

**RISK FACTORS IN THE DEVELOPMENT OF PSYCHOLOGICAL  
PROBLEMS IN CHILDREN WITH EPILEPSY: WITH A  
PARTICULAR FOCUS ON THE FAMILY**

**By Katherine Rogers**

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**Supervisor: Dr Graham Lindegger  
Department of Psychology, University of Natal  
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## DECLARATION

I declare that this research report is my own work. It is being submitted for the degree of Master of Arts (Clinical Psychology) at the University of Natal, Pietermaritzburg. It has not been submitted before for any degree or examination at any other university.

Kate Rogers

Katherine Emma Rogers

28/12/98

Date

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## ABSTRACT

The main aim of the current study was to examine risk and protective factors associated with the development of psychological problems in children with epilepsy. The study aimed to answer the broader question of "Why do some children with epilepsy develop psychological problems while others do not?" A number of risk and protective factors were investigated in children with epilepsy between the ages of 8 - 13 years of age. Three main sets of variables were investigated to determine their association with risk of psychological problems in children with epilepsy:

1) family variables ie. family adaptability, family cohesion and family coping 2) illness variables ie. type of seizures, seizure frequency, type of medication, length of time of diagnosis and 3) demographic variables (including child variables) ie. socio-economic status, number of siblings, age and gender of the child with epilepsy. 45 mothers were interviewed and required to complete questionnaires that provided information related to their child's illness, family functioning and demographic factors. In addition, mothers were requested to provide further information related to behavioural and emotional problems that were experiencing with their epileptic child.

Broadly the study concluded that a number of risk factors were found to be associated with the development of psychological problems in children with epilepsy. Specifically grandmal seizures were associated with an increased risk of disorder when compared to petit mal seizures. Higher levels of family adaptability and cohesion were associated with a decreased risk of disorder, and children from families classified as functioning at balanced levels were additionally associated with a lower risk of disorder. Family coping in contrast did not appear to be associated with risk of disorder. The use of poly-medication by children with epilepsy also increased the risk of disorder when compared to those children who used only one type of medication. Children from families falling within the classification of low socioeconomic status were also at an increased risk of disorder as well as those children with epilepsy who came from families where they had a larger number of siblings.

The study additionally developed a model of risk and protective factors using logistic regression. It was found that there was a "good fit" of the combined illness variables (type of epilepsy, type of medication), family variables (family type) and demographic variables (SES) with the

predicted dependent variable 'risk of disorder'. These results suggest that disease, demographic, family and contextual factors all interacted and overlapped to some extent in predicting the psychological adjustment of epileptic children in the current study.

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## CHAPTER ONE: INTRODUCTION AND AIMS

### 1.1 INTRODUCTION

It has been estimated that approximately 1% to 2% of the population in South Africa suffer from some form of epilepsy (South African National Epilepsy League, 1997). Over half the cases of epilepsy develop in childhood, at a time that is critical to the acquisition and development of basic social, emotional and cognitive competencies (Seidenberg & Berent, 1992). Epilepsy is often a chronic and intractable condition that can exert its influence on the affected person's development over an extended period of time (O'Donohue, 1985a).

Epilepsy is a descriptive term for a neurological condition involving seizures that consists of a variety of symptoms and medical characteristics that cluster together. Seizure activity may best be described as behavioural events resulting from abnormal neuronal excitability (O'Donohue, 1985b). Various forms of seizures and types of epilepsy can be observed and a number of classification systems have been proposed as temporary guidelines, which are continually undergoing revision (Stafstrom & Holmes, 1995). Epileptic seizures may vary widely in their symptomatic presentation, duration, frequency of occurrence and their response to medication. For example, epileptic seizures may vary from a brief "absence" seizure lasting a few seconds ("petit mal") to a typical "grand mal" seizure involving total loss of muscle control, loss of consciousness, and convulsions, with a recovery period that may last from hours to days.

Although many chronic childhood illnesses involve concomitant emotional disturbances, research suggests that children with epilepsy are particularly prone to poor social and psychological adjustment (Austin, 1988; Carlton-Ford et al., 1995; Vining, 1989). Children with epilepsy have been repeatedly shown to exhibit more behaviour problems than other children (both with and without other chronic illnesses) (Austin, 1988; Hoare, 1984a; Hoare & Kerley, 1991; Mathews et al., 1982; Rutter et al., 1970a) and to have lower levels of self-esteem as well as higher levels of depression (Austin et al., 1982; Austin & McDermott, 1988; Rutter et al., 1970a). Despite this associated higher risk of psychological problems, a number of children with epilepsy have minimal or none of these difficulties (Austin, 1988; Hoare & Kerley, 1991; Lavigne & Faier-Routman, 1992). This leads one to question why some children appear to avoid these associated difficulties while others remain at risk for psychological problems? The current study aims to

address this question by examining the factors associated with both positive and negative outcomes in children with epilepsy.

A major limitation of past research in the area of childhood epilepsy (and childhood chronic illness in general) is that it has suffered from what has been termed "the difference/deficit" strategy. This type of research typically makes use of two-group comparisons between children with and without a chronic illness, and has aimed to investigate whether children with a chronic illness such as epilepsy have an increased rate of psychological adjustment problems compared to children with no chronic illness (Ferrari et al., 1983; Holden et al., 1997; Lavigne & Faier-Routman, 1992, 1993; Viberg et al., 1986; Ziegler, 1981). This two-group approach often assumes that chronic illness imposes more homogeneity among its members because of the health impaired condition. Research suggests however, that heterogeneity of response to such disabling conditions is more common and that many additional variables play an interactive role in the development of psychological problems linked with pediatric chronic illness (Pless et al., in Harper, 1991). There have been relatively few within-group studies in the area of childhood epilepsy aimed at identifying the risk factors and mechanisms associated with the development of psychological problems in this group.

As opposed to psychological resilience, 'risk' has been identified as indexing the degree of vulnerability or susceptibility to physical or psychological morbidity and has been associated with exposure to life stressors and demands as well as a number of other factors (e.g genetic factors, attention deficit disorder etc.) (Silver & Wortman, in Holahan & Moos, 1987). Risk research is concerned with the identification of factors that accentuate or inhibit disease and deficiency states and the processes that underlie them (Haggerty et al., 1994). Protective factors can be defined as assets that individuals actively use to cope with and overcome vulnerability and risks, but may also include external factors such as the family or social context (Gilgun, 1996). Only a limited amount of research in the area of childhood epilepsy has investigated risk and protective factors associated with psychological adjustment in children with epilepsy. Of the available studies, the majority have focused on illness variables as risk factors, while considerably less research has identified and examined the potential role of the family (ie. family relations or family coping) as either a risk or protective factor (Austin, 1988; Carlton-Ford et al., 1995; Hermann & Whitman, 1984). Further research in this area can be seen as important, firstly in the identification of children with epilepsy at risk for the development of psychological problems and secondly to

assist in the design of appropriate counselling methods and services for these children and their families.

The main aim of the current study was the identification of risk factors associated with the development of psychological problems in children with epilepsy between the ages of 8 and 13 years old. Three main sets of variables were investigated to determine their association with risk of psychological problems in children with epilepsy: 1) family variables (family adaptability, family cohesion and family coping); 2) illness variables (type of seizures, seizure frequency, type of medication, length of time of diagnosis and 3) socio-demographic and child variables (socio-economic status, age and gender of child, number of siblings). These dimensions can be seen to be consistent with Wallander et al's (1989) conceptual model which emphasizes the transactional and reciprocal interaction among children, illness variables, the family and the social environment in accounting for the differential psychosocial adjustment in chronically ill and handicapped children (Wallander et al., 1989). Only a limited amount of research has investigated family variables such as family cohesion and adaptability in the area of risk factors in relation to psychological adjustment in childhood epilepsy, and there has been virtually no examination of family coping in this regard. A specific focus of the current thesis was the investigation of these three family variables (in addition to other variables) in relation to psychological adjustment in children with epilepsy.

The structure of this study will be as follows: Chapter Two commences with a discussion of the theoretical issues surrounding notions of risk and resilience in the development of childhood psychological problems, which is followed by an introduction to family systems theory, and the concepts of family coping and family functioning as used in the current study. Given that childhood epilepsy falls within the definition of a chronic illness, Chapter Three broadly examines the literature in the area of childhood chronic illness relevant to the aims of the current study. Chapter Four provides a brief description of the nature of childhood epilepsy, and discusses the effects of epilepsy on both the child and the family. The literature will also be reviewed with regard to studies investigating risk factors in the development of psychological problems for children with epilepsy. In Chapter Five the research methodology and the hypotheses of the current study are outlined. Chapter Six presents the results of the study, which will be followed by a discussion and conclusion of the results in Chapter Seven.

## **CHAPTER TWO: THEORETICAL BACKGROUND**

### **2.1 INTRODUCTION**

This chapter aims to introduce and discuss some of the theoretical and conceptual issues relevant to the present study. Chapter Two consists of two sections: Section One aims to provide the reader with an understanding of the concepts of risk and resilience (or protective factors) with regards to psychological adjustment in children. Specific theoretical models related to risk and protective factors in relation to child psychological functioning will be examined as they form important background literature to the main research question of the current study ie. What are the factors and processes involved in the psychological adjustment of children with epilepsy? Given that the current study additionally has a specific focus on examining family variables associated with risk and resilience in children with epilepsy, Section Two will provide a brief discussion of family systems theory, and will additionally examine concepts of family coping and family relations as used in the current research. In addition, as childhood epilepsy can be considered a form of chronic illness, theoretical issues related to childhood chronic illness and epilepsy will be discussed briefly in this section and will be elaborated on in Chapter Three.

### **SECTION ONE: RISK AND RESILIENCE**

#### **2.2 THE CONCEPT OF RISK AND RESILIENCE**

##### **2.2.1 Definition of Psychological Risk**

"Developmental risk" can be seen to be a relative term used to express the likelihood of vulnerability or susceptibility of an individual to psychological or physical morbidity in both the future and present (Holahan & Moos, 1987; Werner, 1986). Risk research aims to identify the factors (ie. individual or aspects of one's life situation) that either accentuate or inhibit disease and deficiency states, as well as to gain an understanding of the processes that underlie them (Gilgun, 1996; Haggerty et al., 1994; Holahan & Moos, 1987; Rak & Patterson, 1996). Earlier studies frequently compared children with or without a specific medical illness in order to determine levels of risk and have been criticized due to their assumption that deviation is a "characteristic of the child independent of context" (Sameroff & Seifer, in Lewis et al., 1988:

425). Recent research has begun to shift to the more complex question of investigating the contextual factors associated with this increased risk in children with chronic illness. Sameroff and Seifer (in Lewis et al., 1988) has proposed that risk be seen as a transaction between the individual and the environment rather than as a property of the individual and suggest that individuals move in and out of risk status depending on a multitude of individual and environmental transactions. Garmezy et al (1984) similarly outline that stressors are rarely single events but are parts of complex environmental and transitional influences. For example, schizophrenia in a parent has been identified as a risk factor that increases the likelihood of emotional problems among children, but the risk for the child may be related to a large number of factors such as genetic risk factors, parent-child interaction etc. (Sameroff et al., 1982). Many problem behaviours are seen to have multiple causes or risk factors where the majority of children with one problem behaviour tend to have other problem behaviours. Garmezy et al (1984) propose that the co-occurrence and/or interrelatedness of risk factors is therefore an important direction focus for current and future research.

Although some risk factors may eventuate in disorders (which identifies vulnerability) others in many instances may be overcome and lead to positive adaptive behaviour (which identifies resilience) (Haggerty et al., 1994). Research in the area of resilience has indicated that various other factors may counter the effects of risk factors and promote adaptive functioning (Gilgun, 1996).

### 2.2.2 Definition of Protective Factors and Resilience

Research on risk and resilience has been guided in recent years by a concern with stress moderating processes, a dynamic through which harmful effects are offset by various coping resources. Psychological stress is defined as "a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well being" (Lazarus & Folkman, 1984: 21). Individuals are seen to make either a satisfactory or unsatisfactory adaptation to stressors, where poor adaptation is seen to be related to psychological and physical symptomatology. As suggested by O'Grady & Metz (1987) "various influences may interact complexly to support a vulnerable child's self-righting tendencies or, conversely, critically overtax and defeat the child's coping mechanisms" (p. 5). Protective factors can be defined as assets that individuals actively use to cope with, adapt to, or overcome vulnerability or risks but may also include factors within the family or social context

(Gilgun, 1996). Phipps and Mulhern (1995) point out that protective factors are those variables that operate indirectly and whose effects are seen only in the presence of a specific stressor.

Resilience is defined as "the capacity of those who are exposed to identifiable risk factors to overcome those risks and avoid negative outcomes" eg. behavioural problems, psychological maladjustment, physical complications etc. (Rak & Patterson, 1996: 368). As suggested by Cowen et al (1990) research in this area aims to answer the question: How does wellness come about in spite of certain life stresses and what can be done to promote it? (Cowen et al., 1990). Haggerty et al (1994) explain that to speak of resilience does not necessarily reflect an imperviousness to stress, but instead is designed to reflect the capacity for recovery and maintained adaptive behaviour following stressful events. Multiple adjustments particularly of the negative variety (ie. death of a parent, divorce etc) are thought to tax the coping strategies of children and their families, in turn weakening their resistance to emotional disorders (Wolff, 1995).

### 2.2.3 Risk and Resilience Studies

Studies on risk and resilience have sought to 1) identify the risk factors associated with psychological problems in children and 2) to understand how children who are subjected to risk factors in childhood can overcome negative consequences. Studies in this area have followed various methods of investigation ranging from individual case histories, to cross-sectional studies and longitudinal investigations (Cowen et al., 1990; Haggerty et al., 1994; O' Grady & Metz, 1987; Rutter, 1979; Werner, 1986). A broad range of adversities (or "risk factors") have been explored in recent years documenting specific effects on children eg. genetic factors, poverty or harsh living conditions, inadequate child parent interactions etc (Emery & Forehand, 1994; Rutter, 1979; Seifer, 1995). As will be discussed Chapter Three, and Four respectively, childhood epilepsy (as well as other chronic illnesses) additionally places the child at risk for the development of psychological problems and has been included in studies examining risk and protective factors.

A number of studies have concluded that risk and protective factors reside not only within the individual but more broadly within families, other social groups and communities (Cowen et al., 1990; Garmezy et al., 1984, Haggerty et al., 1994; O' Grady & Metz, 1987; Rutter, 1979; Sameroff et al., 1982). Studies have specifically found the following triad of protective factors

that have the potential to mediate the effects of stress, some examples of each are mentioned ie. a) Individual factors: such as age (being older), sex (female gender), IQ (higher intelligence), and early temperamental predispositions in the child (e.g. responsiveness, outgoingness, attractiveness of the child to others, perceived efficacy etc.), higher self-esteem, problem solving skills, and internal locus of control (Garmezy et al., 1984, Haggerty et al., 1994; Kyrios & Prior, 1990; Masten et al., 1988; Rak & Patterson, 1996; Rutter, 1979); b) Family factors: family cohesion and supportive milieus within the family, and good parent-child relations (Billings & Moos, 1985; Gore & Eckenrode, 1994; Rutter, 1979); c) Extrafamilial factors: the availability of extrafamilial identification models and family ties to supportive social relationships (Cowen et al., 1990; Gore & Eckenrode, 1994; Rutter, 1983; Werner, 1986). Although it is beyond the scope of this thesis to review such studies, research examining risk and protective factors related to psychological adjustment in chronically ill children and children with epilepsy will be discussed further in Chapter Three and Four respectively.

### **2.3 MODELS OF RISK AND RESILIENCE**

Various models have been developed to explain both how risk factors might increase psychological problems among children at risk and the way in which protective factors might contribute to competence (Garmezy et al., 1984). Some of these models are general in nature in that they investigate risk factors as they apply to any population at risk, rather than being specific to pediatric physical disorders, while other models specifically examine factors related to childhood chronic illness (Pless & Pinkerton in Lavigne & Faier-Routman, 1993; Wallander et al., 1989). Three main models have been proposed by Garmezy et al (1984) to evaluate the relationship between risk and resilience: 1) a compensatory model, in which stress and personal attributes combine additively to predict competence (Keogh & Weisner, 1993; Rak & Patterson, 1996); 2) a challenge model in which stress is viewed as a "potential enhancer" of competence as long as it is not excessive, resulting in a curvilinear relationship between stress and competence and 3) the conditional model which postulates that the presence of certain personal attributes work to modulate (dampen or amplify) the impact of risk factors (Rak & Patterson, 1996) eg. temperament, internal locus of control. Many of these models attempt to measure levels of stress through specific life events scales.

Wallander et al (1989) have presented a more articulated model that is a variation on the main theme of models outlined above and attempts to examine risk and protective factors associated

with psychological and physical adjustment to physical illness. This model emphasizes the transactional and reciprocal interaction among children, parents and the environment (Lavigne & Faier-Routman, 1993) and operationally conceptualizes specific groups of variables as predictors in evaluating the child's reciprocal response to disability and illness in the family unit. These risk factors include disease/disability parameters, functional independence, and psychosocial stress. A number of resistance factors are hypothesized as important such as social-ecological factors (family environment, socio-economic status, social support, family members' adaptation, utilitarian resources) and stress processing variables (cognitive appraisal, coping strategies). The combination of risk and resistance factors are seen to affect the child's adaptation (mental health, social functioning, and physical health) (Harper, 1991). Adjustment is determined in part by competence, which is defined in terms of the coping responses emitted when an individual is confronted with problematic situations (Varni & Wallander, in Eiser, 1990). Temperament is also seen to play a role in adjustment and seen to be a way of describing "traits" or natural tendencies brought by the child (Combrinck-Graham, 1989). This framework is based on the principles of stress and coping theory in which groups of stressors and resources may serve to mediate differences in psychosocial functioning for both 'at risk' and healthy individuals (Lazarus & Folkman, 1984). In addition, it can be seen to take into account a large range of contextual factors and processes that additionally impact on the chronically ill child's adjustment (See fig. 1 below).

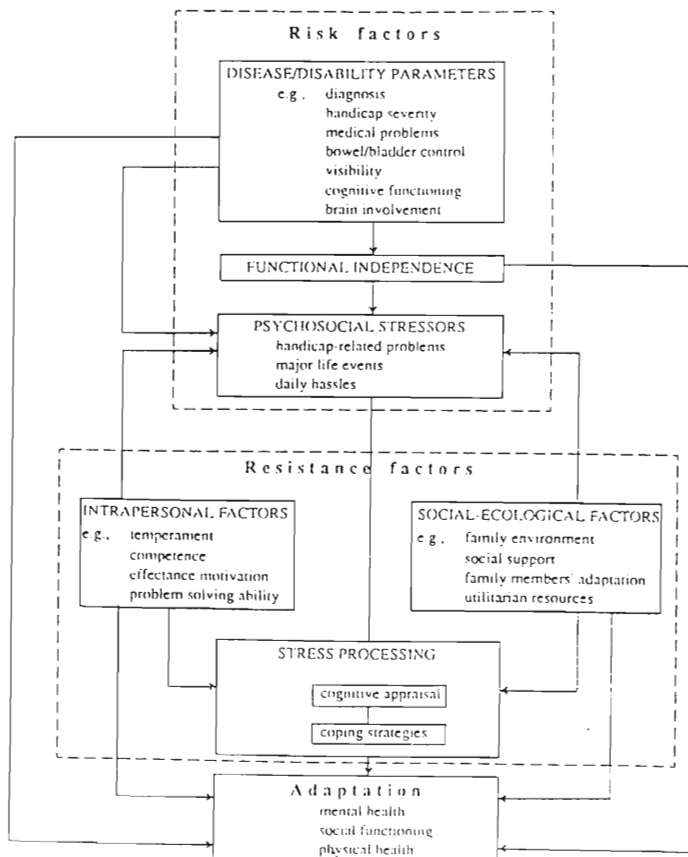


Figure 4-1. Biopsychosocial systems of childhood.

