOL as being lower. Parents' subjective evaluation – how they perceive having a child with epilepsy to have affected their lives - is therefore emphasized. It is further argued that the severity, type and frequency of the child's seizures as well as particular demographic information is less important than parent's perceptions of the illness and its impact on their lives (Abbey & Andrews, 1986; Buelow & Ferrans, 2001; Nuamah et al., 1999; Szalai, 1980). It is further argued that the parents should be the primary source of information regarding their QOL (Coen et al., 1999). QOL changes over time and parent's perceptions of their QOL may be different at different stages of their child's illness, their child's development as well as the parent's own life. It is further argued that an improvement in QOL cannot be achieved unless the individual is motivated and changes his/her perceptions and circumstances (Grimes & Cole, cited in Coetzee, 2002; Weisgerber, 1991).

Traditionally the failure or success of treatment was based on whether or not the treatment rendered patients seizure free. It is only in the last decade that QOL in epilepsy has emerged as an important outcome measure and has been included in epilepsy research (Hermann, 1992; Selai & Trimble, 1995). A great deal of QOL research has been done on adults with epilepsy. QOL in children with epilepsy has recently been acknowledged as an important health outcome to address, as children appear to be at special risk and the research in this area is increasing (Austin et al., 1994; Baker, 1995; Buelow & Ferrans, 2001).

6. RESEARCH FINDINGS ON THE QOL OF PATIENTS WITH EPILEPSY

According to Ellis et al. (2000) the last decade has seen an increase in the number of research articles which focus on psychosocial aspects of epilepsy, with areas such as patients' QOL and social support

increasingly being addressed. The studies have clearly demonstrated the detrimental influences epilepsy may have for the individual; however, a major oversight has been the lack of investigation into the influence of epilepsy on family members and family functioning. This section of the present review highlights some of the findings from selected studies completed on the QOL of adults and children with epilepsy. A comparison of this section of the present review with the section exploring the research findings of QOL studies on parents who have children with epilepsy, appearing later in the present review, clearly illustrates the argument made by Ellis et al. (2000). Research on the QOL of parents who have an epileptic child has been neglected compared to QOL studies focusing on the individual with epilepsy.

QOL, as reported above, is a multidimensional concept that encompasses the whole of life and this makes it a particularly salient concept in the context of epilepsy because of the far-reaching effects of the disorder (Buelow & Ferrans, 2001; Vickrey, 1993). According to Leidy, Rentz and Grace (1998) the QOL of people with epilepsy can be adversely affected by the threat and experience of seizures and the side effects of AED therapy. The authors further argue that seizure activity has been shown to be a significant predictor of overall HRQOL, anxiety, depression and self-esteem. They conclude that treatments designed to reduce seizure frequency and severity, increase seizure free periods, and minimize undesirable side effects will have a positive impact on patients' psychological well-being and social functioning and will contribute to improvements in their HRQL. However, Baker, Hesdon and Marson (2000) argue that the management of epilepsy is not only aimed at the cessation of seizures with minimal side effects, but also at an improvement in the patient's QOL. It seems that the first group of authors propose that a reduction in seizures results in an improvement in QOL whereas the second group of authors seem to argue that the cessation of seizures with minimal side effects does not automatically lead to an improvement in QOL. According to Vickrey et al. (2000) there are some researchers who describe seizure severity as an aspect of HRQOL while others consider it to be distinct. A common thread throughout the QOL research in epilepsy is the connection between seizure severity and frequency and HRQOL.

Three studies on the treatment of epilepsy with AED have used cognition and QOL as outcome measures and not seizure severity and frequency (Dodrill, Arnett, Somerville & Sussman, 1993; Dodrill, Arnett, Somerville & Shu, 1997; Mortimore, Trimble & Emmers, 1998). The findings in each of the studies seem to suggest that the AED tested do not seem to have an adverse effect on QOL and cognition in patients and that the length of each of the studies were too short for any comment to be

made on improvements in QOL. The authors do, however, suggest that complete seizure relief was not obtained, which resulted in none of the patients being allowed to obtain a driver's license or assume new roles which may have led to some improvement in their QOL. It has been reported that patients well controlled on monotherapy have better QOL than those on bi- and poly-therapy (Lam, Rozsavolgyi, Soos, Vincze & Rajna, 2001). In a study comparing two AED treatments in patients with newly diagnosed epilepsy, the authors seem to conclude that the adverse effects of drug therapy does not only complicate the patient's life, but also that of the researchers and clinicians. Clinicians have to employ sensitive tools to measure the impact of side-effects on patients' lives and these have to be self-report measures (Gillham, Kane, Bryant-Comstock & Brodie, 2000). It seems that the difficulty in using HRQOL as an outcome measure is that accurate measurement tools seem to be unavailable and this is further complicated by the fact that HRQOL has a different meaning for each patient.