Pless and Pinkerton (in Lavigne & Faier-Routman, 1993) presented a model specific to the adjustment of children with physical disorders, which placed self-concept as a central variable affecting the child with a physical disorders. This model emphasizes the interrelationships between family, personal and disease factors, with self-concept and coping abilities playing an essential role in affecting psychological adjustment.

Research has additionally concluded that stressors have an interactive effect on each other, rather than an additive effect, with a disproportionate rise in risk associated with the presence of two or more stressors (Gilgun, 1996; Rutter, 1979, 1994; Sameroff et al; 1982). The complex nature of studying risk factors in children is noted by Luthar (1993) who suggests that "In reality, biological or psychosocial risk factors rarely act in isolation, and the simultaneous consideration of multiple stressors accounts for far more variance in outcomes than any one stressor considered individually" (Luthar, 1993: 445). Researchers also suggest that one needs to consider risk variables in conjunction rather than individually in order to predict individual difference in adjustment (O'Grady & Metz, 1987). Past research has indicated that there is substantial variability in terms of adverse outcomes for children which tends to vary as a function of interactions between different risk and protective factors or different environmental circumstances in which the child is embedded. As indicated by Werner (1986) risk factors "are not black boxes into which one fits children neatly stored away. They are probability statements, the odds of a gamble whose stakes change with time and place" (Werner, 1986: 18). Ideally a multidimensional approach is proposed for comprehensively assessing the degree of a child's risk for emotional disorder which incorporates the complex interplay of risk and protective factors that can be categorized as child-based factors, family factors, illness factors and environmental factors ((Lewis et al., 1988; O'Grady & Metz, 1987; Wallander et al., 1989).

## **SECTION TWO: THE FAMILY AND CHILDHOOD CHRONIC ILLNESS**

### **2.4 INTRODUCTION**

The family can be seen as "central in people's lives because it is the place where crucial needs are both created and satisfied" and it is often the primary context within which the child copes with chronic illnesses such as epilepsy (Pearlin & Turner, 1987: 143). The family is the environment where the individual learns a sense of belonging and a sense of being separate (Minuchin, 1974). As such it can be seen to potentially play a significant role in the psychological adaptation of the

chronically ill child. One of the goals of the current study is to better understand the relationship between family variables ie. family cohesion, adaptability and family coping and psychological problems in children with epilepsy. It is first necessary however, to present a brief description of family systems theory which provides a contextual approach to the understanding the relationship between family variables and child psychological problems.

## **2.5 THE FAMILY AS A SYSTEM**

### **2.5.1 An Introduction to Systems Theory**

Systems theory highlights the principles of organization and interrelatedness of the family, where among the most important tenets are the beliefs (a) that systems are composed of interrelated parts, (b) that a change in one part is associated with change in all others, (c) that systems maintain a balance of periods of homeostasis and periods of change and stability (Von Bertalanffy, 1968). In addition the family can be seen as an open system, with its boundaries being selectively permeable, which has links with a larger community and various other systems ie. other families, school, work, doctors etc. (Gochman, 1985). Systems theory can be seen to emphasize wholeness, where the family system has been defined as an organic unit, a dynamic system in which every part is simultaneously organizing and being organized by other parts. Component subsystems exist on the one hand, such as parental, marital and child subsystems, while the family itself is a component subsystem of suprasystems such as larger social contexts (Bloch, 1984; Bronfrenbrenner, 1979; Minuchin, 1974). According to the systems perspective, what is important is interaction and modes of communication between family members rather than the actual content of the relationship of the members themselves (Turk & Kems, 1985). A systems approach emphasizes feedback loops among all members of a family and distributes responsibility for dysfunction throughout the family system (Kazak, 1989; Okun & Rappaport, 1980). In addition, the family contains homeostatic mechanisms to restore balance and equilibrium when faced with external demands for change. The family may respond with growth, flexibility and structural evolution or conversely with rigidity and stagnation (Okun & Rappaport, 1980; Shapiro, 1983).

### 2.5.2 An Ecosystemic Approach to Child Symptomatology

As suggested by Turk and Kerns (1985) children engage in a variety of circumstances within the school system and with peers, neighbours, the media and so forth and therefore it should not be assumed that the family plays the exclusive shaper of the individual's conceptions of themselves and the world. Combrinck-Graham (1989) additionally notes that "we have biological models to explain events within the individual, psychological models to explain events of the individual, and family models to elaborate upon events around the individual" (p. 67). She suggests, however that although such individual models are useful they can be seen as limited to the extent they lack the integration of modifying influences of several other levels. In recent years however family systems theorists have described themselves as "ecosystemic" in order to incorporate the various contextual systems that may impact on the individual (Combrinck-Graham, 1989).

An integration of systems thinking with theories from developmental psychology can be seen to play an important role in the consideration of child symptomatology. The social-ecological perspective (Bronfenbrenner, 1979) provides such a framework and proposes that the child is at the centre of a series of concentric circles, which represent settings that have bidirectional influences on the child (Bronfenbrenner, 1979). The microcosm is "a pattern of activities, roles, and interpersonal relations experienced by the developing person in a given setting with particular physical and material characteristics (Bronfenbrenner, 1979; p. 22) (eg. emotional assistance, childrearing sanctions, modelling etc). Contextual factors such as the family, the neighbourhood, as well as larger cultural and political systems are seen to impact on the individual's development and vice versa.

The biopsychosocial influence on a child can be represented by a series of concentric spheres creating a continuum of three dimensional domains either encompassing or being encompassed by others (See fig. 2). Each of these domains may shape or alternatively be shaped by the relationships of events in other spheres in the ecology (Combrinck-Graham, 1989: 68).

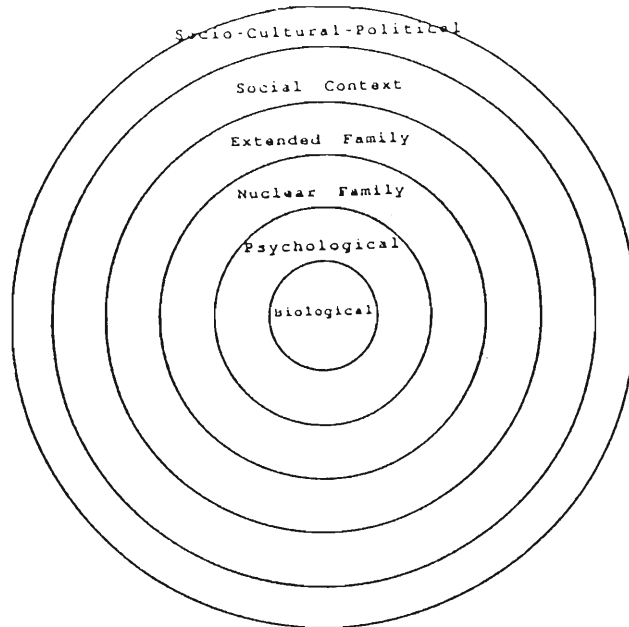


Fig. 2. Biopsychosocial Systems of Childhood (Combrinck-Graham, 1989; p. 72)

Ideally, when attempting to examine factors that may play a role in the development of the child with chronic illness, one needs to take into account as many domains as possible which may include biological factors, social factors, genetic predisposition, illness factors etc. The so-called "organismic family therapist" is seen to work with the understanding of the symptomatic behaviour as "intrinsic to the operations of the entire ecological system, of which the family is a most significant level for children" (Combrinck-Graham, 1989: 19). Additionally, one would need to determine to what degree psychological functioning and behaviours are determined by the specific contexts within which they occur (Combrinck-Graham, 1989).

## 2.6 THE CIRCUMPLEX MODEL OF FAMILY RELATIONS

### 2.6.1 Introduction

The current study is particularly interested in the relationship between family relations and child psychological functioning in the child with epilepsy and has specifically used the Circumplex model of marital and family systems in order to examine this relationship. This section will briefly describe this theoretical model and examine some of the main concepts that have been used in the present research.

The Circumplex Model of Marital and Family Systems is a theoretical model developed by Olson et al (1979) used to describe different types of marital and family systems. This model has been

strongly influenced by general systems theory and "was developed in an attempt to bridge the gaps that typically exist between research, theory, and practice" (Olson, 1993: 104). The three primary dimensions of family behaviour integrated in the Circumplex Model are cohesion, adaptability and communication (Olson et al., 1985). The two main dimensions of family relations examined in the current research are family cohesion and adaptability and will be the focus of the present discussion (Olson et al., 1985).

### 2.6.2 Family Cohesion

Family cohesion refers to the connectedness of relationships within the family and the degree of individual autonomy a person experiences in the family system. Four different levels of cohesion are seen to exist in families at different times along the family lifecycle and these include disengaged, separated, connected and enmeshed family relations (Olson et al., 1992). According to the Circumplex Model, extremely high cohesiveness represents "enmeshment" within the family system, whereas extremely low cohesiveness represents "disengagement." Highly cohesive or enmeshed systems are thought to promote the overidentification of family members with one another and to prevent differentiation and individuation among them (Olson et al., 1992). Children may experience lack of privacy, where family members may be overly responsive to signs of distress or intrude on each others thoughts and feelings. Extremely low cohesion (disengaged levels) on the other hand is equivalent to unusually great autonomy, limited commitment of individual family members, and low bonding of members to one another (Minuchin, 1974). Disengaged families have been described as developing overly rigid boundaries leading to strained communication across subsystems. Both extremes therefore are hypothesized to be hazardous to the development of social competence and psychological development in children. Smets and Hartup (1988) suggest that the family is required to promote the child's self sufficiency as the child needs to be engaged with family, peers and school in a balanced way. Moderate cohesiveness allows family members to experience being both independent from and connected to their family which permits the development of more flexible relationships. These family conditions are regarded as promotive of more adaptive psychosocial functioning in children (Smets & Hartup, 1988).

### 2.6.3 Family Adaptability

Minuchin (1974) described the family as a system that adapts to the changing demands of the different developmental phases of the family's life cycle as well as to changes in the demands of society. In terms of the Circumplex Model (Olson et al., 1985) family adaptability refers to the capacity of the family system to be flexible in its ability to change its power structure, role relations, and rules in response to situational and developmental stress. The specific variables that are of interest in terms of this dimension are family power structure (assertiveness and control), negotiation styles, role relationships and relationship rules, and feedback (positive and negative). The four levels of adaptability range from rigid (very low) to structured (low to moderate) to flexible (moderate to high) and to chaotic (very high) (Olson et al., 1985). Extremely high family adaptability (often described a "chaotic") describes families that have no clear social rules, erratic leadership, and laissez-faire discipline. Extremely low adaptability (often described a "rigid") on the other hand, typifies families with rigid social rules, authoritarian modes of discipline, and the absence of negotiated problem solving (Minuchin, 1974). Olson et al (1985) maintain that both of these extremes are dysfunctional to families if they can only function at these levels. The most viable family systems are hypothesized to be those that fall in the balanced area of adaptability (structured or flexible), which allow family members to be chaotic at times but with some degree of stability.

Smets and Hartup (1988) have additionally suggested that moderate adaptability is most adaptive to child psychological functioning with the reasoning that "since one indicator of social competence is effective accommodation to change, one would expect moderate adaptability to be associated with better functioning and fewer behavioural symptoms than either chaotic or rigid family conditions" (p. 234). Cohesion and adaptability are seen to vary depending on the particular developmental stage of the family (eg. following birth of a child, yaunching young adults) and are not therefore conceptualized as static traits (Schulz et al., 1996).

### 2.6.4 Family Type and The Circumplex Model

Olson, Russel and Sprenkel (1979) have further combined the dimensions of adaptability and cohesion into a Circumplex Model that theoretically distinguishes 16 family "types." Among these types, it is possible to distinguish three subgroups according to their levels of cohesion and adaptability: a) "Balanced" systems include those families that are both moderately cohesive and

moderately adaptable and are predicted to promote adaptive psychosocial functioning in both children and adults. b)"Midrange" systems include families which are classified as moderate on one dimension but extreme on another dimension. c) The remaining families can be classified as "extreme," since cohesiveness and adaptability are both extremely high, extremely low, or high and low in combination. Neither midrange nor extreme conditions should be conducive to good psychological functioning but may be tolerated as long as the family does not continually function in these areas (Olson, 1993). Olson et al (1985) additionally suggests that different family types function better at various stages of the family life cycle depending on the needs of the individuals within the family.

## **2.7 SYSTEMS THEORY AND CHILDHOOD CHRONIC ILLNESS**

From a systems perspective a chronic illness (such as epilepsy) in a child is not contained within the child, but has ramifications for all members of the family system and the system as a whole (Kazak, 1989). The interaction between the family and illness can be seen to be reciprocal where Shapiro (1983) suggests that "an undeniable relationship exists between family and illness, and a specific illness both affects and is affected by the family context" (p. 913). In addition, the family has been considered a powerful determinant of behaviour in both children with and without chronic illness and has been found to play a crucial role in various components of child development ie. cognitive, emotional, and social development (Belsky, in Kronenberger & Thompson, 1990; Moos & Tsu, 1977; Turks & Kerns, 1985)

Kerns and Curley (1985) propose a biopsychosocial model for understanding chronic illness and the family, which takes into account the interaction between the biological, psychological and social dimensions of the illness. Kerns and Curley (1985) apply this model to neuropsychological diseases, of which childhood epilepsy can be considered an example. Within the biological dimension, the specific nature of the illness is considered and how this may impact on psychological functioning (eg. severity of illness). The psychological dimensions of illness are seen to include the psychological functioning of the individual pre-morbidly, the nature and severity of deficit, and the individual's abilities to cope with the various deficits related to the psychological, neurological and social changes associated with the illness. The social dimension includes the social organization of the family (ie. family background, social and family roles) and the bidirectional transaction between the individual and the social and family environment. As suggested by Kerns and Curley (1985) the past decade has seen a "rapidly expanding interest

in multidimensional and integrative models of health and illness" and "one function of these developments has been a growing awareness of the relevance of the social context, in addition to biological and psychological dimensions, in determining or predicting a variety of health outcomes" (p. 147).

The impact of illness on the family has received a large amount of attention within the area of childhood chronic illness in general but as this is not the main focus of the current study, will only be described in brief. Many of the prevalent approaches to describing the family's response to chronic illness in the child has been through the use of stage models which describe the family's response to diagnosis of illness as going through a number of stages (Shapiro, 1983). The first stage typically relates to the parents' dealing with the diagnosis of illness, the second stage typically emphasizes dealing with guilt and helplessness, the third stage emphasizes the reassignment of family roles and delayed reactions to depression and the last stage typically refers to the adjustment to the permanency of the outcome (Northhouse, 1984; Patterson & Garwick, 1994; Shapiro, 1983). These stage approaches have been viewed as overly simplistic due to the fact that families and individuals may not respond to illness in this fixed manner. These approaches tend to view families as passively moving through different stages in response to illness rather than attempting to find ways to actively cope with specific stressors (Shapiro, 1983). Shapiro (1983) in contrast describes the family as actively attempting to delineate the goals of family coping strategies in response to major illness as follows 1) Responding to the challenge of adaptation; 2) Maintaining a sense of membership in the family; 3) Reorganizing the family and reassigning roles; and 4) Re-establishing an emotional baseline, and the mastery of resentful, self-accusatory and negative feelings.

Ziegler (1981) proposes a model to specifically explain how the family responds to a child with a seizure disorder that additionally relates to child psychological adjustment. In this model, the family's reaction to the seizure disorder is seen to "set the stage" for whether or not the child interprets his or her seizure disorder as catastrophic or simply inconvenient, which may have serious implications for the child's self-esteem and sense of self. Thus the child and family are seen to form a "reverberating circuit" within which fears or loss of control can be either magnified or contained.

Maladaptive familial situations have additionally been found to constitute the conditions sufficient to increase susceptibility to disease, impact on compliance to medications, as well as

exacerbate physical and psychosomatic illnesses (Johnson, 1980; Shapiro, 1983; Turk & Kerns, 1985). Minuchin (1974) has theorized that childhood physical illness may serve as a stabilizing function within the family, where the sick child may become the focus of attention thereby preventing family conflicts. These authors have classified a specific type of family ie. the "psychosomatic" family, that is characterized by enmeshment, overprotectiveness, rigidity and lack of conflict resolution. This family type is suggested to play a role in the development of psychosomatic symptoms in children. Other theorists have similarly suggested that the presence of disease has been related to a set of behaviours described as "sick role behaviour" which is characterized by behaviour that includes prescribed responsibilities and the relinquishing of some previous role responsibilities (Levin et al., 1988).

Rolland (1987) built on Olson, Russel & Sprenkle's (1989) Circumplex Model of family relations and focused specifically on the family dealing with chronic illness. Changes in family organization (adaptation) are considered necessary for both the family's and individual's development, and may differ depending on the phase of the family's lifecycle and child's developmental stage (Rolland, 1987; Zilbach, 1989). Families at extreme ends of adaptability are predicted to have more problems with certain types of conditions, where families that are chaotic and disorganised, may have difficulty coping with chronic illnesses where strict adherence to regimens or medications is required eg. diabetes or epilepsy (Rolland, 1987). Because enmeshed families maintain rigid boundaries around the family unit and tend to be wary of outsiders, certain types of illnesses that necessitate outside professional help may be particularly problematic for them (Rolland, 1987). This in turn may deprive the child of experiences necessary for social and emotional development (eg. peer interaction, counselling etc).

## **2.8 FAMILY COPING**

### **2.8.1 Introduction**

Family Stress Theory describes the adaptation of families in response to various stressors. These changes can manifest themselves in different areas of family life such as interaction, goals, roles, rules, and boundaries. This section will discuss the concept of family coping in terms of family stress theory and additional conceptual issues will be discussed.

### 2.8.2 Family Stress Theory

Lazarus and Folkman (1984) describe coping as "efforts", both action-oriented and intrapsychic to "manage (master, tolerate, reduce, minimize) environmental and internal demands and conflicts among them, which tax or exceed a person's resources" (p. 141). A large volume of the research and literature on coping tends to have focused on individual coping rather than family coping per se (Stetz et al., 1986). Family stress models offer theoretical models to understand how families adapt and cope with stress (Hill, 1949; Turks & Kerns, 1985). These models depict the family as capable of change and adaptation in response to stress, where it is the interaction between the family's resources and the objective event (stressor) that is seen to determine the degree of stress experienced by the family (Hill, 1949). In the original ABCX model, Hill (1949) defined the stressor as a situation for which the family has little or no prior preparation eg. a chronic illness in a child may represent such a stressor which is accompanied by considerable emotional strain (Pearlin & Turner, 1987). The family is seen as the manager of family resources (Hill's B factor, 1958) which refers to the broad range of reserves and aids characterizing the family that are potentially available in times of need (McCubbin et al., 1980). Community resources include social support networks, such as extended family members, friends, neighbours, medical services (Bronfenbrenner, 1979; McCubbin et al., 1980, 1983, 1989). It is the quality rather than the quantity of specific resources (eg. support networks) that have been found to be important in coping (Billings and Moos, 1981). In addition, family stress theory can be seen to be based on what Lazarus has called "primary appraisal" of the stressor event, where the perception of the event becomes more important than the actual reality of the event in terms of stress response (Folkman et al., 1986).

The Double ABCX Model of family coping modified the original ABCX model to include additional factors that appeared to influence the course of family adaptation (McCubbin et al., 1983; Patterson & McCubbin, 1983). These included a) the pile-up of additional stressors and strains, b) family efforts to activate, acquire, and utilize new resources from within the family and the community, c) modifications in the family definition of the family's predicament and d) family coping strategies designed to bring about changes in family structure in order to achieve positive adaptation (McCubbin et al., 1983). Within this model family coping is seen as a process rather than a static attribute, which is progressively modified over time (McCubbin et al., 1989). Family coping strategies were defined to include both cognitive and behavioural strategies (Lavee et al., 1985) such as altering meanings so as to make a situation manageable (e.g believing this is

God's will for our family and we were chosen because we can handle it (See Chapter Five, 5.6.4) (Patterson & Garwick, 1994).

### 2.8.3 Conceptual Issues

The concept of family coping as used in past research has suffered from "imprecision of definition, a lack of systematic categorization of coping methods accompanied by a trend toward overinclusiveness in which all responses to a stressful event are defined as coping responses" (Garmezy and Rutter, 1983: 47). For example, in the literature on childhood chronic illness, coping responses in the family have included the "effects" of chronic illness on the family, as well as stages that the family goes through in adjusting to illness, with very few studies examining active coping strategies used by the family to cope. Reiss and Oliveri (1980) suggest that in making the shift to the family level of analysis of coping the subjective reality of the family becomes an entity in its own right. He describes this as the "family's paradigm" defined as the "set of assumptions, convictions, or beliefs each member holds about its environment" (Reiss, in Turk & Kerns, 1985: 10). As indicated by Shapiro (1983) in her review of family reactions and coping with physically ill and handicapped children, general questions regarding family coping still remain unaddressed by theorists, such as 1) how can family coping be understood in terms of an aggregate of coping of individual family members? 2) How are the discrepancies between family members accounted for? 3) How can one provide further clarity regarding the operationalization of family coping? It is apparent that a general lack of clarity still appears to exist with regard to family coping definitions, which is exacerbated by the limited availability of instruments to measure this concept (Olson et al., 1985).

Further research is needed to examine aspects of family coping in relation to adjustment of individual members, particularly in the area of childhood epilepsy where there has been virtually no research to date. In the current study family coping will be defined as "the active process of family adaptation involving coping strategies within the family, and family coping patterns in transactions with the community" as outlined in the Double ABCX Model (McCubbin et al., 1992: 121).

## 2.9 CONCLUSIONS

The current chapter aimed at providing the reader with a general theoretical understanding of some of the major concepts and issues related to risk and resilience in the development of psychological problems in children. In addition, the reader was introduced to the family models that were specifically used in the current study in relation to the development of psychological problems in children with epilepsy. It was considered necessary in the current research to draw on a number of theoretical models in order to provide a more complete theoretical understanding of the relationship between risk and protective factors and psychological problems in children with epilepsy. In recent years a vast amount of literature and research has emerged that has specifically focused on family relationships and family problems which have been useful in understanding how families adapt and respond to stress throughout their lifecycle. The Circumplex model was considered useful in the current study as it integrates theory, research and clinical practice and has been used in a number of studies within the area of health and illness (Olson et al, 1992). In addition, the Circumplex model has been found to be useful in discriminating between symptomatic and nonsymptomatic families (Olson et al., 1985) suggesting evidence for both the applicability and validity of the Circumplex model. Many of the family models however are limited in that they have paid little attention to the impact of family system dynamics on child psychological functioning, particularly in the area of childhood chronic illness. There appears a tendency within the literature in general to focus on the overall dynamics and structural changes within the family as a whole without taking into account how specific structural changes may impact on individual family members. It can be suggested that further research is needed to understand how specific family relations impact on child behaviour and psychological adjustment, particularly in the area of childhood epilepsy where there is very little research in this regard.

## **CHAPTER THREE: CHRONIC ILLNESS AND RISK OF PSYCHOLOGICAL PROBLEMS**

### **3.1 INTRODUCTION**

Childhood epilepsy is a chronic condition, which fits the definition of chronic illness as "an illness or other physical condition that generally is present for longer than three months and is likely to persist into or recur in subsequent years" (Lavigne & Faier-Routman, 1993: 119). Research and literature pertaining to various other pediatric chronic conditions in the area of psychological adjustment can be viewed as important comparative background literature to the current study and is the focus of Chapter Three. This literature can be considered particularly important when considering the scarcity of research in the area of childhood epilepsy that has examined risk and protective factors in the development of child psychological problems. Given the vast amount of research in the area of different childhood chronic illnesses, this chapter aims to provide a broad background to issues related to child adjustment, family coping, and risk variables associated with symptomatology in chronically ill children.

### **3.2 RESEARCH APPROACHES TO STUDYING CHRONIC ILLNESS IN CHILDREN**

There have been two main approaches to the examination of psychological problems in children with chronic illness (including children with epilepsy) ie. categorical approaches and noncategorical approaches (Jessop & Stein, 1985). Noncategorical approaches to chronic childhood illness have tended to assume that it is chronicity of the illness itself, rather than specific variables related to the individual illness that are associated with adjustment problems in this group of children (Holden et al., 1997; Stein & Jessop, 1984, 1989; Wallender et al., 1988). Researchers that use this approach typically include several different types of chronically ill children in research samples and attempt to explore the common dimensions of diverse illnesses that influence the child and the family. eg. visibility/invisibility of symptoms, whether the condition is life threatening or not etc. (eg. Nelms, 1989; Pless & Nolan, in Holden et al., 1997; Wallander et al., 1989). Alternatively, the categorical approach to chronic childhood illness assumes that the specific pathophysiological processes and psychosocial demands placed on individual patients and their families by specific illnesses account for a major proportion of the variance in adjustment outcomes. The basis of both frameworks however is that the presence of a

chronic illness is a significant stressor, one that increases the demand for adaptation and coping (Pless & Stein, 1994).

### 3.3 PSYCHOLOGICAL PROBLEMS AND PEDIATRIC CHRONIC ILLNESS

Historically, research on pediatric chronic illness has tended to follow a psychopathological model which has focused on either searching for syndrome-specific personality types or attempting to identify deficits or differences between chronically ill children and their peers (Droctar et al., 1981; Harper, 1991; Holden et al., 1997; Johnson, 1980; Wallander et al., 1988, 1989). Little evidence has been found to substantiate claims of specific personality types and many of the studies investigating psychological adjustment tend to have overemphasized maladaptive responses of children coping with chronic illness. Much of this research has been criticized due to its reliance on clinical impressions, descriptive methods, small sample sizes and clinic based samples (Jacobson et al., 1986; Johnson, 1980; Kovaks et al., 1985; Perrin & MacLean, 1988). Although some researchers have found no evidence for increased risk of psychological problems (Kovaks et al., 1986; Tavormina, 1976) the majority of findings support the fact that children with chronic illness (with a wide range of different types of illnesses) appear to be at an increased risk for psychological and behavioural problems, although the vast majority of children have no adjustment problems (Cadman et al., 1987; Gortmaker et al., in Holden et al., 1997; Lavigne & Faier-Routman, 1988; 1992; Nelms, 1989; Perrin & Maclean, 1988; Shalev et al., 1995; Wallander et al., 1988). Neurological and sensory disorders eg. childhood epilepsy have been suggested to increase a child's risk for psychological problems, although a large amount of variability of adjustment has been found both within and across disorders (Eiser, 1990; Lavigne & Faier-Routman, 1992; Rutter et al, 1970a).

Chronic illness can be considered a stressor which provides the child with specific demands and experiences which may include limitations in activity, peer interactions, stigma, medication regimens, and symptoms of illness (Holmes, 1986; Johnson, 1985; Nelms, 1989). Positive coping in the child with chronic illness has been associated with independence, good peer interaction, school achievement and a sense of competence (Shapiro, 1983). Prolonged poor adjustment to chronic illness has been described by Shapiro (1983) as being characterized by "fearfulness, inactivity, dependency; or in contrast an overly independent attitude, engaging in prohibited risk-taking behaviours or aggressive behaviours" and "regression, neurotic utilization of organic symptoms, clowning and low self-esteem" (p. 916). Studies specifically related to

children with epilepsy and psychological adjustment and will be discussed in further detail in Chapter Four.

Recent recognition of the fact that positive adaptation to illness is a more common outcome to childhood disability than was previously thought has led to current research shifting from global statements of maladaptation to a focus on the identification and understanding of factors associated with both positive and negative psychological outcomes in children with a chronic illness (Harper, 1991; Holden et al., 1997; Johnson, 1985; Lavigne & Faier-Routman 1992; Nelms, 1989; Walker et al., 1989; Wallander et al., 1989).

### **3.4 FAMILY ADAPTATION TO CHILDHOOD CHRONIC ILLNESS**

Given the current study's additional focus on family functioning in relation to the child's development of psychological symptoms, background literature related to family adaptation (already discussed briefly in Section 2.7) will be further examined.

Chronic childhood illness generates specific demands on the family which include the monitoring of the illness and treatment, maintaining family integrity, and the provision of emotional support to the child and other family members (Hauenstein, 1990; Shapiro, 1983). In addition, childhood chronic illness has been suggested to serve as an ever-present stressor that may lead to family disruption and disorganization or conversely to greater family cohesion and a higher level of functioning (Harper, 1991; Kazak et al., 1988; Shapiro, 1983; Turk & Kerns, 1985). A large amount of research has focused on the family's response and adaptation to chronic illness, and the literature is replete with descriptions of the dysfunctional responses of families to childhood chronic illness (Daniels et al., 1987; Harper, 1991; Patterson & Garwick, 1994). Problems related to family communication have been reported (Harper, 1991) and chronic illness have been found to disrupt normal regulatory processes, such as routines and rituals (Patterson & Garwick, 1994). A number of studies have indicated increased levels of depression and maladaptation in mothers of children with chronic illness and higher levels of marital discord (Daniels et al., 1987). Other studies have indicated that mothers may develop unrealistically low expectations of their child, may become overprotective or overinvolved with the ill child while excluding other family members from this "magic circle" (Shapiro, 1983). In addition, healthy siblings have been found to have lower self-concepts than other children, and to be resentful of their parents involvement with their sick sibling (Droctar et al., 1981; Johnson, 1980; Kerns & Curly, 1985). Some studies

however have found that siblings of chronically ill children do not necessarily show high levels of disorder (Kazak & Nachman, 1991). McDaniel et al. (1992) suggest that sometimes the child's illness may form part of dysfunctional triangles in the family, which may take the form of *devouring*, in which parents maintain their unity by focusing on the child, or *cross-generational coalitions*, in which one parent forms an alliance with the child against the other parent. Frey (1984) suggests that chronically ill adolescents additionally use illness-maintaining behaviours in order to regulate marital distance or parental conflict.

Less research has focused on the large proportion of families and individuals who adapt and cope with chronic illness in a positive way (Johnson, 1985; Kazak & Marvin, 1984; Nelms, 1989; Shapiro, 1983). As indicated by Turk and Kerns (1985) "very little attention has been directed towards understanding how these patients and families restructure their lives, how some develop effective ways of responding to the illness and life circumstances that confront them and others do not" (p. 17). Some studies have indicated however that many families adapt relatively well to the diagnosis of chronic illness in their child (Kovaks et al, 1985). Turks and Kerns (1985) suggest that the high risk of family problems found in many research studies may be related to the use of restricted samples in these studies (usually clinic samples), as well as the fact that many of the studies are cross-sectional and do not take into account the changes within the lifecycle of the family.

### **3.5 RISK AND PROTECTIVE FACTORS IN CHILDHOOD CHRONIC ILLNESS**

#### **3.5.1 Introduction**

More recent research has moved towards understanding children with a chronic illness as normal children coping with specific stressors (Perrin & MacLean, 1988). In view of the wide range of possible outcomes for children with chronic illness, the identification of factors that either contribute or moderate psychological morbidity can be considered of considerable importance. Studies investigating this issue have indicated that factors within the child as well as environmental factors (family factors, SES) and illness factors (eg. illness severity, type of medication etc.) play a role in psychological adjustment (Lavigne & Faier-Routman, 1993; Wallander et al., 1988). Some of these findings will be discussed only briefly below as background information and will be expanded on in Chapter Four in relation to childhood epilepsy.

### 3.5.2 Illness Factors and Risk of Psychological Problems

Disease parameters such as illness severity and functional disability have been studied more than any other variable with regard to psychological risk in children with chronic illness, and appear to be correlated with adjustment to some extent (Lavigne & Faier-Routman, 1993; Wallander et al., 1989). Severity of illness is one factor that has been investigated and mixed conclusions have been reached. Some studies have shown that children with intermediate levels of disability are at greatest risk (Pless and Stein, 1994) while other studies have concluded that diseases that are more serious, debilitating, or painful are at higher risk for psychological dysfunction. Daniels and Moos et al (1987) for example found that juvenile rheumatic disease patients with a more severe diagnosis and longer disease duration was associated with significantly more psychological disturbance than those with mild or inactive disease. Garralda et al (1988) similarly found that there was a trend towards more marked psychological problems in children with more severe renal conditions. Interestingly, the less severely physically ill children in this study tended to have increased difficulties in school adjustment. Other studies however have found that although measures of illness severity were found to be related to behavioural adjustment, they were only moderately predictive of the child's social adjustment (Drotar et al., 1981; Wallander et al., 1988; 1989). Age of onset and duration of the disorder are additional variables that have been investigated but mixed conclusions have been reached, with some studies indicating an association between these variables and psychological problems, while others finding no such association (Daniels et al., 1987).

Lavigne and Faier-Routman's (1993) meta-analytic study which reviewed risk factors associated with child psychological problems in different chronic illnesses, found that disease/disability variables had lower correlations with child psychological problems than family variables and child variables in their analysis. Given the relatively weak predictions of disease variables in their meta-analysis, Lavigne & Faier-Routman (1993) suggest that "greater attention needs to be paid to life stress, parent/family variables and child variables because they currently appear to have the greatest predictive ability in relation to child adjustment" (p. 121).

### 3.5.3 Family Risk and Protective Factors in Childhood Chronic Illness

The family often plays an essential role as the primary unit of health care and is considered a vital force that may act either to ameliorate or exacerbate stressors (Johnson, 1985, 1988; Shapiro, 1983). Research has focused both on the interaction between family variables and the child's psychological health, as well as between the family and the child's physical health (Johnson, 1985; Perrin et al, 1993). As suggested by Johnson (1985) research studies on children with chronic illness "are just beginning to study the relationship of parent or family variables to good versus poor adaptation" (p. 227). The general literature in child adaptation has suggested that the family plays an important role for most children's development (Kronenberger & Thompson, 1990; Pearlin & Turner, 1987). Factors that have been identified as family risk factors in the area of psychological adjustment in children with chronic illness have included aspects of the family "environment" (Moos & Tsu, 1977) and additionally such factors as family cohesion and adaptability (Olson et al., 1985), and family coping characteristics and resources (McCubbin et al., 1983; Rutter, 1979). In addition, to direct measures of family functioning, other related variables of specific subsystems within the family have been examined such as parental coping (which emphasizes maintaining family integration), parenting style (overcontrolling or undercontrolling parental behaviour), marital satisfaction and parental psychopathology. These factors have been associated with adjustment outcomes in children either with or without a chronic illness (Garmezy, 1983).

The epidemiological study by Rutter et al (1970a) was among the first to report poorer psychological adjustment among chronically ill children than in the general population and found that family functioning emerged as the most powerful predictor of psychological functioning in chronically ill children. Kronberger and Thompson (1990) similarly found in their study with 109 chronically ill children that those children with higher behaviour problems were found to have less supportive, more conflicted families. Hauser et al (1985) researched diabetic children, using self-competence as a measure of adjustment and found higher levels of self-competence among children in families that were rated high on independence, achievement, activity, and organization. Daniels et al (1987) found that higher parental depression, medical symptoms, sibling problems, more family stressors, and burden of illness on the family predicted more problems among children with juvenile rheumatic disease. These relationships held even when disease duration and severity were controlled. Wertlieb et al (1986) additionally found there to be

an association between behaviour symptomatology and high levels of family conflict in children and adolescents with either diabetes or acute illnesses.

Higher family cohesion has been related to better psychological adjustment among children with sickle cell anemia (Moise, in Daniels et al., 1987). Phipps and Mulhern (1995) additionally investigated family cohesion, expressiveness and resilience to the stress of pediatric bone marrow transplant. It was determined that higher levels of perceived family cohesion and expressiveness act as protective factors, promoting resilience to the stresses of bone marrow transplant, whereas family conflict acts directly as a risk factor that adversely affects adjustment regardless of stress level. Similarly child adjustment to the experiences of cancer and juvenile rheumatic disease have been found to be associated with numerous family variables, including family cohesion (Phipps & Mulhern, 1995). Lavigne and Faier-Routman's meta-analysis (1993) indicated that within the family/social variables, maternal maladjustment, marital and family adjustment, and family support/cohesion were all significantly correlated with child maladjustment.

Another interesting factor that has emerged in various studies is that certain variables appear to interact with others in terms of psychological adaptation. Steinhausen et al (in Wallander et al., 1989) found differences in the relationship between psychological family resources and child adjustment in children with different disorders, with a stronger relationship existing in the typically less severe condition (asthma) while no relationship existed between these variables in the more severe life-threatening condition of cystic fibrosis.

Of particular interest in the current study was the variable of family coping. Although there are a growing number of studies examining family adaptation to chronic illness, very few studies appear to have investigated family coping in relation to child psychological functioning. Of the limited number of studies found in this area, findings suggest that there is a relationship between family coping and child adjustment (Johnson, 1985; Hamlett et al., 1992). Hamlett et al (1992) for example found that family functioning and maternal social supports were significantly related to children's adjustment to asthma and diabetes. These authors additionally concluded that family coping had the greatest impact on the psychological adjustment of children diagnosed with these two chronic physical disorders. Garralda et al (1988) similarly found that psychiatric disturbance

in children with chronic renal failure was associated with lower levels of parental support and higher levels of total stress. Chaney and Peterson (1989) found that the use of a greater number of family coping behaviours by mothers of children with juvenile rheumatoid arthritis was associated with higher levels of compliance to medication by these children. Family problem solving ability has been found to be associated with child psychological adjustment in children with cystic fibrosis, where children who were classified as well-adjusted were more likely to come from families with better problem solving ability (Johnson, 1985).

#### 3.5.4 Demographic Variables

Poverty and disadvantaged environments have been found to increase the risk of dysfunction in healthy children due to the fact that heightened levels of poverty engenders a host of stressors eg. unemployment, financial difficulties etc. (Haggerty et al., 1994, Lavigne & Faier-Routman, 1993). It is evident that much of the research in the area of childhood chronic illness either fails to take this risk variable into account or attempts to control for this variable within studies. Wallander et al (1989) examined the hypothesis that psychological adjustment is related in part to the resources present in families of chronically ill children. The sample consisted of 153 children who had one of five chronic disorders: juvenile diabetes, juvenile rheumatoid arthritis, chronic obesity, spina bifida or cerebral palsy. Socio-economic status appeared to be negatively related to behaviour problems in this study. Other studies have found no significant correlations between SES and psychological problems (Daniels et al., 1987; Lavigne & Faier-Routman, 1993).

Studies have also found that child temperament and individual coping plays a role in whether children with a chronic illness develop psychological or behavioural problems (Lavigne et al., 1988). Lavigne & Faier-Routman's (1993) meta-analysis of correlates of psychological adjustment to pediatric physical disorders found that child variables ie. poor coping, low self-concept, and low IQ were moderately strong significant predictors of adjustment problems. Gender was also a significant predictor of child adjustment with boys showing more adjustment problems than girls. Temperament was not found to be a significant predictor of more adjustment problems in this analysis. Other studies have similarly found that boys with a chronic physical illness were more likely to display behavioural and adjustment problems (Gortmaker et al., in Holden et al., 1997), although some studies have shown that girls may have higher levels of neurotic symptoms than boys with a chronic illness (Holden et al., 1997).

### 3.6 CONCLUSION

In summary, research in the area of childhood chronic illness indicates that chronically ill children, particularly those children with a neurological condition such as epilepsy, are at an increased risk for psychological problems. There is a need for more within-group approaches to identifying specific risk and protective factors involved in the psychological adjustment of children with epilepsy. Studies investigating risk and protective factors involved in the psychological adjustment of epileptic children suffer from specific limitations related to the use of small sample sizes as well as the use of clinic population groups (Droctar, 1981; Lavigne & Faier-Routman, 1993).