Kellett, Smith, Baker and Chadwick (1997) reported that chronic drug resistant epilepsy is a disabling condition that impairs QOL. For some of these patients surgery may eliminate seizures, but it is a destructive procedure which carries a small risk of death or permanent neurological deficit. Freedom from seizures is presumed to improve QOL, but some patients experience difficulty adapting to freedom from seizures while others experience surgical complications which may be as disabling as chronic epilepsy. A more detailed knowledge about the degree to which patients benefit from surgery which extends beyond merely seizure relief and includes HRQOL is necessary (Bladin, 1992; Gilliam et al., 1999; Malmgren, Sullivan, Ekstedt, Kullberg & Kumlien, 1997; Vickrey et al., 1994). Findings related to QOL of epilepsy patients who have undergone surgery indicate that patients who are rendered completely seizure free have the highest HRQOL scores. The higher the reduction in seizure frequency, the more significant the improvement in HRQOL (Kellett et al., 1997; Malmgren et al., 1997; Markand, Salanova, Whelihan & Emsley, 2000; McLachlan et al., 1997; Vickrey, 1993). It has also been found that patients who are rendered seizure free show more improvement in HRQOL than patients who are seizure free but continue to experience auras (Malmgren et al., 1997; Vickrey et al., 1995). Gilliam et al. (1997) reported that surgery eliminates seizures and reduces AED requirements in most children; however, further research on the impact of surgery on QOL is necessary.

Patients who are rendered seizure free are able to live independently, show improvement in psychological well-being and show improved rates in the area of employment (Kellett et al., 1997; Malmgren et al., 1997). It has been reported that HRQOL is better in patients who have been rendered seizure free after surgery than in patients with hypertension, diabetes, heart disease or depressive

symptoms (Vickrey et al., 1994). Rose, Derry, Wiebe and McLachlan (1996) reported that patients who report poorer HRQOL prior to surgery are likely to show the greatest improvement in HRQOL post-operatively. It is further reported that patients who score high in neuroticism prior to surgery exhibited poorer outcomes in psychosocial adjustment and HRQOL post-operatively (Rose, Derry & McLachlan, 1996). It is concluded that not all patients achieve seizure freedom post-operatively and of those that do, a proportion do not show significant improvements in HRQOL. Pre-operative factors such as family relationships, personality variables and patient expectations impact on post-operative HRQOL. An important research finding, therefore, is the importance of pre-operative counseling for both patients and their families. It seems the more realistic patients are of possible outcomes and the more available their resources are pre-operatively, the greater the improvement in their HRQOL post-operatively (Ho, Ng, Chan & Lee, 2000; Lane et al., 1998; McLachlan et al., 1997; Mihara et al., 1996; Schwartz et al., 1995; Vickrey et al., 2000; Wheelock, Peterson & Buchtel, 1998). Chronic uncontrollable epilepsy has a profound impact on the patient's QOL and surgery has been reported to improve their QOL. However, even in patients with well controlled epilepsy QOL can be negatively impacted on.

According to Devinsky and Penry (1993) the ways in which epilepsy impacts on a patient's life is as individual as fingerprints. The patient's perspective in assessing QOL has therefore been an important finding and is emphasized in the QOL research completed on the general epilepsy population. It is acknowledged that the clinician cannot always explore the full spectrum of QOL issues; however, the exclusive focus on seizures and medication side effects limits the clinician's capacity to help his/her patients (Baker, Smith, Dewey & Chadwick, 1994; Buelow & Ferrans, 2001; Devinsky & Cramer, 1993; Devinsky & Penry, 1993; Hermann, 1993; Kugoh, 1996; Wagner & Vickrey, 1995; Whitefield, 1999). A great deal of attention has also been focused on which dimensions of QOL are important to focus on in research involving epilepsy patients. It has been argued that physical health, psychological health, level of independence, social relationships as well as frequency and severity of seizures are important issues (Cramer, 1994; Jacoby, 1992). Bishop and Hermann (2000) include symptoms, stigma, physical, social, family, cognitive and psychological functioning as well as energy and vitality.