In addition, the concept of child "adjustment" has been used in studies to encompass a variety of meanings, such as acceptance of the disease, competence, mechanisms of coping, compliance to medication, freedom from psychopathology, age appropriate functioning, self-esteem, depression, or global levels of adjustment (Eiser, 1990; Hauser et al., 1985). Family coping is another concept that appears to have lacked clarity of definition, and has been used to describe the family's response to illness, the effects on the family, as well as individual reactions to childhood chronic illness (Turk & Kerns, 1985). The lack of clarity in various studies regarding the operationalization of these concepts, makes drawing comparisons between studies and the development of general conclusions from these studies difficult. It can be suggested however that research reviewed provides some support for Wallander et al's (1989) model which emphasizes the transactional and reciprocal interaction between child, family and environmental factors in attempting to understand risk and resilience factors in children with chronic illness. Further studies are needed to investigate combinations of variables further in order to provide theoretical clarity regarding the processes involved in the psychological adjustment of chronically ill children.

## **CHAPTER FOUR: THE CHILD WITH EPILEPSY**

### **4.1 INTRODUCTION**

Chapter Four aims to review the literature in the area of childhood epilepsy that has specifically examined issues related to the development of psychological problems in children with epilepsy. Background literature will firstly be provided regarding definitional and classification issues related to childhood epilepsy and then studies investigating the impact of epilepsy on the child and family will then be reviewed briefly. The main focus of this chapter, however will be to review research that has specifically examined risk and protective factors in relation to the development of psychological and behavioural problems in children with epilepsy. In particular demographic factors, illness factors and family factors will be examined. This review of the literature will restrict itself to studies pertaining to psychological factors in children with epilepsy, thus excluding studies focusing on adults with epilepsy.

### **SECTION ONE: DEFINITION AND CLASSIFICATION ISSUES**

#### **4.2 THE NATURE OF CHILDHOOD EPILEPSY**

Epilepsy can be described as a chronic neurological condition affecting adults and children which involves two or more seizures that are unprovoked and are not due to an acute disturbance of the brain (Freeman et al., 1990). In the medieval English literature "falling evil" or "falling sickness" were the most common definitions of the term "epilepsy" which acquired its name because it was seen to attack or "seize" both the senses and the mind (Temkin, 1994). Epilepsy has a long history of associated prejudice and stigma, which it still carries with it to a certain degree in modern times (Boshes & Keinast, 1972; McLin, 1992; Temkin, 1994). Epilepsy is a relatively common childhood neurological disorder, affecting approximately 1% to 2% of the population (based on American prevalence studies) (Newacheck & Taylor, 1992). Although etiological factors are unclear, epilepsy can result from genetic predisposition, a variety of brain insults or no identifiable cause (Berg, 1995; Heisler & Friedman, 1981; Hermann & Whitman, 1992). Childhood epilepsy is an episodic illness, characterized by periods of stability (no seizures) and periods of symptom flareups. Seizures themselves are usually unpredictable and certain types of seizures of a longer duration may be life threatening (eg. status epilepticus) (Rolland, 1987;

Seidenberg & Berent, 1992). Children with epilepsy have additionally been found to be at an increased risk for both hyperactivity and learning problems (Vining, 1989). Evidence suggests however, that children with epilepsy and no other neurological abnormality tend to have normal intelligence (Seidenberg & Berent, 1992; Shalev et al., 1995; Vining, 1989). Some of the more intractable syndromes, however, such as Lennox Gastaut syndrome and West's syndrome are associated with progressive cognitive impairment leading to possible mental handicap (Berg et al., 1995).

### 4.3 DEFINITION AND CLASSIFICATION ISSUES

#### 4.3.1 Introduction

Because there are many types of seizures, epilepsy can take on many different forms and one can speak of epileptic syndromes (clusters of symptoms) to incorporate these many types (Freeman et al., 1990). A number of classification systems have been proposed in order to provide temporary guidelines for the diagnosis of epileptic seizures and syndromes (See Dreifuss, 1989: 268-275 for further reference). These classification systems are complex in nature, and only simple definitions of more common seizures and syndromes will be presented here. The majority of parents (as well as diagnoses by doctors) in the current study tended to describe the child's condition in terms of types of seizures evidenced by their child (eg. petit mal seizures) and therefore these will be focused on in this section.

#### 4.3.2 Definitions

In medical terms an epileptic *seizure* can be described as "an episodic alteration in neurological function due to paroxysmal, synchronous discharge of neurons in one or more regions of the brain" (Stafstrom & Holmes, 1995: 39). A seizure can manifest as anything from a subtle decrease in alertness to a motor convulsion, depending on the part(s) of the brain affected (Stafstrom & Holmes, 1995). Seizures are divided into two main types depending on the site of seizure onset. Seizures can begin in localized brain region (*partial seizure*) and produce signs and symptoms appropriate to that region and may spread to other areas. Conversely, a *generalized seizure* begins in both cerebral hemispheres simultaneously (Dreifuss, 1989; Stafstrom & Holmes, 1995). An *epileptic syndrome* in contrast is characterized by a cluster of signs and symptoms often occurring together and includes such aspects as type of seizure, EEG

characteristics, etiology, anatomy, age of onset, severity and chronicity (Dreifuss, 1989; Stafstrom & Holmes, 1995). Epileptic syndromes are often tightly age-related, however and a syndrome may sometimes evolve into a different syndrome as the brain matures.

#### 4.3.3 Types of Seizures

The most common types of seizures found in children are described briefly below and are classified within the primary generalized epilepsies:

- 1) *Tonic-clonic seizures* (also called '*grand mal*' seizures) are the most common seizure type in children (usually 75-80% of children have these forms of seizures), where the person typically stiffens while simultaneously losing consciousness causing the individual to fall to the ground (tonic phase) and rhythmic jerking of the extremities (clonic phase) follows. Vocalizations, possible loss of bowels and/or bladder control may accompany either phase. The seizure lasts for approximately two to three minutes and the patient usually awakes in a state of confusion and extreme fatigue (O'Donohue, 1985a; Freeman et al., 1990).
- 2) *Typical absence seizures* (also called '*petit mal*' seizures) involve brief (few seconds) loss of awareness with staring, occasionally accompanied by a few eyelid twitches or rarely by other motor signs. Dozens or hundreds of seizures may occur in a day and when the seizure ends the child is usually alert (Lockman, 1989; Stafstrom & Holmes, 1995).
- 3) *Myoclonic seizures* are characterized by brief, lightning-like muscle contractions and may involve muscles of the limb, trunk or neck. If they occur when a child is standing, s/he may be suddenly be thrown violently to the ground (Freeman et al., 1990). Myoclonic seizures are serious because they may be difficult to control and are often one manifestation of a mixed seizure disorder commonly associated with mental retardation (Freeman et al., 1990).
- 4) *Atonic seizures* are characterized by sudden loss of muscle tone, causing the child to fall and are commonly seen as a manifestation of Lennox Gastaut syndrome (Stafstrom & Holmes, 1995).
- 5) *Nocturnal Seizures* usually occur during sleep, most typically while awakening or going to sleep. Diagnostic features include focal or generalized tonic or clonic attack, waking or bitten tongue, and post-ictal phenomena such as tiredness.

#### 4.3.4 Specific Epileptic Syndromes

In addition to the many types of seizures, there are various patterns of recurrent seizures sufficiently distinctive in their course and outcome and in their response to specific medications to warrant distinct names (Dreifuss, 1989). Distinct types of epileptic syndromes include benign rolandic epilepsy, juvenile epilepsy of Janz, West's syndrome, Lennox Gastaut syndrome and temporal lobe epilepsy. Benign rolandic epilepsy is considered to be a less serious form of epilepsy and is characterized by infrequent seizures (which children often outgrow in adolescence), eg. petit mal 'absences', neonatal seizures and so-called benign rolandic seizures. Juvenile epilepsy of Janz includes nocturnal seizures and typically begins in early adolescence. West's syndrome and Lennox Gastaut syndromes are more typically severe forms of epilepsy associated with frequent seizures and high rates of mental handicap (Brown & Livingston, 1985). Patients with temporal lobe epilepsy tend to have complex partial seizures (focal discharges involving loss of consciousness) arising from the temporal lobe that are usually very difficult to control (Wyllie et al., 1989).

#### **4.4 TREATMENT**

The main approach to treatment (control of seizures) is through the use of antiepileptic drugs (AED's). A large range of AED's are available to control different types of seizures and types of epilepsy. The number and type of drugs used to treat epilepsy are determined by various factors including the age of child, and frequency and length of seizure occurrence (O'Donohue, 1985b). Anticonvulsant drugs commonly used with children include clonazepam, phenytoin, sodium valproate, phenobarbital and carbamazepine. Some of the AED's can have serious side effects on children's psychological and cognitive development particularly when multiple drugs are used (O'Donohue, 1985b; Seidenberg & Berent, 1992). Phenobarbitone for example may cause drowsiness, irritability, aggressiveness and overactivity and is considered to be associated with higher rates of side effects than other anticonvulsants (O'Donohue, 1985b). Approximately 20% - 30% of children with epilepsy do not enter remission but the majority (approximately 80%) respond well to medication and have good control over seizures (Amir & Joseph, 1995; Freeman et al., 1990). Another form of treatment that has been used to control more intractable forms of epilepsy is the ketogenic diet, which involves a specialized diet found to help reduce seizure

activity. This approach is less popular however due to side effects and difficulty of administration.

## **SECTION TWO: SOCIAL AND PSYCHOLOGICAL ASPECTS OF EPILEPSY**

### **4.5 CHILDHOOD EPILEPSY AND EMOTIONAL /BEHAVIOURAL PROBLEMS**

Much of the earlier research in the area of psychological adjustment and childhood epilepsy has focused on determining whether such a personality type as the "epileptic personality" exists. No conclusive evidence has been found to support such claims and the majority of studies in this area lacked adequate control groups, were based on small clinic samples and used inadequate measurement instruments (Hermann & Whitman, 1984). A large amount of additional research has typically used between-group designs either comparing children with epilepsy to children with no chronic illness, or with a different chronic illnesses (typically diabetes and asthma) to determine the risk of interictal (between seizure) emotional and behavioural problems associated with childhood epilepsy.

Studies have found an increased risk for psychological problems in children with epilepsy when compared to the general population (Austin et al., 1982; Carlton-Ford et al., 1995; Long & Moore, 1979), comparison siblings (Austin et al., 1982; Hoare, 1984a) and even when they are compared with populations of children with other chronic medical populations e.g. diabetes and asthma (Austin, 1988; Hoare, 1984a; Hoare & Kerley, 1991; Mathews et al., 1982; Rutter et al., 1970a). When compared to children with different chronic illnesses children with epilepsy have been found to have the second highest level of adjustment problems following children with inflammatory bowel disease (Lavigne Faier-Routman, 1992). Rutter, Graham and Yule (1970a) in their carefully controlled large scale Isle of Wight study in England compared the incidence of psychiatric disorders in children with various physical disorders (eg. epilepsy, blindness, deafness) with children from the general population. The children were similar in age (5-14 yrs), sex, and IQ and 86 children with epilepsy were included in the study. The highest incidence of emotional problems was found in children with both epilepsy and other neurological problems (58.3%). The incidence of emotional problems for children with epilepsy and no other complications was 28.6%, which was much higher than for children with other physical disorders (11.6%) or from the general population (6.6%) (Rutter et al., 1970a). Other studies have also indicated a higher risk of psychological problems in children with epilepsy where Hoare (1984a)

found that 48% of the sample of children with epilepsy had behaviour problems in comparison to 17% of children with diabetes and 13% of the control group who had no epilepsy. This study used a sample that consisted of more severe forms of epilepsy (eg. Lennox Gastaut Syndrome) which probably inflated the rates of psychological problems in this group. In another study, Austin (1988) used a sample of epileptic children taken from the general population and found that approximately 30% of children with epilepsy appeared to be at risk for emotional problems in comparison to 12% of the asthma sample of children. An advantage of this study was that it did not rely on clinic samples and therefore contained children with a range of epilepsy types (ranging in severity) that were more representative of children with epilepsy in the general population.

Various aspects of emotional and behavioural adjustment have been examined in studies, with results generally indicating that epileptic children have lower levels of self-esteem (Austin, 1988; Matthews et al., 1982; Viberg et al., 1986), higher levels of hyperactivity, dependency and immaturity (Ferrari et al., 1983; Hartlage et al., 1972; Hoare, 1984b; Long & Moore, 1979) as well as increased school behaviour problems when compared to children with either no chronic illness or other chronic illnesses (Austin, 1988). Children with epilepsy have been found to have academic performance below expected levels (Seidenberg & Berent, 1992; Shalev et al; 1995) and research indicates that social adjustment problems are longterm in that they tend to continue through adolescence into adulthood (Dodrill & Mathews, 1992; Levin et al., 1988).

In conclusion, one can suggest that the majority of studies indicate that children with epilepsy are indeed at an increased risk for both behavioural and emotional problems. However, it is evident that despite this increased risk, a large number of children do not develop psychological or behavioural problems. A number of studies appear to have assumed a causal connection between epilepsy and disturbed behaviour without considering the range of possible intervening variables (Bagley, 1971). Some interesting questions still remain about the basic mechanisms and factors associated with the development of psychological problems found in some children with epilepsy, as well as a need to further understanding why a large number of children do not appear to develop emotional or behavioural problems. More contemporary research appears to have shifted to examining these more complex questions and will be the focus of section 4.7.

#### 4.6 FAMILY ADJUSTMENT TO CHILDHOOD EPILEPSY

Given that the current study aims to investigate the family as a risk factor in the development of psychological problems in children with epilepsy, it is considered important to briefly review literature that has investigated family adaptation to childhood epilepsy. Studies in this area have investigated the impact of childhood epilepsy on the family as a whole as well as various sub-systems of the family eg. the parental subsystem or siblings.

The majority of studies investigating family coping with childhood epilepsy have emerged in the form of descriptions of responses of parents to the diagnosis of childhood epilepsy. Studies often appear to have focused on the negative patterns of response by the family to the diagnosis of epilepsy in a child and have included such responses as increased anxiety, guilt and anger, feelings of isolation and frustration, avoidance, or sadness (Kitamoto, in Carlton-Ford et al., 1995; Levin et al., 1988). Various behaviours have been associated with these reactions, including ostracism, poor compliance in administering medications, overindulgence or rejection, alterations in family activities, jealousy in siblings, and decreased expectations of the epileptic child (Ferrari, in Carlton-Ford et al., 1995; Levin et al., 1988; Long & Moore, 1979; Ritchie, 1981; Ziegler, 1982). In Rutter et al's (1970a) Isle of Wight study, mothers of children with epilepsy were twice as likely to have psychiatric disturbance than mothers without epilepsy. Siblings of children with chronic epilepsy have additionally been shown to have higher rates of psychological disturbance than children from families where there is no epileptic child (Hoare, 1984c).

A survey of the empirical literature reveals that there is great variability in family adjustment outcomes to childhood epilepsy, and chronic illness in general (Austin, 1988; Ferrari et al., 1983; Richie, 1981). In a study by Austin (1988) families with children with epilepsy (n = 54) were found to score lower than families of children with asthma (n = 57) on family esteem and communication, and extended family support. Interestingly there were no differences between the two groups on the family resource of mastery and adaptation, in the amount of perceived control over events, family mutuality and physical and emotional health. These authors suggest that these two illnesses share a similarity of disruptive effects on some aspects of family functioning and resources. Ferrari et al. (1983) conducted a study that investigated family functioning in families of children with epilepsy (n = 15) in comparison to children with diabetes (n = 15) or healthy children (n = 15). These authors similarly concluded that the presence of

epilepsy in children places the family at risk for problems involving poor family communication, but additionally found that children with epilepsy had lower levels of family cohesion and integration. However, sample sizes were small in this study and family structure was not controlled which may have indirectly affected the results. In an earlier study examining family functioning in epileptic children, Richie (1981) used observational techniques to rate family problem solving ability in families with a child with epilepsy, as well as control families with no child with epilepsy. Families with a child with epilepsy were found use more rigid decision-making style in terms of coping styles than families with no child with epilepsy. In addition, the child with epilepsy was found to have a reduced level of involvement in family interaction when compared to control children (Richie, 1981). Both a rigid decision-making style and decreased level of family involvement of the child have been found to be associated with increased behavioural problems when compared to matched control families (Richie, 1981). Family stress is another family variable that has been investigated with families with an epileptic child, and research suggests that families with a child with epilepsy tend to have higher levels of family stress when compared to comparison families (Hoare & Kerley, 1991; Ward & Bower, 1978).

In conclusion, it is evident that only a limited number of studies mentioned in this review have examined family cohesion and adaptability and even less have attempted to identify family coping styles used by families to cope with their child's epilepsy, and the impact of these coping styles on family adjustment.

## **4.7 RISK AND RESILIENCE FACTORS IN RELATION TO THE PSYCHOLOGICAL ADJUSTMENT OF EPILEPTIC CHILDREN**

### **4.7.1 Introduction**

This section will review studies that have examined risk and resilience factors associated with the development of psychological problems in children with epilepsy that are of relevance to the current study. The limited number of studies that have emerged in this area have examined a wide range of variables which include such factors as parental attitudes to epilepsy, parental psychopathology, biological and medical aspects of the condition, demographic factors and family processes and structure (Carlton-Ford et al., 1995; Seidenberg & Berent, in Lothman & Pianta, 1992). In addition, child factors have been examined such as child coping, IQ as well as co-occurring conditions such as learning problems (Carlton-Ford et al., 1995). In order to provide

clarity regarding the conclusions of research in this area of relevance to the current study, this section aims to limit the discussion of the literature to three broad classifications of types of risk variables studied in children with epilepsy 1) demographic factors; 2) biological and illness related factors and 3) family factors. These categories will only be used loosely in order to provide some main points of discussion regarding the literature in this field.

#### 4.7.2 Demographic Variables

Research findings suggest that boys with epilepsy tend to have more problem outcomes than girls and with greater frequency (Carlton-Ford et al., 1995; Hoare & Kerley, 1991; Lewis et al., 1988; Pianta & Lothman, 1994; Vining, 1989). Pianta and Lothman (1994) found that there were higher levels of externalizing problems (behaviour problems) among boys with epilepsy when compared to girls. An interesting finding of this study was that boys showed significantly lower behavioural problems when maternal support/affect was scored as high, while for girls there was no such association. Child IQ has also been examined in relation to behaviour problems. Pianta and Lothman (1994) for example did not find any association between child IQ and behaviour problems. However, as indicated by these authors, child IQ was based on a short form of the WISC-R which does not substitute for a battery of psychological and neuropsychological tests to measure intelligence.

Only a limited number of studies have either controlled for, or examined such demographic factors as socioeconomic status within their research design and those that have examined this variable have suffered from various limitations. Hoare and Kerley (1991) for example found that lower socioeconomic status and the presence of younger siblings was associated with increased psychiatric problems in children with epilepsy. However, no mention was made of how this variable was measured and no multiple regression analyses were performed to determine the relative contribution of these variables in relation to the other variables measured. In general, studies that have examined SES through such means as income measures, have found that there is an association between low incomes and poorer child psychological adjustment across a broad range of measures (Hermann et al., in Carlton-Ford et al., 1995). Carlton-Ford et al (1995) conducted a study examining risk factors in children with epilepsy, and is one of the few studies reviewed that takes into account a wide range of demographic variables. These variables included the child's age, gender, race and poverty status. Boys were found to have a higher risk of epilepsy, as well as home behaviour problems. Children living in poverty (as measured by

comparing the family's current economic status relative to family size) were about 50% more likely to be among those with school behaviour problems. In addition higher parental education was found to be associated with lower levels of home behaviour problems. Another interesting finding in this study was that after controlling for SES, black children were found to have lower levels of behaviour problems than white children suggesting that racial factors do not play a role as risk factors apart for their association with low SES.