In addition to the dimensions of QOL, instruments to accurately measure QOL as well as changes in QOL over time have also been explored. It seems that satisfactory instruments have been developed and applied; however, much research is still needed in this area (Baker et al., 1994; Baker et al., 2000; Buck, Jacoby, Baker, Ley & Steen, 1999; Buelow & Ferrans, 2001; Vickrey, 1993; Wiebe, Rose, Derry

& McLachlan, 1997). Further findings of QOL studies are that reducing side effects, achieving better control of seizures as well as reduction in seizure frequency are important in improving the QOL of patients (Baker, Jacoby, Buck, Stalgis & Monnet, 1997; Whitefield, 1999; Leidy, Elixhauser, Vickrey, Means & William, 1999). Reducing the stigma of epilepsy as well as the associated handicap is also linked to improvement in QOL in patients (Baker et al., 1997). It has also been reported that depression is a strong indicator of HRQOL, with an increase in depressive symptoms being associated with poor HRQOL (Lehrner, 1999). Patients who perceive themselves as having more control over and an increased ability to cope with their seizures as well as strong social support and hence less social isolation report greater QOL (Amir, Roziner, Knoll & Neufeld, 1999; Suurmeijer, Reuvekamp & Aldenkamp, 2001). A major finding seems to be that not all problems in epilepsy relate directly to seizure severity and frequency, but that the individual's perception and interpretation of living with the illness is a contributing factor to his/her QOL. Patients who are seizure free may still feel that their condition impacts negatively on their QOL (Devinsky & Penry, 1993; Jacoby, 1992; Whitefield, 1999).

According to Baker et al. (2001) older people diagnosed with epilepsy in later life are also more likely to have a negative perception of their QOL and are more likely to be anxious and depressed than those diagnosed earlier in life. It seems that there has been an increase in the incidence and prevalence of epilepsy after the age of 60, with epilepsy reported to be the third most common neurological condition of older age. The incidence of epilepsy sharply increases after the age of 50 and by the age of 80 it exceeds that of children (Baker et al., 2001; Frey, 2001; Tallis, 2000). Despite the high numbers it is argued that this is the most poorly researched area in epilepsy and little has been documented on the impact of the illness on the QOL of older people. Preliminary findings suggest that older people do not necessarily experience a poorer QOL than younger people, but those diagnosed for the first time in later life do appear to have a QOL which is more impaired (Baker et al., 2001; Tallis, 2000).

The findings of QOL research in children and adolescents appear similar to what has already been discussed in previous paragraphs. The research is scarce; the child's perceptions are important as are his/her parents'; and the development of more accurate measuring instruments that assess QOL across childhood and into adolescence is needed. Researchers have also focused on the QOL domains that are important to include in research on children and adolescents and these include the experience of epilepsy, the impact of epilepsy, life fulfillment and time use, driving, adverse affects of medication, as well as school performance (Arunkumar, Wyllie, Kotagal, Ong & Gilliam, 2000; Brown, 1994; Hanai, 1996; Ronen, Rosenbaum, Law & Streiner, 1999; Sabaz et al., 2000). Dunn and Austin (2000) focus on

the potential problems associated with epilepsy and it seems the argument is that these problems have a negative impact on the QOL of children and adolescents. The researchers include behavioural consequences of epilepsy in childhood as well as the risk factors for behavioural problems. In addition, they focus on academic achievement problems and the risk factors associated with these problems. The researchers also focus on treatment and interventions for problems affecting QOL in children. These include education programmes as well as psychotropic medication. Austin et al. (1994) found that children with epilepsy had a relatively more compromised QOL in the psychological, social and school domains than did children with asthma. Austin, Huster, Dunn and Risinger (1996) found that adolescents with epilepsy had a poorer overall QOL than those with asthma and that those with more severe seizures appear to report the poorest QOL. It has also been reported that children with additional handicaps, for example, mental retardation, are at a greater risk for poor QOL (Dunn & Austin, 2000; Sabaz, Cairns, Lawson, Bleasel & Bye, 2001). Espie and Kerr (2000) conclude that there are many challenges in the evaluation of QOL of those with mental retardation, specifically in relation to subjective measures of QOL. The researchers further argue that the domains impacting on QOL may be different for this population as compared to the general population. The authors conclude that clinically relevant tools to assess the QOL of patients with mental retardation and epilepsy do exist and the challenge that remains is for clinicians to apply these measures in their every day clinical practice.