#### 4.7.3 Biological and Illness Related Factors

Studies in this area suggest that biological and illness related factors such as type of epilepsy, onset of epilepsy, length of illness, and seizure control play a role in the psychological adjustment of the child with epilepsy, but that their impact is only minimal when compared to other variables (Carlton-Ford et al., 1995; Pianta & Lothman, 1994; Seidenberg & Berent, 1992). Children with less controlled seizures have been found to have poorer overall psychosocial adaptation as well as lower self-esteem, poorer self-images, more depression and higher levels of social withdrawal (Austin, 1988; Hermann et al., in Carlton-Ford, 1995; Hoare & Kerley, 1991). Hoare and Mann (1994) found in their study investigating self-esteem and behavioural adjustment in children with epilepsy (n = 62) and diabetes (n = 91), that children with an earlier age of onset (younger than 4 yrs) and with a longer duration of treatment were consistently associated with higher levels of behaviour problems (using the Child Behaviour Checklist, Achenbach, 1991). It must be noted however that this sample consisted of children diagnosed with types of epilepsy that were more difficult to treat. A regression analysis of demographic and illness variables including age, family size, social class, schooling, age of onset, treatment duration, seizure classification and anticonvulsant drug regime, showed that duration of treatment and male gender made the most important contributions.

Frequency of seizures is another variable that has been measured in relation to behavioural and psychological problems. Hoare and Kerley (1991) used the Rutter Parent scale to measure child psychological problems, and found that children with severe seizure frequency (at least once a week) were more likely to be disturbed than children with less frequent fits. Carlton-Ford et al (1995) compared 32 children (aged 6-17yrs) with active epilepsy (defined as having epilepsy with seizures in the last year) to 86 children with inactive epilepsy (defined as having epilepsy and no seizures in the last year). Children with active epilepsy were consistently more likely than children without epilepsy to be rated by mothers as being at the extremes of poor psychological

and psychosocial adjustment. However, the two groups did not differ significantly from one another. This suggests that frequency of seizures may play a role in either increasing or decreasing the risk of behavioural/emotional problems in children with epilepsy.

In Carlton-Ford et al's (1995) study biological and medical variables such as seizure type, medical polytherapy, use of specific drugs, early age onset, and longer duration of epilepsy were found to be significantly correlated with psychological and social adjustment. After controlling for other relevant variables this study and others have concluded that biological and medical variables only weakly predicted poorer adjustment (Carlton-Ford, 1995; Lothman & Pianta, 1992). Pianta and Lothman (1994) found in their study on risk factors that there was no significant relationship between epilepsy type, type of anticonvulsant medication and behavioural problems. These authors suggest that these lack of significant findings may be due to small cell sizes in this study, particularly in view of the fact that the rate of behavioural disturbance was particularly high in this study. These lack of significant findings may suggest however that there is indeed a weak relationship between illness variables and child behaviour problems. A similar lack of significant relationships between illness variables and psychological problems was found in Rutter et al's (1970a) population based study investigating risk factors in child psychopathology. The authors attempted to identify causes of psychiatric disturbance in childhood epilepsy and found that frequency of seizures, visibility of the handicap and age of onset appeared to be unrelated to rate of psychiatric disorder. In addition, no association was found between type of medication and psychiatric disorder, while type of seizures, particularly children with partial complex seizures was associated with an increased risk of psychiatric disorder.

In two additional studies (Hoare, 1984a; Hoare & Kerley, 1991) it was found that early onset, high fit frequency, longer duration of treatment, specific EEG characteristics, poly-medication and complex partial seizures were similarly associated with an increased likelihood of disturbance. These factors have been associated with more severe intractable syndromes such as Lennox Gastaut Syndrome and West's Syndrome (Hoare & Kerley, 1991). It has been found however, that even under conditions in which the disease is completely controlled with AEDs, there still remains a longterm process of psychological and social adjustment to epilepsy (Seidenberg & Berent, 1992). As mentioned while reviewing some of the studies above, polytherapy and anti-epileptic drugs have additionally been associated with an increased risk of psychological problems (Freeman et al., 1990). Hoare (1984a) found that children who were on phenytoin plus another drug were more likely to be disturbed using the Rutter scale than children

using phenytoin alone ie. mono-medication ( $p < 0.008$ , Fisher's Exact test). These authors also found an interaction between type of epilepsy and poly-medication where the children who were on poly-medication and had complex partial seizures were at an increased risk for psychopathology. AED's have been found to exacerbate behavioural problems as well as cognitive ability, particularly phenobarbital which has been found to increase the child's susceptibility to depression, learning difficulties and behaviour problems (Ferrari et al., 1983; Freeman et al., 1990; Hoare, 1984a; O'Donohoe, 1985a; Shalev et al., 1995; Vining, 1989).

Other researchers have suggested that the behavioural problems that are frequently found in children with epilepsy are related to neurological factors associated with their condition. Hoare (1984a) conducted a study in which children with newly diagnosed epilepsy were compared with children who had been diagnosed with chronic epilepsy for a longer time period in relation to level of behavioural/emotional problems (using the Parent Rutter Scale). The author found no evidence of a significant difference between the two groups and therefore concluded that children with epilepsy appear to have a neurological predisposition to behavioural/psychological problems. It can be suggested however, that one must be cautious regarding such conclusions, for as suggested by Hoare (1984a) himself other stressors inherent in the diagnosis of chronic illness itself may have been responsible for the high rate of psychiatric disturbance found in children with newly diagnosed epilepsy. This paper does however highlight the important point that the psychological adjustment of the child prior to the onset of illness, may play a significant role in the adjustment of the child to the illness.

#### 4.7.4 Family Factors

It is especially appropriate to investigate the relationship between family variables and psychological adjustment in children with epilepsy, given that the child with epilepsy functions and adapts to the illness largely within the context of the family environment (Austin & McDermott, 1988). Past research in the area of childhood epilepsy has tended to focus on the impact of epilepsy on the family (particularly the mother), with very little research investigating the role of the family in the child's psychological adjustment.

Much of the research in this area indicates that poorly adjusted children with epilepsy tend to come from families that have less well-adjusted interactional resources and higher levels of family stress than the families of well-adjusted children with epilepsy (Austin, 1988; Lothman et

al., in Carlton-Ford, 1995). Austin (1988) for example examined family functioning and family resources of 54 children with epilepsy and measured child adjustment in terms of self-esteem and behavioural problems. Children with poor psychosocial adaptation were found to come from families with "less adaptive family functioning, less esteem and communication among family members, less social support from extended families, and less financial efficacy than families of children with good psychosocial adaptation" (Austin, 1988: 21). A major strength of this study was that the sample included children from both clinic and private populations and consisted of both teachers and parents as raters of behavioural functioning. In addition, various aspects of child psychological functioning were examined. The epileptic child has additionally been found to have a reduced level of involvement in family interaction when compared to children without epilepsy, which has been suggested to be detrimental to the child's social development (Levin et al., 1988; Ritchie, 1981).

Another area that has been investigated includes parental attitudes to epilepsy as well as to the child with epilepsy. Hartlage and Green (1972) reported correlations between parental attitudes towards epilepsy and indexes of social and academic achievement in children with epilepsy. Frequency of seizures also negatively correlated with social development, although type of seizure did not significantly correlate with social or academic achievement. Austin et al (1982) similarly found that positive maternal attitudes towards epilepsy affected child adjustment to epilepsy. Parents of children with epilepsy have been found to perceive their child as differing from other children and are seen to communicate with their child in such a manner that encourages dependency (Ritchie, 1981). Parent-child relationships and parent-child communication have been implicated as important predictors of outcomes such as self-esteem, dependency, and academic achievement in children with epilepsy (Long & Moore, in Lothman & Pianta, 1992; Matthews et al., 1982). Hoare and Kerley (1991) reported associations between family stress, maternal attitude to epilepsy, past maternal psychiatric treatment and overall child psychological functioning, self-esteem and dependency. The children in this study, however, were restricted to clinic samples with more severe forms of epilepsy. Grandparents have additionally been identified as playing a role in behaviour problems in epileptic children as well as exacerbating any family problems that may exist due to overprotective and interfering responses to the epileptic child (Romeis, 1980).

In the literature on children who do not have a chronic illness, quality of parent-child interaction has been frequently linked with child behaviour problems and competence at home and in school

(Lothman & Pianta, 1992). The threat of continued and unpredictable seizures and the associated feelings of lack of control by parents have additionally been seen to directly affect child-parent relationships by increasing anxiety and resulting in either overcontrolling responses or conversely undercontrolling the child's behaviour (Austin & McDermott, 1988; Ferrari et al., 1983; Ritchie, 1981; Seidenberg & Berent, 1992). These factors have been suggested to form a link between epilepsy and child behaviour where such responses as "restrictiveness on the part of the parent may rob the epileptic child of vital opportunities for social interaction and may make him feel different from, or inferior to, his peers" (Long & Moore, 1979: 300). Some of these symptoms may include adoption of a sick role with accompanying suppression of normal responsibilities, withdrawal and denial, dependency and low self esteem (Levin et al., 1988).

As mentioned previously, family variables have been found in a number of studies to have a more significant association with psychological adjustment of children with epilepsy than illness variables. Pianta and Lothman (1994) for example examined the relative role of parent-child relationships, family stress and disease factors in predicting behaviour problems in children with epilepsy (aged 7-13yrs). Observational measures were used to measure such parental expression of emotion, maternal support and child's self-reliance in a dyadic problem solving situation. Child self-reliance and ratings of dyad coordination and expression of affect was significantly related to parent reported externalizing problems. This study found that these child-parent relationship measures accounted for as much, or greater percentage of variance on average than child, contextual, or disease related factors.

#### **4.8 CONCLUSIONS AND LIMITATIONS OF RESEARCH STUDIES**

Relatively very little research is available in the in the area of childhood epilepsy focusing on risk and protective factors associated with child psychological adjustment. Much of the research has been based on small sample sizes (Austin et al., 1982; Ferrari et al., 1983; Richie, 1981) which may limit the statistical power of the statistical analyses and conclusions that can be drawn from these studies. Numerous studies have produced documentation of the negative impact that epilepsy can have on different aspects of the child's psychological functioning. Only a few studies however have examined the wide range of variables included in Wallander et al's (1989) model of risk and resilience eg. disease/disability parameters, social-ecological factors, stress processing variables etc. Research specifically appears to be lacking in the area of family

variables (eg. family coping, family adaptability), demographic variables (socioeconomic status) and factors related to the child (eg. temperament, age, child coping).

Carlton-Ford et al (1995) note that despite some general knowledge of the behavioural and psychological correlates of epilepsy and the impact of epilepsy on family processes, little is known regarding the moderating or mediating effects of demographic background, family structure, family processes, or cooccurring conditions on the social and psychological conditions of children with epilepsy. Of the studies that have examined family variables, the main focus has been on family resources and family stress, while less research has investigated such factors as family cohesion or adaptability in relation to child psychological adjustment. In addition, research to date does not appear to have examined family coping in terms of Lazarus & Folkman's (1984) definition of coping which includes active "efforts" to "manage" stress. Research investigating family adaptation to childhood epilepsy appears to have conceptualized the family as a passive recipient to demands rather than actively attempting to cope with stress and problems. Further studies are needed in the field of childhood epilepsy that examine family coping in terms of specific coping strategies used by families, as well as how the use of specific family coping strategies impacts on child psychological adjustment.

Many of the samples in studies have been drawn almost exclusively from clinic populations which tend to include children who have more severe forms of epilepsy (eg. Hoare & Kerley, 1991; Pianta & Lothman, 1994). Although this research usually excludes more complicated cases (eg. those involving mental handicap or degenerative neurological conditions) these subjects represent atypical or unrepresentative populations of children with epilepsy which may potentially bias results of studies. It is true that researchers face practical difficulties in attempting to obtain representative samples of children with epilepsy unless the study forms part of a larger scale epidemiological study (eg. Rutter et al., 1970a). Few studies however, appear to have attempted to overcome this problem by recruiting subjects through other sources (eg. newspaper advertisements, schools etc) where the majority of studies have used clinic samples as the sole access point for recruitment. In addition, studies have additionally frequently failed to provide adequate descriptions of their final sample, which can be seen as essential when attempting to generalize from studies to other population groups. Socio-economic status is frequently not described, measured or controlled for despite its prior association with psychological problems in previous studies with children with or without a chronic illness (Haggerty et al., 1994, Lavigne & Faier-Routman, 1993; Rutter et al., 1970a).

In conclusion, it is evident that there is a paucity of research focusing on risk factors and/or resilience in the area of childhood epilepsy. Given that research indicates that illness variables appear to play only a minor role in the development of psychological adjustment of children with epilepsy, future research is needed that takes into account a variety of contextual factors such as family functioning and coping in addition to other factors included in Wallander et al's (1989) model of adjustment. Ideally an eco-systemic approach is needed that takes into account the factors within the various systems in which the child lives that may impact on child psychological adjustment. It is apparent that additional studies are needed in the field to further understand the processes involved in the child's psychological adjustment to epilepsy.

## CHAPTER FIVE: RESEARCH METHODOLOGY

### 5.1 INTRODUCTION

In the four previous chapters, background literature pertaining to the development of psychological problems in children with epilepsy and chronically ill children has been reviewed. Drawing from this literature, the current chapter sets out to elucidate the aims and methods of the present thesis and specific research hypotheses are formulated. The procedure followed in the current study will be outlined, and the instruments used in the current study will be described in terms of the constructs that they measure as well as their validity and reliability.

### 5.2. AIMS AND OBJECTIVES

#### 5.2.1 Introduction

After reviewing some of the literature in relation to psychological adjustment in children with epilepsy, it is apparent that previous research appears to have frequently failed to take into account important contextual factors that may play a role in either exacerbating or moderating children's psychological adjustment to epilepsy. The paucity of research examining family variables as either risk or moderating factors in relation to the psychological adjustment of the child with epilepsy is surprising when one considers the large volume of research that has examined the range of difficulties that families may have in coping with their child's epilepsy. Studies that have specifically examined a range of risk factors associated with child psychological adjustment indicate that risk factors can be loosely categorized into illness factors, child factors and social factors (eg. family, peer groups etc). Moderating factors have been found to include intrapersonal factors (eg. temperament, problem solving ability) as well as factors in the environment (eg. family). There appear to be very few studies in the area of childhood epilepsy that have investigated family variables as risk variables with regard to psychological functioning, and the majority of studies that have included family variables have focused largely on levels of family stress or family attitudes to epilepsy. It is evident however, that studies are lacking that examine the impact of family structure, as well as family coping in relation to child psychological adjustment. Much of the research appears to have placed a large amount of focus on illness variables, with relatively fewer studies taking into account broader contextual factors eg.

sociodemographic status or child variables (such as child coping).

Few specific theories have emerged that account for the large array of factors that have found to be associated with child psychological adjustment within the context of childhood chronic illness. The current study draws broadly on systems theory in order to further understand the relationship between family relations and child psychological functioning and specifically makes use of the Circumplex Model of Family Functioning (which has a sound basis in systems theory). In addition, the current study applies ecosystemic principles in order to understand child psychological adjustment whereby a variety of factors within the various systems in which the child exists are seen to play a role in the child's psychological adjustment (eg. child factors, illness factors, the family, peer groups, school environment, broader social factors etc.). This approach can essentially be considered to be biopsychosocial, whereby biological factors could include factors related to the illness, intelligence, temperament, psychological factors could include problem solving abilities, coping abilities and social factors could include factors within the family, the school system, and more broadly socio-cultural factors.

### 5.2.2 The Aims of the Current Study

The study aims to answer the broad question of 'Why do some children with epilepsy exhibit high levels of psychological symptoms while other children appear to be largely unaffected?' In particular the current thesis will examine specific risk and protective factors that are hypothesized to play a role in child psychological adjustment in children with epilepsy. The design of the study can thus be considered a cross-sectional relational design as it aims to determine strength of relationships and associations between variables, rather than cause-effect relationships. Given the practical time and financial constraints imposed on the current study however, it was necessary to limit the focus of the current study to sets of specific factors hypothesized to play a role in psychological adjustment of the epileptic child. The independent variables under consideration in the current study can be seen to fall into three main categories:

- 1) family variables: family adaptability, family cohesion, family coping
- 2) illness variables: epilepsy type, seizure frequency, length of time since diagnosis and type of medication (whether poly-medication or mono-medication)
- 3) demographic variables: socioeconomic status, age of child, number of siblings and gender of child.

The dependent variable in the current study was level of behavioural or emotional symptoms of the epileptic child as perceived by the mother, which is seen as an expression or measure of risk of psychological disorder.

### **5.3 HYPOTHESES TO BE EXAMINED**

The principal hypotheses for the present study were as follows:

#### Hypothesis 1

There will be an inverse relationship between levels of family adaptability and risk of psychological problems in children with epilepsy.

#### Hypothesis 2

There will be an inverse relationship between levels of family cohesion and risk of psychological problems in children with epilepsy.

#### Hypothesis 3

The use of specific family coping strategies used by families may either increase or decrease the risk of psychological problems in children with epilepsy.

#### Hypothesis 4

Higher frequency of seizures in children with epilepsy will be associated with an increased risk of psychological problems.

#### Hypothesis 5

The type of seizure that the child is diagnosed with (ie. in the current study, grand mal or petit mal) will impact on risk of psychological problems in children with epilepsy.

#### Hypothesis 6

Whether the child with epilepsy is on mono-medication or poly-medication will impact on risk of psychological problems, where the use of poly-medication is hypothesized to be associated with a greater risk of psychological problems than use of mono-medication.

### Hypothesis 7

Children who have been diagnosed with epilepsy for a longer length of time are hypothesized to be at a greater risk for the development of psychological problems than children who have been diagnosed with epilepsy for a shorter time period.

### Hypothesis 8

Level of SES will impact on risk of psychological problems in children with epilepsy, where children from low SES groups are predicted to have a higher risk of psychological problems than children from middle or high SES groups.

### Hypothesis 9

An investigation of combined predictors of psychological problems in children with epilepsy.

## **5.4 PROCEDURE**

### 5.4.1 Recruitment of Sample and Informants

45 mothers of children with epilepsy was recruited as informants to provide information needed for the current study regarding demographic data, and information related to child and family functioning. The sample and informants were obtained from a wide range of sources in order to provide a sample that was as representative as possible of the general population of children with epilepsy. Two specialized schools for children with epilepsy in the Western Cape were approached and permission was obtained from both the Department of Education and headmasters to conduct the study at these schools. Both these schools granted permission to approach teachers to recruit a sample of children that met the criteria of the current study, and one school gave permission for the researcher to present the aims of the study at a quarterly parent meeting to encourage participation of mothers in the study. One school provided the researcher with a list of names of children that appeared to fit the required criteria to be included in the study, and the other school gave the researcher access to school files which included contact numbers of parents as well as medical information regarding the child's epilepsy. In addition, specialists running epilepsy clinics at two general hospitals in the Western Cape were approached. One hospital gave the researcher access to files of pediatric patients attending the epilepsy clinics, and the other hospital granted permission to approach parents attending weekly pediatric epilepsy clinics in the hospital waiting room. SANEL (South African National Epilepsy

League) was additionally approached and the researcher presented the general goals of the study at a parent coffee meeting, and a request for volunteers was placed in their quarterly newsletter. In addition, a private doctor specializing in pediatric epilepsy agreed to privately contact patients known to her who met the criteria for inclusion for the study. Advertisements were also placed in community newspapers in the Western Cape region. Although it is acknowledged that probability sampling is the most desirable method to obtain a representative sample of the desired population in research, this method was not possible in the current study due to the limited number of children with epilepsy who met the criteria required by the study (Bless & Achola, 1988). Attempts were made however to obtain a sample that was as representative as possible of children with epilepsy in South Africa and who were from a variety of different socioeconomic and cultural backgrounds.

#### 5.4.2 Informed Consent Procedures and Data Collection

Mothers of children with epilepsy were introduced to the study either by telephone, at epilepsy clinics or at parent meetings and the broad aims of the study were explained. Mothers were told that the study aimed to investigate issues around family coping and child coping with childhood epilepsy and that their participation in the study was entirely voluntary. Only general goals of the research were given so as to comply with informed consent procedures while at the same time minimizing response bias (eg. compliance of the respondent to the perceived desired outcome of the study). Subjects were additionally told that their participation would involve an interview as well as the completion of questionnaires and would take approximately an hour of their time. Consent was obtained from all participants and assurance was given regarding the confidentiality of their responses. General feedback was offered to participants on the completion of the research study (via schools and individually).