It can be concluded that QOL has become recognized as a valuable outcome measure in epilepsy treatment and management and is consequently receiving much attention. Particular emphasis has been placed on the patient's subjective experience of his/her illness and the impact it has had on his/her QOL. However, noticeably absent from the research on QOL of patients with epilepsy is the QOL of the patient's carer or significant other. It is only in the research on children that parents are acknowledged and this is only in relation to the parents' perception of the QOL of their child and whether or not parents should complete the relevant QOL questionnaires (Arunkumar et al., 2000; Hanai, 1996; Sabaz et al., 2000). Espie and Kerr (2000) seemed to be the only authors who mentioned that epilepsy has a profound effect on the QOL of the individual with mental retardation as well as their carers and that clinicians should be more cognisant of this. The following section of the present review focuses on the importance of the QOL of parents caring for a child with epilepsy.

7. THE IMPORTANCE OF THE QOL OF PARENTS CARING FOR A CHILD WITH EPILEPSY

Parents play a significant role in the life of their child with epilepsy. Their functions include providing a stable environment within which the child can develop and function, seeking treatment and ensuring the child's compliance with treatment, as well as facilitating the child's functioning outside the home and regulating the impact that the attitudes of others have on the child. Parents are largely responsible for the long term outcome that epilepsy might have on their child. Parents also face a considerable burden and an increase in the amount of stress in their daily lives when caring for a child with epilepsy. The stress and burden together with the disruption they face in many areas of their life can lead to them feeling less satisfied with their lives and that the gap between the expectations they have of life and their actual experience of life is large and ever increasing. Ultimately parents may experience a reduction in their QOL and it is argued that a decrease in their QOL may render them less capable of coping with the many important roles they assume responsibility for, the most important being the care of their child with epilepsy. Research focusing on the QOL of carers of patients with different chronic illnesses emphasizes the importance of the carers' QOL.

The type of care the patient receives as well as determining how effectively carers are able to perform their different roles is directly related to carers' perceptions of their QOL (Aronson, 1997; Gunnell et al., 2000; Medeiros, Ferraz & Quaresma, 2000; Weitzner, Jacobsen, Wagner, Friedland & Cox, 1999; Ziegler et al., 2000). Ammerman, Van Hasselt and Hersen (cited in Cummins, 2001) have concluded that children with disabilities, across disability types, have a higher risk than normal of abuse by carers, which includes emotional as well as physical abuse. Schor (1998) stresses the fact that children's health and health behaviours are especially sensitive to the social context in which they live, specifically their home environment. Poor QOL in parents may lead to family relationships characterized by a great deal of conflict and this could impact on the child's seizures. As mentioned earlier, stress-related factors can precipitate seizures (Cull et al., 1996; Martens & Addington, 2001). It is further argued that parents who have a poor QOL may feel incapable and unable to cope with the increase in roles and this may lead to an increase in anxiety and depression. These feelings may filter down onto their child with epilepsy as well as to their other children, which could in turn lead to additional burden and stress for the parents. They may have to cope with a child's acting out behaviours as well as having to provide increased emotional support to their children, which may lead to further impairment of their QOL. Parents may be unable to use or increase their resources, which may result in a further decrease in their

QOL. A vicious cycle is thus created and maintained, which may have detrimental consequences including physical illness. It is argued that those parents who have a good QOL are able to cope with their child's illness and the demands of the illness; however, it is also argued that those who perceive themselves as able to cope with a child's illness will report experiencing a good QOL (Hughes, Giobbie-Hurder, Weaver, Kubal & Henderson, 1999; Lindqvist, Carlsson & Sjoden, 2000; Williams et al., 2000). It can be concluded that the child's and parents' QOL are interrelated. The child's QOL impacts on the parent's QOL and vice versa. The QOL of parents is important specifically because of the negative impact that a poor QOL can have on parents, their children and the outcome of the child's epilepsy, even in the child who eventually becomes seizure free.