The researcher interviewed mothers at a place of their choice to obtain data for the current study, which was generally either at their child's school or in the mother's own home. This method of obtaining data was more convenient for mothers and encouraged participation in the study thereby improving the response rate. The interview began with an introduction to the broad purpose of the study and gave mothers the opportunity to ask questions and confirm that they still wished to continue with the study. The demographic data was obtained by the researcher using a semi-structured interview format, while the self-report questionnaires were generally completed individually by the mothers in the presence of the researcher. Some mothers responded orally to

the questionnaires, as they were either tired or had difficulty reading the questions (due to poor eyesight). The researcher was able to observe (and clarify) any questions that the mothers found to be ambiguous as well as to ensure the full completion of the questionnaires.

Despite the initial intention to use one consistent method of data collection (as previously described), it was decided to post questionnaires to mothers who lived too far away or in areas which would have been too difficult or dangerous for the researcher enter. The rationale for this decision was based on the need for a sample large enough for statistical analysis that strictly met the criteria for inclusion. These parents were provided with questionnaires via their children at the schools and requested to complete them and return them to either the school or the researcher. Given this difference in method of data collection a certain amount of bias may have potentially affected the responses of mothers in the study. For example, while the interview context allowed the mothers to clarify questions, parents who were posted questionnaires were less likely to request clarity by phoning the interviewer (as was suggested on the instruction sheet of the questionnaire) if they needed assistance. Although two of the parents phoned for assistance with the forms, these questionnaires were not included in the final sample as they did not fulfill the criteria specified for the study.

It was initially intended to interview both parents for the study, but this became impractical as fathers were often unavailable (usually working) and generally appeared more hesitant regarding their involvement in the study. Ideally if included, fathers and other family members could have provided information from alternative perspectives regarding the family dynamics and psychological functioning of the child.

#### 5.4.3 Criteria for Selection

Prospective subjects were required to meet the following criteria:

1. Children included in the study were required to be within the age range of 8 - 13 yrs.
2. All subjects with severe mental handicap, secondary medical problems, or gross physical impairments were not included in the study.
3. Only children with "active" epilepsy were included in the study (ie. have had seizures in the last year).
4. Only families which consisted of both a mother and father were included in the study.

5. Mothers were selected as the informants of the study due to the fact that fathers were often working at the time and unavailable at the time of the research. It was decided that mothers would be able to provide a more accurate picture of their child's psychological functioning as they appeared to have the most ongoing contact with their epileptic child.

## 5.5 DESCRIPTION OF THE SAMPLE AND INFORMANTS

The final sample consisted of 45 children with epilepsy who were representative of black, coloured and white children, where mothers served as informants. These subjects can be broken down into two groups depending on method of data collection, where in total there were 36 "interviews" and 9 "posted" fully completed returned questionnaires. Approximately 50 "posted" questionnaires were sent out (through schools and hospitals) and although 19 were returned, only 9 were used in the study (10 questionnaires were either incorrectly completed or the families/children did not fully meet the criteria). There was a good response rate from mothers telephoned to be interviewed (where the sample met the criteria for inclusion in the study), and only 4 of the 40 mothers in total (ie. 10%) either did not wish to become involved in the study or failed to be available on the interview date.

A large majority of subjects were obtained through the two specialized schools for children with epilepsy ( $n = 34$ ). Although the response rate from the newspapers was good, the majority of children did not meet the criteria required to be part of the study and thus only two children ( $n = 2$ ) were actually recruited from this source (due to age, associated mental handicap etc.). The other nine subjects were referred through doctors, general hospitals and SANEL ( $n = 9$ ). As is typical of much research conducted within community settings, many of the families attending epilepsy clinics were extremely poor, often did not have time to be interviewed, lived in dangerous areas (with no telephones) or communicated in a language that was different to the researcher (Hamber, 1995). In addition, many of these children had additional medical problems as well as mental handicap. For this reason, a large number of mothers approached in the epilepsy clinics were not included in the study.

The mean age of the children with epilepsy was 10.82 years (Std. Dev. = 1.64) with a minimum age of 8 and a maximum age of 13. Gender was not evenly distributed in the sample where 71% of the sample were boys and 29% of the sample were girls. There was a range of three SES levels included in the study, where children were from families with high SES (16%), middle

SES (31%) and low SES (53%) when using Riordan's measure of SES (Riordan, 1978). The main types of seizures evident in the sample of children with epilepsy consisted mainly of petit mal seizures (40%) and grand mal seizures (44%). Various other classification types were given that included epilepsy type and seizure type which were excluded from the statistical analysis as they did not relate to specific seizure type, or formed groups too small to be included in the analysis (eg. benign rolandic epilepsy (2%), mixed type (4%), temporal lobe epilepsy (8%) and focal lobe epilepsy (2%). The mean length of diagnosis of epilepsy was 7.6 years with a minimum length of diagnosis was 3 years and a maximum length of diagnosis was 12 years.

Only children who were actively experiencing seizures (ie. in the last year) were included in the study and consequently the majority of the children in the sample were on some form of medication for their epilepsy (98%). There were slightly more children on mono-medication (57% or  $n = 25$ ), with 43% on poly-medication ( $n = 19$ ). Only medications prescribed specifically for the child's epileptic condition (rather than for associated problems) were included in this classification. The variable frequency of seizures was coded into five levels of frequency ranging from 1 (at least once a day) to 5 (no more than 3 a year). The median frequency of seizures was 3 ie. at least once a month (Std Dev. = 1.47).

As mentioned previously a large number of children in this study were recruited from specialized schools for epilepsy which additionally cater for children who frequently have associated learning difficulties. It is noted that research in the area of learning difficulties indicates that children with learning problems are at a greater risk for psychosocial problems (Miller, 1994; Morrison & Cosden, 1997; Spekman et al., 1993). It was hoped to control for this variable through the inclusion of both children with and without learning difficulties into the study in order to compare the two groups with regard to risk of psychological/behavioural problems). It was difficult to examine this variable however as the majority of mothers indicated that their children had learning problems and had received confirmations of this from assessments performed at their child's schools.

The current sample can be considered to include a large number of children with learning difficulties that may have impacted on the levels of behavioural and psychological symptoms of children in this group. Future large scale studies could investigate this variable further by including children both with and without learning difficulties to determine to what degree learning problems impact on the psychological functioning of children with epilepsy.

## 5.6 INSTRUMENTS

### 5.6.1 Introduction

It was attempted as far as possible to choose instruments that had acceptable levels of validity and reliability and these will be described briefly in relation to each questionnaire. The various questionnaires that were used in the study will be discussed below:

### 5.6.2 The Demographic Questionnaire

The demographic questionnaire contained questions related to basic descriptive information such as age, gender, socio-economic data, marital status, the psychological history of the mother, educational level and family constellation. It also contained questions related to child's illness ie. number of years since diagnosis, frequency of fits, cooccurring conditions etc. (See Appendix A).

### 5.6.3 The Family Adaptability and Cohesion Evaluation Scale 11 (FACES 11)

The Family Adaptability and Cohesion Evaluation scales, Version 11(FACES 11) was used to assess family functioning in the current study. This instrument is a 30 item self-report questionnaire that was developed to measure family adaptability and cohesion (Olson et al., 1992) (See Appendix C). The questionnaire consists of two scales, in which there are a total of 16 cohesion items and 14 adaptability items. This instrument also uses a five-point Likert response scale to assess the extent to which the respondent feels the item statements are applicable to his or her family.

The FACES 11 is a self-rating scale that is based on the Circumplex Model of family systems as formulated by D. H. Olson, C. Russel and D. Sprenkle (1979). As indicated in Chapter Two (p. 12) family cohesion reflects the degree to which family members are separated from or connected to their families ie. "the emotional bonding that family members have toward one another" (Olson et al., 1985: 48). Family cohesion is categorized into four levels in FACES 11 based on the total score obtained on the cohesion scale. These levels range from extreme low cohesion to extreme high cohesion ie. disengaged, separated, connected, and very connected. The two moderate levels of cohesion have been labelled separated and connected and are

considered to be the most balanced levels of cohesion (Olson et al., 1992). The specific concepts within the Circumplex Model which are used in FACES 11 to diagnose and measure the cohesion dimension are: emotional bonding, boundaries, coalition, time, space, friends, decision-making, interests and recreation.

Family adaptability refers to the ability of a marital or family system to change its power structure, role relationships and relationship rules in response to situational and developmental stress (Olson et al., 1985). Family adaptability is also categorized into four levels in FACES 11, based on the total score obtained on the adaptability scale. These levels range from extreme low adaptability (change) to extreme high adaptability (change): rigid, structured, flexible, and very flexible. The two moderate or balanced levels of adaptability have been labelled flexible and structured. Specific concepts used in FACES 11 to diagnose and measure the adaptability dimension are: family power (assertiveness, control, discipline), negotiation style, role relationships and relationship rules.

#### Reliability and Validity

Olson et al. (1992) reported high internal consistencies (Cronbach's Alpha) for the FACES II cohesion scale ( $r = .87$ ) and for the adaptability scale ( $r = .78$ ) and for the total scale ( $r = .90$ ). Test-retest agreements over 1-month intervals were reported as  $r = .83$  for the cohesion measure,  $r = .80$  for adaptability, and  $r = .84$  for the total scale measure. Factor analysis shows satisfactory items loadings on both a cohesion and adaptability factor, although these dimensions may not be "factorially pure." Predictive validity has been demonstrated through differentiation of families with referred children and nonreferred children as well as with runaway children and a control group (Porter, in Smets and Hartup, 1988). The correlation between the adaptability and the cohesion scales is relatively high ( $r = .25-.65$ ) suggesting that there may be some overlap regarding the two dimensions, where the concepts of adaptability and cohesion are not entirely independent (Olson et al., 1992).

Olson et al (1992) suggest that it is important to have as many family members as possible to fill in the FACES 11 in order to capture the complexity of the family system. In a sample of 1,140 couples and families, the correlation between husband and wife was .46 on cohesion and .33 on adaptability. The correlations between husband and his adolescent was .44 for cohesion and .25 for adaptability, while the correlations between the wife and her adolescent was somewhat

lower (.38 for cohesion and .13 for adaptability). This suggests that the combined responses of different family members are important in determining a more realistic picture of family functioning. The current study specifically requested mothers to complete the questionnaires as fathers were often too busy to become involved in the study. Findings of the current study must therefore be interpreted in terms of mothers perceptions of family relations.

#### Justification for the Use of FACES 11 over FACES 111

Although FACES 111 is the most recent version of FACES, recent reliability and validity comparisons have suggested that FACES 11 has certain advantages over FACES 111 for current research. These advantages include FACES 11 having a higher cronbach alpha reliability on the adaptability scale, cohesion scale and total family type scale (Olson et al., 1992). The concurrent validity for FACES 11 was found to be higher than for FACES 111, especially for family adaptability (ie. other instruments which measure constructs similar to cohesion and adaptability correlate higher with FACES 11 than FACES 111) (Olson et al., 1992). Olson et al (1992) thus concluded that FACES 11 would provide a more successful research tool than FACES 111.

#### Linear Scoring of FACES 11

The original Circumplex Model suggested a curvilinear relationship of cohesion and adaptability with effective family functioning, whereas more recent empirical evidence supports a linear relation between these variables (Hampson et al., 1991; Olson et al., 1992). In addition, because empirical data does not capture the extremely high categories of the levels of "enmeshed" and "chaotic" families, the higher (extreme) scores on the adaptability and cohesion dimensions have been reinterpreted as "very connected" and "very flexible" (Olson & Tiesel, in Olson et al., 1992). The current study used these new categories and analyzed FACES 11 in a linear fashion as suggested by Olson and Tiesel (in Olson et al., 1992).

#### 5.6.4 The Family Crisis Orientated Evaluation Scale (F- COPES)

The Family Crisis Oriented Personal Evaluation Scale (F-COPES) was designed to identify effective problem solving approaches and behaviours used by families in response to problems or difficulties (McCubbin et al., 1992) (See Appendix D). The F-COPES builds upon the coping dimensions of the Double ABCX Model of family stress theory which integrates pile-up factors,

family resources and the meaning perception factors of family stress theory (Hill in McCubbin et al., 1992).

Family resources (Hill's B factor, 1958) include the use of social support networks, such as extended family members, friends, and neighbours as well as the family's approach to problem solving. The "meaning" a family attaches to a stressful situation or the family's appraisal of the situation may also serve as part of the family's coping behaviour. The application of social meaning to a situation is seen to render stressful situations less unacceptable and more understandable in the context of the situation in which they occur. The instrument consists of 30 coping behaviour items which focus on the two levels of interaction outlined in the Double ABCX Model: 1) the ways in which the family internally handles difficulties and problems between its members (internal coping strategies) 2) the ways in which the family externally handles problems or demands that emerge outside its boundaries but affect the family unit and its members (external coping strategies). Families operating with more coping behaviours focused on both levels of interaction were predicted to adapt to stressful situations more successfully (McCubbin et al., in Olson, 1992).

The F-COPES Scale consists of the following five factor derived subscales:

1. *Acquiring Social Support*. Nine items that measure a family's ability to actively engage in acquiring support from relatives, friends, neighbours and extended family. These items identify how a family uses the external resources that it has at its disposal.
2. *Reframing*: This dimension consists of eight items which assess the family's capability to redefine stressful events in order to make them more manageable. This dimension is based on the fact that people change or adjust to problems after they have established meaning or made sense of the change.
3. *Seeking Spiritual Support*: These four items focus on the family's ability to acquire spiritual support.
4. *Mobilizing Family to Acquire and Accept Help*: These four items measure the family's ability to seek assistance from more formalized networks of support such as community resources and from professional persons. This has been shown to be important as a supplemental resource to informal networks (McCubbin et al., 1992; Olson et al., 1985).
5. *Passive Appraisal*: The four items that form part of this subscale assess the family's ability to accept problematic issues minimizing reactivity. This has been shown to be the least useful

coping strategy in dealing with stress (Olson et al., 1985).

A sum score can be obtained for each subscale and a total score by summing the respondent's score for each of the item. Separate norms are available for each of the F-COPES subscales and the total scale. In the initial norming study, internal consistency reliability was computed for each factor and the total scale using a large combined sample of men, women and adolescents (N = 2740) (McCubbin et al., 1992). Scale scores were pooled and then the sample was randomly split into two halves. Cronbach's alpha reliability coefficient for the total scale of the first sample was .86 and .87 for the second sample. Acceptable test-retest reliability has been demonstrated (Cronbach's alpha = .81 for the total scale) although the factors reframing and passive appraisal showed slightly lower test-retest r scores in comparison with the other factors (r = .61; r = .75). The more concrete behavioural items such as 'acquiring social support', appeared to provide more response consistency over time (r = .78) than those factors that related more to cognitive adjustment (McCubbin et al., 1992). The individual alpha reliability coefficients for the various subscales in the two samples provided by McCubbin et al (in Olson et al., 1992) are presented in Appendix E). In the current study only the mother completed the F-COPES and therefore findings using this questionnaire are based on the mother's perception of family coping.

#### 5.6.5 The Rutter Parent Scale

##### Introduction

The Rutter Parent Scale (Rutter et al., 1970b) was the assessment device used in the current study to measure the levels of problematic behaviours and symptoms as perceived by the mother of the child (See Appendix B). This scale was designed to provide a fairly short questionnaire with acceptable validity and reliability that could discriminate between children in middle childhood (ages 9 - 13) who show disorder and those who do not (Rutter et al., 1970b). In addition it is can be used to discriminate between different types of behaviour and emotional disorders.

The Rutter Parent Scale consists of thirty three descriptions of specific behaviours and symptoms to which the parent must decide on a three point scale to what extent they apply to their child (ie. doesn't apply, applies somewhat or certainly applies). Individual item scores (which are weighted according to Rutter's scoring system that takes into account both the frequency and severity of the

particular symptom) are then summed to produce a total score with a range of 0 - 62. Children with a total score of 13 or more are designated as being at greater risk of showing some disorder. In order to further differentiate between risk of specific types of disorders (ie. antisocial and neurotic), a 'neurotic' sub-score is obtained by summing the scores of certain items used to classify the child as 'neurotic' (eg. worries about many things) and an 'antisocial' sub-score is obtained by summing the scores of certain items used to classify the child as 'antisocial' (eg. often destroys own or other's belongings). Those children with a 'neurotic' score exceeding the antisocial score are designated 'neurotic' and those with an 'antisocial' score exceeding the neurotic score are designated 'antisocial'. Children with equal neurotic and antisocial scores remain 'undifferentiated' (Rutter et al., 1970b).

The assessment of childhood symptomatology can be seen to be a complex enterprise and work in this field suggests that assessment at "single symptom" levels (such as bed wetting, nail biting etc.) is generally a weak strategy for examining the antecedents of emotional disturbance as well as for predictive studies (Rutter, 1983; Smets & Hartup, 1988). More recent research has indicated that aggregated symptoms clearly differentiate children who are referred for clinical treatment and those who are not (Rutter, 1983; Smets & Hartup, 1988). In addition, total behaviour problems scores have been more strongly related to clinical status than either subscale scores or the incidence of any single symptom (Achenbach & Edelbrock, 1983). The researcher had intended to make use of a more updated questionnaire that has been used more frequently in the field of developmental research ie. The Child Behaviour Checklist (Achenbach, 1991). However, due to difficulties related to obtaining this questionnaire at the time of the research, it was decided to make use of the Rutter Parent Scale which appeared to have adequate levels of re-test reliability and validity and met the goals of the current study.

In the current study the researcher decided to use the Rutter Parent scale as a general screening device in order to detect children with epilepsy with a high risk of psychological problems rather than attempting to classify children with certain types of disorder. It was initially decided to measure the total level of psychological and behavioural problems using the Rutter Parent Scale, but a boxplot of this variable indicated that there appeared to be high levels of variability in the continuous Rutter scores. When attempting to conduct correlational and chi-squared tests it was evident that no significant correlations were found between the *continuous Rutter scores* and any of the dependent variables. It was apparent that the large amount of variability combined with the small sample size may have limited the power of the correlational results. The author therefore

decided to use the Rutter Parent Scale as it was intended, ie. by using the cut off point as suggested by Rutter which specifically indicates whether the child is at an increased risk of showing some form of disorder. By using the cut off point as an indication of risk of disorder, the variability of the scores appeared to be reduced and further information was provided with regard to specific relationships between variables.

Although the author uses the term "risk of disorder" throughout the study it is not implied that a child scoring within this category actually has a particular diagnosable disorder, but merely that the high number of symptoms suggests that the child is at an increased risk for psychological problems (disorder). It is recognized that given the complexity involved in forming clinical diagnoses that the Rutter Parent Scale would need to be supplemented by a large amount of additional information on the child (from a variety of sources, including an interview with the child) in order to use this device to determine specific child disorders.

Due to the fact that the Rutter Parent scale also uses a number of physical symptoms as indicators of psychological problems (eg. stomach aches, vomiting) it was considered important to check with mothers whether the symptoms experienced were psychological or related to the child's epilepsy. If the mother indicated that the child had frequent headaches related to associated symptoms of epilepsy (eg. as a symptom before a seizure) then this symptom was discarded in the subsequent scoring procedures. This attempted to ensure as far as possible that the scored symptoms were related to psychological factors rather than medical factors. For questionnaires that were posted to mothers this was not possible to determine however (n = 9).

### Reliability and Validity

The *retest reliability* of the questionnaire was by tested Rutter et al (1970b) who requested eighty-three mothers to rate their nine to thirteen year old children twice, with a two-month interval between ratings. The product-moment correlation between the total scores on the two occasions was  $r = 0.74$  (Rutter 1970b). *Interrater reliability* was tested by requesting both fathers and mothers of 35 nine to thirteen year olds children to rate them simultaneously but independently during an interview. The product-moment correlation between the total scores of the mothers and the fathers was  $r = 0.64$ . *The discriminative power* of the scale was tested by comparing the scores of children in the general population with the scores of children attending psychiatric clinics for emotional and behavioural disorders. The general population sample

consisted of a random sample of ninety-nine boys and ninety-nine girls aged nine to thirteen years living in Aberdeen. The clinic sample consisted of a consecutive series of seventy-two boys and forty-eight girls newly referred to the Maudsley Hospital. In line with the results of pilot investigations, it was found that the best discrimination between clinic and non-clinic children was obtained with a total score of 13 or more, where 15.1 per cent of boys and 8.1 per cent of girls in the general population obtained scores of 13 or more compared with 70.8 per cent of the boys and 66.6 per cent of the girls in the clinic sample (Rutter, 1970b).

As indicated by Rutter et al (1970b) the Rutter Parent questionnaire can usefully be employed as a screening instrument to distinguish between those children in the middle age range who are likely to show emotional or behaviour disorder and those children who are not likely to show some emotional or behavioural disorder. This scale was thus considered a useful measure to determine risk of psychological problems in the current study.

#### Further Examination of the Rutter Score on a South African Sample to Obtain Norms

One of the limitations of the Rutter Scale is that it fails to provide norms (means or standard deviations) for children regarding levels of symptoms as measured by the Rutter Parent scale. The author of the current study therefore decided to include a comparison group in the study for the purpose of providing norms for children with no epilepsy. This aimed to provide further information regarding the manner in which one could understand the scores obtained on the Rutter Scale in relation to norms on children without epilepsy in a South African sample of children.

The sample of epileptic children was matched with the normal control group on age and gender of the child. Family members of the normal control group were required to have no history of chronic illness/disability and consist of two parent figures. Given the stringent matching on these variables, the complete matched sample consisted of 36 subjects, which was a reduction of the original sample size ( $n = 45$ ). SES, and racial group was not fully controlled for, but the sample was taken from a school that was in close proximity to the two schools where the epileptic sample was mainly drawn from and consisted of children from a broad range of different racial and SES groups (although mainly lower/middle SES). It is recognized that the lack strict of control over SES in the comparison group may have introduced confounding variables into the comparisons, despite the fact that this variable was partially controlled for. While keeping in mind this

limitation, one can still suggest that the information gleaned from the comparative scores of a typically healthy sample provided useful information.

The children with epilepsy in the current sample ( $n = 36$ ) had a mean score of 17.44 on the Rutter Scale (Std. Dev. = 5.67), while in contrast the mean score on the control was 7.53 (Std. Dev. = 5.67). When using a t-test the two scores can be seen to be significantly different ( $t = 5.83$ ;  $df = 70$ ;  $p < 0.01$ ) where children with epilepsy appeared to have much higher total scores as measured by the Rutter Scale (See Table 1 below).

**Table 1 Comparisons of Means of Rutter Totals in Children with and Without Epilepsy**

Mean Epilepsy	Mean Control	t-value	df	p	N
17.44	7.53	5.83	70	.01	72

This result concurs with previous findings in the literature where children with epilepsy have been found to have an approximately fifty percent increased risk of disorder when compared to children with no chronic illness (Holden et al., 1997; Lavigne & Faier-Routman, 1992). It is interesting that when compared to previous studies using children with no illness as controls, that the control group in the current study was at a higher risk for disorder (Rutter, 1979; Hoare, 1984a). This may suggest that other factors such as SES may play a role in the development of psychological problems in the current study as both the sample and comparison group included families that were living in particularly poor conditions not experienced by low SES samples recruited for studies in typically Western societies (eg. USA, Britain).

#### 5.6.6 Riordan's (1978) Classification of Socioeconomic Status (SES)

In order to classify socioeconomic status it was necessary to obtain a valid definition and measure of socioeconomic status applicable to South Africa. In the current study the researcher decided to use Riordan's (1978) method of quantifying socioeconomic status, which appeared to be suitable for the different ethnic groups included in the current study. This approach utilizes two variables, both of which are seen to be closely associated with socioeconomic status, the first was occupation and the second was educational level of the father or guardian. In the current study both these variables were examined using the demographic questionnaire constructed by the researcher, whereby mothers were required to record both the occupation and educational level of themselves and their husband. Foxcroft (1985) has suggested that the alternative approach of

requesting the income level of a family can evoke emotional responses which can lead to unreliability of the data, while using educational level as an indicator of SES provides a less threatening and thus a more reliable indicator of SES.

The first variable, namely occupation was classified into types of occupations held by the breadwinner. These occupations ranged from top professional to not economically active (or productive) and a numerical value using Riordan's classification, was assigned to each category with scores ranging from 1 to 9 (See Appendix F). The occupational classification scale was designed for breadwinners of the family and thus has limitations in that it does not take into account the relative contributions of the wife. The education of the mother and father is considered important as it is reported that there is a high correlation between the head of the household, family income and occupational status of the household head (Dohrenwen, in Jansen, 1991). In the current study subjects were requested to record their highest educational level and this was then converted into a numerical value from 0 to 7 according to the system devised by Riordan (1978) (See Appendix G). Both the numerical values of occupational and educational categories were added, and the final score, which ranged from two to sixteen, was used to determine the socioeconomic index for each subject. In the current study some of the families had two working parents, or a father who was unemployed despite the fact that his wife was working. In order to provide reliable findings the researcher used the highest combined score of the parent who was the main breadwinner of the family (independent of whether it was the mother or the father).

Riordan's (1978) classification system included boundaries for the upper, middle, and lower socioeconomic levels that were set arbitrarily by Riordan (1978) due to the fact that the population census of 1970 yielded vastly discrepant representation of the different ethnic groups in occupational, educational and income categories. There appeared to be no other way of determining social class boundaries in the current study and thus Riordan's (1978) cut off points for determining socioeconomic class were used (See Appendix H).

## CHAPTER SIX: RESULTS

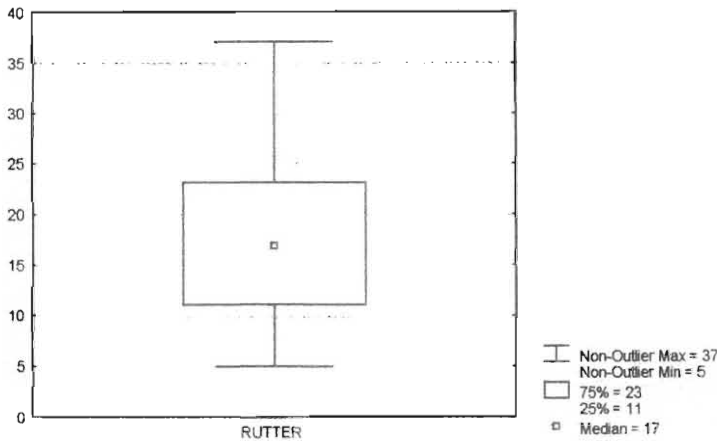
### 6.1 INTRODUCTION

The data collected by means of the questionnaires, i.e. the Personal Details Questionnaire, the Rutter Parent Scale, FACES 11 and F-COPES was subjected to various forms of quantitative analysis. In this chapter the results of the analysis are reported and examined in order to explore the relationship between the independent variables (demographic variables, illness variables and family variables) and the dependent variable 'risk of disorder'. The current study aimed to investigate the type and strength of relationships and associations between variables rather than attempting to determine cause-effect relationships. Correlational analyses, chi-square tests and logistic regression were the three main types of statistical analyses used in this study. The scores obtained on the Rutter Parent Scale, FACES 11 and F-COPES will firstly be presented before attempting to further analyze the results. Following this an analysis of the relationship between the specific risk and resilience variables under study and risk of disorder will be examined according to the hypotheses formulated in Chapter One. The significant correlational results are presented and the classification matrices provide further information regarding the specific type of relationship found between the independent variables and the dependent variable (risk of disorder). Model building techniques of logistic regression are then used in order to formulate a model of combined variables that predicts both 'risk of disorder' and 'no risk of disorder' in children with epilepsy. In general, only significant results are explored, although nonsignificant results considered relevant for discussion (in Chapter 7) will additionally be examined.

### 6.2 RUTTER SCORES AND RISK OF DISORDER

The mean score of the children with epilepsy on the Rutter Scale was 18.02 (Std Dev. = 8.5). Of the 45 subjects included in the epileptic group 64.44% (n = 29) were classified by the Rutter Scale as being at risk of disorder, while 35.55% (n = 16) were classified as not being at risk of disorder. It was evident that there was a large amount of variability in the Rutter scores as is indicated in the boxplot (median = 17), where the scores ranged from 5 to 37 (See Figure 3). The distribution can be seen to be positively skewed.

**Figure 3 Distribution of Rutter Scores**



The researcher initially chose to use the Rutter Scale as a general screening instrument to determine level of psychological symptoms. However, due to the large amount of variability in the Rutter scores, and the fact that the aim of the current study was the identification of risk factors associated with the development of disorder in children with epilepsy, the dummy variable 'disorder' was used as the dependent variable with codes for 'risk of disorder' and 'no risk of disorder.' This variable was derived from the Rutter Scale using the cut off point to classify risk of disorder (Rutter, 1979) and is indicative of the frequency and severity of psychological symptoms of the child with epilepsy as noted by the mother. This variable is dichotomous in that it either indicates risk of disorder or it indicates no risk of disorder.

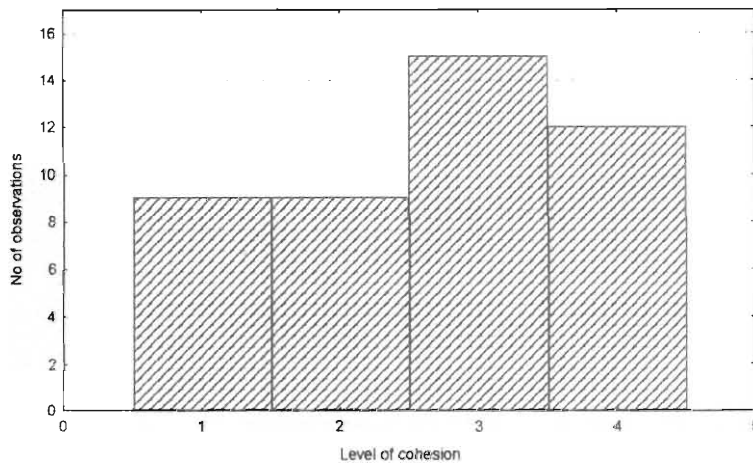
### **6.3 FAMILY ADAPTABILITY AND COHESION (FACES 11)**

#### **6.3.1 Family Cohesion**

When following Olson et al's (1992) method of scoring FACES 11, the score obtained on the cohesion sub-scale falls on a range between 15 and 80. These scores are classified into four levels of family cohesion where scores between 15 and 50 are suggestive of family functioning at a *disengaged* level, scores between 51 and 59 are suggestive of family functioning at a *separated* level, scores between 60 and 70 are suggestive of family functioning at a *connected* level and scores between 71 and 80 are suggestive of family functioning at *very connected* levels of family cohesion. The mean scaled score obtained on the cohesion scale in the current study was 60.53 (Std. Dev. = 13.34) which according to the Circumplex Model suggests that on average the

families in the sample were functioning within the more connected regions of the cohesion subscale. As indicated in Figure 4, levels of family cohesiveness in the sample ranged from very low levels of cohesiveness (disengaged) to very connected levels of cohesiveness.

**Figure 4 Levels of Cohesion in Families with a Child with Epilepsy**

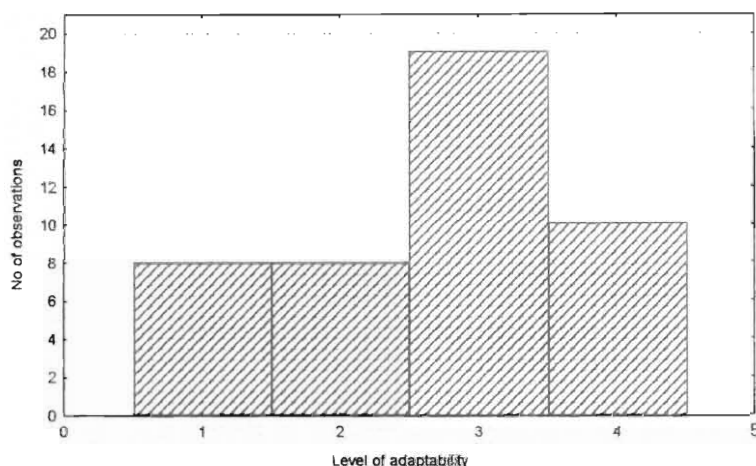


1 -Disengaged 2 -Separated 3 -Connected 4 -Very Connected

### 6.3.2 Family Adaptability

When following Olson et al's (1992) method of scoring FACES 11, the score obtained on the adaptability subscale falls on a range between 15 and 70. These scores are classified into four levels of family adaptability where scores between 15 and 39 are suggestive of family functioning at a *rigid* level, scores between 40 and 45 are suggestive of family functioning at a *structured* level, scores between 46 and 54 are suggestive of family functioning at a *flexible* level and scores between 55 and 70 are suggestive of family functioning at a *very flexible* level. The mean scaled score on the adaptability scale in the current study was 47.73 (Std Dev. = 8.72) which suggests (according to Olson et al, 1992) that families from the epileptic group were functioning on average within the flexible range on the adaptability sub-scale. As indicated in Figure 5 the families in the epileptic group were functioning on a range between very flexible and rigid levels of functioning.

**Figure 5 Levels of Adaptability in Families with a Child with Epilepsy**



1 -Rigid 2 -Structured 3 -Flexible 4 -Very Flexible

### 6.3.3 Family Type (Total combined scores of adaptability and cohesion)

When scoring the FACES 11 in a linear fashion, Olson et al (1992) suggest that by adding the cohesion and the adaptability scores together and dividing by two one can classify the family as a specific "family type" depending on the score obtained (ie. extreme, mid-range, moderately balanced, and balanced) (See section 5.6.3 for further details). In the current sample it was evident that on average the epileptic children's families tended to be classified as mid-range family types ( $\bar{x} = 4.89$ , Std. Dev. = 1.92) although they were bordering on being classified as moderately balanced family types. The median score for family type was 5.50 which falls within the moderately balanced classification of family type as outlined by Olson et al (1992).

### 6.4 SCORES OBTAINED ON F-COPES

The results indicated that on average mothers in the study perceived their families as using a fairly large number of coping behaviours to deal with their everyday strains. The mean of each subscale was calculated, as well as the mean of the total score and compared with the norms provided by McCubbin et al (1992) for adult female women. The mean of the *total scores* on the scale was 105.64 (Std. Dev. = 19.66) which was slightly higher than the norms provided ( $\bar{x} = 95.64$ ; Std. Dev. = 13.24). The use of *social support* as a family coping strategy ( $\bar{x} = 27.73$ ; Std. Dev. = 9.72) was similar to the norms ( $\bar{x} = 27.81$ ; Std. Dev. = 6.5). Perceived use of *spiritual support* as a family coping strategy ( $\bar{x} = 16.04$ ; Std. Dev. = 3.70) was also similar to

norms for adult females ( $\bar{x} = 16.58$ ; Std. Dev. = 2.89). Mothers perception of use of *passive appraisal* as a coping mechanism used by families with chronic illness ( $\bar{x} = 12.40$ ; Std. Dev. = 4.17) was on average higher than the norms provided ( $\bar{x} = 8.19$ ; Std. Dev. = 3.06). Mothers perceived the family as using the coping strategy classified as *mobilization of community resources and accepting help from others* ( $\bar{x} = 16.89$ ; Std. Dev. = 5.04) at a higher rate than the norms provided ( $\bar{x} = 12.66$ ; Std. Dev. = 3.33). Lastly, the average perceived use of the coping mechanism classified as *reframing* for families with epilepsy ( $\bar{x} = 31.84$ ; Std. Dev. = 4.86) was similar to the average scores of norms for women with families with no epilepsy ( $\bar{x} = 30.42$ ; Std. Dev. = 4.86).

## 6.5 PREDICTORS OF RISK OF DISORDER

The main hypotheses examined in the current study involved the relationship between family variables, illness variables and demographic variables in relation to risk of disorder in children with epilepsy. Three basic steps were taken when conducting the statistical analysis in this study in order to test hypotheses outlined in Chapter Five (Section 5.3):

1. Zero order correlations were calculated in order to identify significant variables with regard to their relationship with the dependent variable 'risk of disorder'.
2. Chi-square tests were then conducted on the significant variables and the frequency tables are presented in order to provide further information regarding the distribution of the percentages of those children who were or were not at risk for disorder under certain levels of the IV's (eg. low SES, middle SES or high SES) (that is not specifically provided from the correlational results alone).
3. This was followed by the use of the model building techniques of logistic regression, where combinations of variables were made in order to determine the best predictor model of combined variables. The best model was then taken and the regression parameters were calculated as well as the classification matrix.

## 6.6 RELATIONSHIP BETWEEN RUTTER SCORES AND PREDICTOR VARIABLES

### 6.6.1 Introduction

Correlations were conducted between Rutter scores and the independent variables in the study. The Pearson Product Moment Correlation used in the statistical analysis of the current study is equivalent to point biserial correlation, which allows for the analysis of variables that are measured in the form of a dichotomy (Howell, 1987). The significant correlational results were further used as a guide for the second step in the analysis which involved the model building techniques of logistic regression.

### 6.6.2 Correlational Results

As indicated in Table 2 and 3 below, there were significant results for a number of the correlations between the dichotomous Rutter score 'risk of disorder' and the independent variables specified ( $p < .05$ ) although 'r' was actually low in all cases.

**Table 2 Risk of Disorder Correlated with Age and Gender, Seizure Type, Frequency of Seizures, Length of Diagnosis and Family Coping (social support, reframing, spiritual support, mobilization, appraisal, total)**

\*p is significant at  $p < .05$

	Age	Sex	Type of Seizure	Frequency	Length
r	-.26	-.04	.13	.10	-.03
n	45	45	38	45	45
p	.09	.81	.45	.51	.86

	Social support	Reframing	Spiritual support	Mobilization	Appraisal	Total
r	-.08	.14	.05	-.03	-.25	-.08
n	45	45	45	45	45	45
p	.62	.36	.72	.85	.09	.59

**Table 3 Risk of Disorder Correlated with Number of siblings, Socio-economic status, Family Cohesion and Adaptability, Total Family Type Score and Type of Medication.**

\*p is significant at  $p < .05$

	Nom of siblings	SES	Cohesion	Adaptability	Total (family type)	Medication
r	-.30	-.38	.38	.37	.43	-.37
n	43	45	45	45	45	44
p	.05*	.01*	.02*	.02*	.01*	.02*

There was a significant correlation between SES and risk of disorder ( $r = -.38$ ;  $p < .01$ ), suggesting that lower socio-economic status was associated with higher rates of risk of disorder. Higher rates of cohesion ( $r = .38$ ;  $p < .02$ ) and adaptability ( $r = .37$ ;  $p < .02$ ) were both associated with absence of risk of disorder. A significant relationship was also evident between total combined scores of adaptability and cohesion (ie. family type), and risk of disorder ( $r = .43$ ;  $p < .01$ ) where this score was the highest 'r' although it was still relatively low. The demographic variables age and sex were not significantly correlated with risk of disorder scores as measured by the Rutter Parent scale, although having a higher number of siblings appeared to be correlated with higher risk of disorder ( $r = -.30$ ;  $p < .05$ ). The relationship between number of siblings and risk of disorder in children with epilepsy was a negative one, suggesting that greater number of siblings was associated with higher risk of disorder in children with epilepsy. Number of siblings was also significantly associated with SES ( $r = -.46$ ) where low SES was associated with a larger number of siblings. It was evident that there was no significant correlation between type of epilepsy, length of illness and frequency of seizures in relation to risk of disorder. The only illness variable that was of significance was type of medication (whether mono or poly-medication) and this correlated significantly with risk of disorder ( $r = -.37$ ;  $p < .02$ ).