8. RESEARCH FINDINGS ON THE QOL OF PARENTS OF CHILDREN WITH EPILEPSY

Illness impacts on a patient's QOL but also impacts on the QOL of those involved directly with the patient (Juniper et al., 1996; Levi & Drotar, 1998). The impact of epilepsy on the patient's QOL has been discussed in previous sections of the present review and the impact of the child's condition on the QOL of the parents has also been alluded to. According to Baker (1995) considerable attention has been paid to the physical, psychological and social consequences of epilepsy on the life of patients and an extensive literature search indicated that much of the same work has been done on the families of children with epilepsy, with particular reference to the impact that the illness has on the lives of parents and siblings. Kwong et al. (2000) focus on the concerns and perceptions of parents of children with epilepsy, while Hoare and Kerley (1991) stress the relationship between maternal anxiety and behavioural disturbances in the child with epilepsy as well as the increased burden and responsibility parents have to confront. Scrambler (1989) emphasizes parents' reactions, secrecy and concealment, as well as aspects of coping in the family. Austin (2001) reiterates the important role of the family and especially the parents in the life of the child with epilepsy and the consequences of negative parental responses. Freeman et al. (1997) as well as Appleton et al. (1997) emphasize the dangers of overprotection and overindulgence of the child with epilepsy as well as effective ways for parents to cope with the siblings of the child who has epilepsy.

Despite the importance of parents in the life of their child with epilepsy and the acknowledgement that the QOL of parents is as important as the QOL of the child with epilepsy, research in the area of QOL

of parents of children with epilepsy is scarce (Ellis et al., 2000). After an extensive literature search only three articles on the QOL of parents of children with epilepsy were found.

Hoare (1993) employed two questionnaires to provide a measurement of the QOL of children with chronic epilepsy and their families. The first questionnaire is a modified version of the impact of epilepsy schedule, a questionnaire that focuses on three areas, namely the medical care and treatment of epilepsy, the child's adjustment and development, and the effects on the family. The questionnaire was modified to allow for three possible responses to each question. The second questionnaire was the Holroyd Questionnaire on Resources and Stress which includes sub-sections covering areas such as dependency, restrictions on the family, family disharmony and lack of personal satisfaction (Holroyd, cited in Hoare, 1993). The subjects included 108 children and their families who were recruited from a larger study on the psychosocial adjustment of children with epilepsy. The children were aged between 5 and 15 years. The mean age of the children was 10.4 years and there was a greater number of boys than girls. Results of the study showed that age at diagnosis, treatment duration, current fit frequency, seizure type, additional disabilities and educational placement had an effect on the child and family's daily life and activities. Children diagnosed at a younger age, with longer treatment duration, mixed and complex seizure types and the presence of additional disabilities such as special educational placement, were more likely to be a source of concern for their parents than were children with a different clinical picture. Social restrictions on the family were more common in the aforementioned group, as well as adverse effects on the father's career and the mother's work. Parents in this group also showed an increase in concerns in the areas of seizure management, adverse effects of AED and the deleterious effects on the child's adjustment and development. Hoare (1993) concluded that early onset of intractable epilepsy accompanied by additional disabilities had a widespread adverse effect on the child's and family's QOL and overall adjustment.

Hoare and Russell (1995) argued that no adequate measuring instrument that captures the impact of chronic epilepsy in childhood on the QOL of the afflicted children and their families exists. Their aims therefore included the modification of an existing questionnaire in order to provide a more comprehensive assessment of the impact of epilepsy on the QOL of the child and family, as well as to provide data on the preliminary validation of the questionnaire on a selected group of children with epilepsy and their families. The subjects were children and their families recruited from an epilepsy clinic. There were 21 children involved, twice as many boys as girls aged between 6 and 17 years with a mean age of 11 years. The modified questionnaire, referred to as the Impact of Childhood Illness

Scale, consisted of 30 questions divided into four sections which included the impact of epilepsy and its treatment, the impact on the child's development and adjustment, the impact on parents and the impact on the family. The design of the questionnaire was influenced by several considerations. The first was that it should be brief and capable of completion by a non-specialist. The second was that it should assess the impact of epilepsy from several perspectives and thirdly it should discriminate satisfactorily between children according to the severity and the degree of control of the epilepsy. Preliminary findings indicated that parents of children with poorly controlled seizures had consistently higher mean scores on all sub-scales, suggesting that epilepsy affected parents and children in this group more adversely. Parents' concerns included injury from seizures, medication side effects and a wide variety of aspects of daily living. The results indicated that the modified questionnaire had validity and might be useful in measuring the impact of chronic childhood epilepsy on the QOL of children and their parents.

Yang et al. (1996) completed a study on children who had undergone a corpus callosotomy and their families. The purpose of the study was twofold. The first purpose was to investigate the mental performance, behavioural patterns and changes in QOL in children who had undergone corpus callosotomy for severe intractable epilepsy. The second purpose of the study was to evaluate the overall satisfaction with QOL and changes in QOL of the families of the children who had undergone the corpus callosotomy. Twenty-five children with medically refractory seizures were included in the study. All the children were younger than 15 years and the majority had an additional diagnosis of mental retardation. The children underwent anterior two-thirds corpus callosotomy and were followed up at a mean period of 19.3 months post-operatively. Neuropsychological testing as well as intelligence tests were performed on the children pre- and post-operatively. A short form of the Behaviour Checklist for Chinese Children was completed by parents pre- and post-operatively. At least six months after the operation parents were asked to rank changes in the child's seizure severity and frequency as well as their satisfaction with the operation and their QOL since the operation. The results of the study indicated that mental performance was not an important indicator of QOL from the parents' point of view, as IQ score did not correlate with post-operative QOL satisfaction. Parents' anxiety levels decreased after the callosotomy and improvements in attention span and social skills in the child correlated with improvements in QOL in parents. The researchers concluded that successful corpus callosotomy could reduce seizure severity, improve behaviour, and lead to greater family satisfaction with their QOL.

The research findings cited above are limited to parents who have children with severe and intractable epilepsy who have attended specialist clinics on a regular basis. The findings are also based on explorative studies on small groups of subjects. It may therefore be unwise to generalize the findings and apply them to other groups of children with epilepsy and their parents. The researchers involved in the three studies cited above, however, concur that epilepsy impacts negatively on the QOL of parents caring for a child with epilepsy and that further research in the area is a useful and necessary endeavor. Evidence of the impact of epilepsy on the QOL and activities of daily living explored in previous sections of the present review confirms that research in the area of QOL of parents caring for a child with epilepsy is essential. It seems that they are a vulnerable and underserved group. Directions for future research will be put forward in the next section of the present review.

9. DIRECTIONS FOR FUTURE RESEARCH

Family members and not professionals are the primary healthcare providers for most patients, and family caregiving has led to increasing physical and psychological burdens on family members and resulted in physical and psychological problems for many caregivers (McDaniel & Campbell, 1998). The impact of epilepsy and its treatment extends beyond the patient to one or more caregivers. Despite this, however, most of the research on epilepsy has been directed toward the patient alone (Ellis et al., 2000; Lane et al., 1998). This has been highlighted in the present review. Epilepsy is reported to be the most common neurological disorder in childhood with the disease impacting on all aspects of the child's life, resulting in the child experiencing a poor QOL. The present review has explored the important roles parents play in the life of their child with epilepsy as well as the impact that the child's condition has on his/her parents and family. While attention has been focused on the impact of the illness on the child's family very little research has been completed on the QOL of parents caring for a child with epilepsy.

Fallowfield (1990) argues that the failure to monitor QOL could lead to the acceptance of treatments which have a deleterious effect and the rejection of those which have a beneficial or less harmful impact on all the dimensions contributing to QOL. Undoubtedly Fallowfield was referring specifically to the patient and his/her QOL. However, it is argued that since parents are an integral part of their child's treatment and have a profound impact on the outcome of their child's illness, failure to measure their QOL could lead to treatment failure as well as poorer QOL for their child (Strauss & Glaser, 1975). Extensive research is therefore needed on the QOL of parents who have children with epilepsy.

Research concerning the development of appropriate instruments that include the appropriate domains of QOL, that reflect the perceptions of the parents regarding the impact of the disease on their QOL, and that are sensitive to changes over time, are necessary.

QOL is a multidimensional construct and the specific dimensions that are impacted on by raising a child with epilepsy require further research so that appropriate programs and interventions can be developed. The dimensions may differ according to the severity of the child's epilepsy as well as the specific socio-cultural setting parents find themselves in. For example, those parents living in developed countries who have access to more specialized clinics as well as a great deal of support from professionals may report negative impact in different areas as opposed to parents living in a developing country where access to treatment is limited. Furthermore, a parent caring for a child with refractory epilepsy and additional handicaps may report negative impact in different dimensions of QOL.

In addition to the multidimensional nature of QOL, it also changes over time and across the disease trajectory (Abetz et al., 2000; Calman, 1987; Jacoby & Baker, 2000; Schipper et al., 1990; Wiebe et al., 1997). Parents of newly diagnosed children may report a different QOL than those who have a child whose epilepsy has been well controlled on AED for a long time. Changes in QOL across the disease trajectory may provide useful information for clinicians on factors that reduce or improve QOL in parents and their child with epilepsy. For example, parents of a child newly diagnosed with epilepsy may report a poor QOL; however, with the development of coping skills and a strong support system the parents may indicate improvements in their QOL. This may provide the clinician with useful information to convey to parents in similar situations.

The nature of the child's epilepsy, seizure severity and frequency, the presence of additional handicaps, and how these factors interact with parents' QOL is an additional area of research that could provide valuable information to those working with families and children in the area of epilepsy. In addition to this, it may be useful to explore and compare the QOL of parents caring for a child with epilepsy and those involved in the care of children with other chronic illnesses such as diabetes or asthma. Valuable information on aspects unique to parents caring for a child with epilepsy may be forthcoming. The impact of different treatment options on the QOL of parents is a further worthwhile area of research, because difficult decisions in this regard may result in considerable burden for parents. Parents may be faced with having to decide between AED treatment and surgical treatment. Considering the side effects of AED and the risks involved with surgical treatment, parents may experience a great deal of

anxiety and possible future guilt. Knowledge about parents' perceptions of epilepsy and the impact this has on their QOL as well as their child's QOL is essential for effective treatment and management.

It has been pointed out in this review that caring for a child with epilepsy may increase the burden and stress of parents and reduce their QOL. It is further argued that spouses living with and performing certain caregiver roles as well as individuals caring for an older person with epilepsy may also experience an increase in role stress and burden and consequently a decrease in QOL. A wife whose husband is diagnosed with epilepsy may report a poor QOL. She may become the sole breadwinner, worry about when the next seizure may occur, and as a result may feel unable to allow her children to be left in the care of her husband. Because of felt stigma she may isolate herself and her family, irrespective of the severity of her husband's epilepsy. Research therefore needs to be extended to those caring for or living with older individuals who have epilepsy (Ellis et al., 2000). A child who has a parent that suffers from epilepsy may also experience a considerable amount of stress and burden. The stress and burden experienced by the child may be directly linked to the epilepsy. For example, the child may experience feelings of shame, guilt and anxiety at having a parent who has an incurable illness with much stigma attached to it. Children may also be negatively influenced by parental conflict, which may result from one parent suffering from epilepsy and the other parent having to assume additional roles in the family and consequently experiencing an increase in stress and burden. Research done on these children may produce valuable insights for parents as well as for clinicians.

To the knowledge of the present researcher only one study on the QOL of South African patients with epilepsy has been completed (Whitefield, 1999). According to Whitefield (1999) research on the cross-cultural differences of people with epilepsy is warranted, as well as specific concerns relating particularly to the South African population. According to Pahl (2001) issues facing people with epilepsy in Africa include social and cultural beliefs about epilepsy that contribute to poor help seeking behaviours, the stigma that exists even among health care workers, as well as the non-availability and inaccessibility of AED. These findings are confirmed by Christianson et al. (2000) who reported that a significant number of children in their study did not receive AED and that parents were hesitant to seek treatment for their children because of the stigma attached to epilepsy. Research on epilepsy in South Africa is necessary in a wide range of areas, including an exploration of the different cultural beliefs and meanings attached to the illness, the availability of treatment, as well as the QOL of patients and their parents, significant others or caregivers. Instruments that are reliable, valid and sensitive and that can be used for the South African population needs to be developed (Selai & Trimble, 1995).

10. CONCLUSION

Epilepsy is a medical diagnosis and a social label with the potential to impact on all dimensions relating to the individual's QOL. Epilepsy diagnosed in childhood, irrespective of whether or not the individual's condition is controllable or uncontrollable, accompanied by additional handicaps, characterized by severe and frequent seizures or the occasional simple partial seizure, can have a negative impact on the individual's life that extends into adulthood. Parents play a variety of significant roles in the life of their child with epilepsy and their management of these roles has a profound impact on the outcome of the illness for the child. These additional roles cause parents considerable stress and burden and impact on their QOL and hence on their ability to adequately perform their roles. Research on the QOL of parents caring for a child with epilepsy is essential and may contribute to a decrease in the negative impact of childhood epilepsy on patients as well as facilitate management and treatment decisions.

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