## **6.7 FURTHER EXPLORATION OF RELATIONSHIPS INVOLVING DEMOGRAPHIC VARIABLES**

### **6.7.1 Socio-economic Status (SES)**

When observing frequency tables it was evident that children from families from low SES groups had a 83.3% risk of disorder in contrast to families from middle SES categories (42.9%) and high SES categories (42.9%) (See Table 4).

**Table 4 Levels of SES on Risk of Disorder**

	High SES	Middle SES	Low SES
At risk of disorder	3 (42.9%)	6 (42.9%)	20 (83.3%)
Not at risk of disorder	4 (57.1%)	8 (57.1%)	4 (16.7%)

\*Numerical values indicate number of children (and percentages) in combined categories

### 6.7.2 Illness Variables

#### (i) Seizure Type

As discussed on page 48 the main research hypothesis regarding type of seizure and risk of disorder was as follows: The type of seizure that the child has been diagnosed will impact on risk of psychological problems in children with epilepsy. As already mentioned no significant differences were found between risk of disorder for children with grand mal seizures and children with petit mal seizures. When observing the classification matrix however (See Table 5) it is evident that grand mal seizures tended to be associated with a slightly higher risk of disorder when compared to the risk of disorder associated with petit mal seizures.

**Table 5 Type of Seizures on Risk of Disorder**

	At risk of disorder	Not at risk of disorder
Grand mal	13 (72%)	5 (28%)
Petit mal	12 (60%)	8 (40%)

#### (ii) Frequency of Seizures

The main hypothesis regarding frequency of seizures and risk of disorder was as follows: Higher frequency of seizures in children with epilepsy will be associated with an increased risk of psychological problems. Initially five groups were identified with varying levels of seizure frequency (ie. daily seizures, at least once per week, at least once per month, at least once every 3 mths, and no more than 3 a year). As mentioned, no significant correlations were found between seizure frequency and risk of disorder. Even when the categories were collapsed into two categories to reduce the problems associated with small sample size, there was still no significant result (chi-square = 1.84; df = 1;  $p < .17$ ). It was evident however that there appeared

to be a trend for children with more frequent seizure type (more than once a month) to be at a higher risk of disorder than children with infrequent seizures (less often than once a month). This trend is evident in Table 6, where children with more frequent seizures appeared to have a higher risk of disorder (73.9%) when compared to children with infrequent seizures (54.6%).

**Table 6 Frequency of Seizures on Risk of Disorder**

	At risk of disorder	Not at risk of disorder
Frequent Seizures	17 (73.9%)	6 (26.1%)
Infrequent Seizures	12 (54.6%)	10 (45.5%)

\*Due to the fact that the literature indicates a tendency for frequency of seizures to be associated with risk of disorder, it was decided to collapse the identified categories for further analysis.

(iii) Mono-medication vs Poly-medication

The research hypothesis regarding the relationship between medication and risk of disorder was that poly-medication would be associated with a greater risk of psychological problems than mono-medication. When observing the classification matrix it is apparent that children with epilepsy who were on more than one epileptic medication appeared to be at a very high risk for disorder (84%) when compared to those children who were on only one epileptic medication (48%) (See Table 7).

**Table 7 Type of Medication and Risk of Disorder**

	At risk of disorder	Not at risk of disorder
Mono-medication	12 (48%)	13 (52%)
Poly-medication	16 (84%)	3 (16.8%)

6.7.3 Family Variables

(i) Family Adaptability

The main hypothesis regarding family adaptability was that there would be an inverse relationship between levels of family adaptability and risk of psychological problems in children with epilepsy. When observing the table of frequencies, (See Table 8) it is evident that there appears to be a very high risk of disorder for children who have families classified as "rigid"

(ie. 100% or n = 8). The pattern does not appear to be completely linear where children with epilepsy from families classified as flexible appear to have a slightly higher risk of disorder than children from families classified as structured. Children from families that were classified as very flexible (n = 10) appear to have a noticeably reduced risk of disorder.

**Table 8 The Association Between Levels of Family Adaptability and Risk of Disorder**

	Rigid	Structured	Flexible	Very Flexible
At risk of Disorder	8 (100%)	5 (62.5%)	13 (68.4%)	3 (30%)
Not at risk of disorder	0 (0%)	3 (37.5%)	6 (31.6%)	7 (70%)

(ii) Family Cohesion

The main hypothesis regarding family cohesion was that there would be an inverse relationship between levels of family cohesion and risk of psychological problems in children with epilepsy. When analyzing the relationship between cohesion and risk of disorder it was evident that 88.9% of the sample from disengaged families were at risk for disorder, while 77.8% of the sample from separated families were at risk for disorder. This figure decreases somewhat for families classified as connected (60%), and the level of family cohesion with the lowest risk of disorder was those children with epilepsy from very connected families (41.7%) (See Table 9). The results indicate that children with epilepsy from families classified as more connected appeared to have less risk of disorder when compared to children from families that are less connected.

**Table 9 The Association Between Levels of Family Cohesion and Risk of Disorder**

	Disengaged	Separated	Connected	Very Connected
At risk of disorder	8 (88.9%)	7 (77.8%)	9 (60%)	5 (41.7%)
Not at risk of disorder	1 (11.1%)	2 (22.2%)	6 (40%)	7 (58.3%)

**6.8 LOGISTIC REGRESSION**

The next step in the analysis was to determine which variables in the correlational analysis shown to be significant would be able to predict disorder within a model of combined predictors. This aimed to examine multiple predictors of psychological problems in their combinations in children

with epilepsy as indexed by the Rutter Parent scale classification. Although multiple regression allows one to predict Y (the dependent variable) on the basis of simultaneous knowledge of all predictors where the dependent variable is an interval variable, it was not possible to use this technique in the current study as the continuous Rutter score appeared to have a large amount of variability and therefore did not satisfy the normality assumption or homogeneity of variance required for multiple regression analysis (Howell, 1987). Given that the current study makes use of a binary dependent variable, ie. risk of disorder or no risk of disorder, an alternative form of regression was called for. The statistical approach that was considered the most useful in terms of the goals of the current study was logistic regression which is explained by Howell (1996) as "a technique for fitting a regression surface to data in which the dependent variable is a dichotomy" (p. 548). This approach does not rely on assumptions of either normality or homogeneity of variance, and does not produce probabilities beyond 0 and 1 (Howell, 1996). This technique was considered useful in the current study, which had as its goal the prediction of risk of disorder from the independent variables (illness variables, demographic variables and family variables).

In using a dichotomous dependent variable in the current study, the data is termed "censored data" in that there is a cut off point where one talks about a child being classified as being at risk of disorder or not being at risk of disorder, depending on the total score obtained on the Rutter Parent Scale. Howell (1996) suggests that logistic regression can be thought of as applying linear regression to censored data. The aim of logistic regression is to find a model of combined variables that is able to predict the dependent variable at greater than chance levels. This is obtained through a step by step approach, where new predictors are added to the model, and the difference in chi-squares in relation to the previous model is observed. If a predictor fails to improve the model, then it can be considered unimportant to that particular combination of predictors chosen in the model and can be dropped from the model (Howell, 1996).

## **6.9 MODEL BUILDING IN THE CURRENT STUDY**

### Introduction

The initial approach to entering the independent variables was to enter variables in terms of their level of significance ie. with the most significant variable added first (as indicated by significant correlations). SES was added first in order to control for this variable in the analysis. At each

step the difference in chi-square from the previous model was calculated in order to determine whether the increase in chi-square was significant. The variables found to contribute significantly to this particular model (where all the variables except the F-COPES were added) were SES, total (family type), medication and type of seizures. It was interesting to note that once total family type was entered into the model, then both family cohesion and family adaptability were unable to further contribute to the model. The four significant predictors were then used to construct an additional model which is presented below. It must be pointed out that this model represents only one model of combined predictors and that other models may additionally be constructed using alternative predictors. The results were as follows:

### 1. Socio-economic Status (SES) in the Model

Socio-economic status was introduced first to the model in order to control for this variable and was found to contribute to the model significantly (See Table 10 below).

**Table 10 Logistic Model with SES introduced to the Model to Predict Risk of Disorder**

\*log likelihood for this model = 52.072 Intercept only = 58.57

Chi-square = 6.501 df = 1 p < .01

	Constant B0	SES
Estimate	1.97	-1.11
Standard Error	1.10	.46
t(42)	1.78	-2.40
p-level	.08	.02

### 2. Addition of Total Family Type Score (FACES 11) to the Model

The total family type score (derived from FACES 11) was then added to the model in order to determine to what degree this variable would further contribute to the model. It was noted that this variable improved the chi-square to 11.46 (df = 2; p < .001) (See Table 11 below) and that this improvement from the previous model was significant (Chi-square difference = 4.96, p < .026).

**Table 11 Logistic Regression Model: SES and Total Family Type to Predict Risk of Disorder**

Final loss: 23.55 Chi-square = 11.46 df = 2 p < .001

	Constant B0	SES	Total
Estimate	-1.51	-.69	.48
Std. Error	2.03	.51	.24
t (42)	-.75	-1.36	2.03
p-level	.46	.18	.05

3. Addition of Type of Medication (Mono or Poly-medication) to the Model:

In order to determine to what degree type of medication (whether mono or poly-medication) would be able to further predict disorder, this variable was added to the regression model. The addition of type of medication to SES and Total score changed the overall chi-square value to 20.68 (df = 3; p < .001) (See Table 12 below). This difference was significant (chi-square difference = 10.11, df = 3, p < .001).

**Table 12 Logistic Regression Model: SES, Total Family Type and Medication to Predict Risk of Disorder**

Final loss: 18.50 Chi<sup>2</sup> = 20.68 df = 3 p < .001

	Const.B0	SES	Total	Medication
Estimate	1.13	-.87	.72	-2.52
Std.Err.	2.36	.58	.30	1.01
t(40)	.48	-1.51	2.38	-2.51
p-level	.63	.14	.02	.02

4. The Addition of Type of Seizures to the Model

The variable type of seizures was then added to the model as this was found to be a significant predictor in the initial logistic regression model. This variable changed the chi-square value to 29.55 (df = 4, p < .0001) (See Table 13 below). The difference in chi-square when type of seizures was added to the model was also highly significant (Chi-square difference = 18.58, p < .00001).

**Table 13 Model Combining SES, Total Family Type, Medication and Type of Seizure to Predict Risk of Disorder**

Final loss: 9.21 Chi<sup>2</sup> = 29.55 df = 4 p < .0001

	Const.B0	SES	Total	Medication	Seizure Type
Estimate	14.94	-2.57	1.79	-8.09	-5.25
Std.Error.	7.07	1.35	.76	3.24	2.31
t(32)	2.11	-1.90	2.35	-2.50	-2.27
p-level	.04	.07	.03	.02	.03

It was then attempted to separately enter each of the additional independent variables examined in the current study in order to determine whether they could further contribute to the model. None of the other variables examined in the study were able to further improve this model at a significant level. The final model that was retained was the combination of type of seizure, type of medication, total (family type) score and SES (See Table 13 above). A classification matrix was calculated for the final model and is presented below.

**Table 14 Classification Prediction Matrix for Final Model**

	<i>Predicted</i> At risk of disorder	<i>Predicted</i> Not at risk of Disorder	Percent Correct
<i>Observed</i> At risk of disorder	22	2	91.67
No risk of disorder	3	10	76.92

This model was able to predict risk of disorder 91.67% of the time, while being able to predict absence of disorder 76.92% of the time (See Table 14). The average predictive ability of the model when combining SES, total (family type), type of medication and type of seizure to predict both risk of disorder and no risk of disorder was 86.49%.

## **CHAPTER SEVEN: DISCUSSION**

### **7.1 INTRODUCTION**

Throughout the previous chapters the relevant literature was examined as background to the current study, and the methodology and the results have been presented. The primary focus of the current study was the examination of risk and protective factors in the development of psychological problems in children with epilepsy, where specific variables were investigated in this regard. In this final chapter, a summary of salient results will be discussed in relation to the literature in the area and the original hypotheses outlined in Chapter Five will be examined. In addition the implications of the study for further research will be discussed while taking into account the limitations of the study.

### **7.2 BRIEF SUMMARY OF RESULTS**

The results indicated that a number of variables played a role in the development of psychological problems in children with epilepsy. The variables specifically found to be associated with risk of disorder included family adaptability, family cohesion, total family type, number of siblings, SES and type of medication. Specifically higher levels of family cohesion and adaptability, as well as more balanced family functioning was associated with lower risk of psychological disorder. Higher SES was also associated with decreased risk of disorder in children with epilepsy and those children with epilepsy with higher numbers of siblings additionally appeared to have an increased risk of disorder. Children on poly-medication were also found to be associated with higher risk of disorder when compared to children who were on mono-medication. It was found that level of SES, type of medication, total family type and type of seizures contributed significantly to the final logistic model. The results suggest that gender, age and sex, type of seizures, seizure frequency, length of diagnosis and family coping were not significantly associated with risk of disorder in the current study as measured by the Rutter.

The results indicated that a range of variables played a role in either increasing or decreasing risk of disorder in children with epilepsy in the current study. This supports previous research in the field that has similarly found that child factors, illness factors, family factors and demographic factors all appeared to play a role in child psychological adjustment (Austin & McDermott, 1988;

Carlton-Ford et al., 1995; Hoare & Kerley, 1991; Lavigne & Faier-Routman, 1993; Pianta & Lothman, 1994; Rutter et al., 1970a). Firstly a discussion of the scores obtained on the Rutter Scale will be presented and this will be followed by a discussion of the individual variables in relation to risk of disorder.

### **7.3 RUTTER SCORES**

Children with epilepsy in the study appeared to have significantly higher levels of psychological problems when compared to 'normals' (ie. children with no chronic illness). This finding is consistent with previous literature in the field although it is evident that risk of disorder in both the epileptic sample and 'normals' was higher than numerous previous studies using similar measuring instruments (Austin, 1988; Hoare, 1984a; Rutter et al., 1970a).

### **7.4 DEMOGRAPHIC VARIABLES**

The results suggest that gender and age were not associated with risk of disorder in the current study as measured by the cut off score of the Rutter. Previous research in contrast has indicated that boys with epilepsy consistently tend to have a higher level of psychological and social adjustment problems than girls with epilepsy (Carlton-Ford et al., 1995; Hoare & Kerley, 1991; Pianta & Lothman, 1994; Vining, 1989). One can suggest however that due to the disproportionately large amount of male children with epilepsy included in the current study, one would have to interpret the findings of the current study with caution as the unequal numbers of boys and girls may have affected the power of the correlations. The finding that age did not appear to be associated with child adjustment was expected to a certain degree, given that only a limited age range of children with epilepsy was examined in the current study (ie. 8-13 yrs). Past studies that have examined a more limited age range of children with epilepsy such as the study by Pianta and Lothman (1994) (which included children between the ages 7-13 years) have similarly found no significant associations between age and aspects of child psychological adjustment. Other studies in contrast, such as the study by Carlton-Ford (1995) using larger age ranges (eg. 6-17 yrs) have found differing results where older children with epilepsy were found to be at a greater risk of depressed mood than were younger children with epilepsy.

The results of the current study support the hypothesis that level of socioeconomic status impacts on risk of psychological problems, where children from lower SES backgrounds were found to

have a higher risk of disorder when compared to children from either middle or high SES backgrounds. When considering the limited number of children in the high SES group in comparison to the larger proportions of children from the low/middle SES group in the study, one could suggest that the power of the correlations may have been subsequently reduced and may have obscured the actual influence of this variable in the study. Although the correlations in the study were relatively low, one can tentatively suggest that SES could be considered a contextual vulnerability factor that impacts on the child's vulnerability to disorder when a child has epilepsy. Low SES in South Africa can be seen to incorporate a multitude of additional problems and life stressors such as low income, unrest in the townships, inadequate housing, higher risk of alcoholism etc. This suggests that counselling and treatment programmes are particularly needed in groups of children with epilepsy who additionally come from low SES backgrounds. Previous research in the area of childhood epilepsy has seldom measured demographic variables such as SES and mixed results have emerged. In some studies SES has not been significantly correlated with psychological adjustment (Lavigne & Faier-Routman, 1993) while in other studies there has been an association between SES and risk of psychological problems (Carlton-Ford et al., 1995; Hoare & Kerley, 1991; Rutter et al., 1979). In the current study, a large number of families had the benefit of various services provided for by the specialized schools that they attended (such as therapy, doctors etc). Other groups of children with epilepsy from low SES backgrounds who attend mainstream schools without such special services may provide even higher levels of risk of disorder and may be an important focus of future studies.

The number of siblings in the household was also significantly associated with risk of disorder in children with epilepsy in the current study, where a larger number of siblings was associated with higher risk of disorder in children with epilepsy. Low SES was additionally found to be associated with a larger number of siblings and it can be suggested that both these variables may overlap and measure similar stressors (eg. larger financial pressures, less resources, additional stressors etc.).

## **7.5 RESULTS IN RELATION TO THE CIRCUMPLEX MODEL**

Significant correlations were found between both family cohesion and family adaptability in relation to child adjustment and although these were relatively low, they support the two hypotheses that suggest that there would be an inverse relationship between both family cohesion and family adaptability and child psychological adjustment.

The results of this study are in accordance with the recently updated theory provided by Olson and Tiesel (in Olson et al., 1992) as well as various other researchers in the area, which has indicated that FACES 11 fails to capture extreme (enmeshed or chaotic) families and suggests a linear scoring of the instrument (Hampson et al., 1991). The findings of the current study indicate that the presence of a cohesive and adaptive family reduces the risk of disorder in children with epilepsy. Given the large range of variables and the relatively small sample size in the current study, it was not possible to further examine the moderating function of family cohesion and adaptability as well as interactions between variables in relation to child psychological functioning.

Future research is needed to determine under what conditions family cohesion or adaptability plays either a risk or moderating role in child adjustment in relation to other variables. For example, one could speculate that the interaction between the developmental stage of the child and levels of family cohesion may play an important role in relation to child psychological development. The age range of children in the current study roughly falls into the developmental stage of "middle childhood" (8-13 yrs) which has been suggested by Smets and Hartup (1988) to represent a stage of development that has been described as "corregulated" and which is characterized by high involvement with parents (Maccoby & Martin, in Smets & Hartup, 1988). The family is required at this time to help promote the child's self-sufficiency, which is the developmental task of this period (Hibbs, 1989). This is in contrast to the "parent regulated" years of early childhood and the "self-regulated" years of adolescence. As indicated by Smets and Hartup (1988) middle childhood requires sensitive and continuing negotiations between parents and children to work out their interdependent situations and families marked by rigidity and a lack of cohesion in interpersonal relations appear to have an especially difficult time during this period (Smets & Hartup, 1988). These authors have suggested that as the child gains greater maturity and is more self-regulated, factors other than the family system may furnish the context for psychological adjustment (e.g. the peer subculture). Virtually no research in the area of childhood epilepsy appears to have examined specific interactions between variables (eg. developmental stage and family variables in relation to child adjustment) and future research is needed to examine such interactions in order to provide further understanding of the processes involved in the development of psychological problems in this group of children. In addition, adolescents with epilepsy have received very little attention in the psychosocial epilepsy literature and further studies are needed to specify the risk and protective factors associated with this age group (Westbrook, 1995).

One could suggest that the patterns found between family cohesion and adaptability in relation to risk of disorder could be related to the shared variance in the method of measurement (i.e. self-report) rather than actual associations between family and psychological adjustment dimensions measured. For example, mothers reporting "socially desirable" responses may have either exaggerated problems or alternatively covered up family problems in specific questionnaires. This is a problem related to self-report methods in general and additional forms of assessment of both family and child functioning (observational techniques etc.) as well as the use of different informants would be useful in validating the current results.

The need to include as many family members as possible in the assessment of family relations using the FACES 11 has additionally been proposed by Olson et al (1985) who have suggested that this ensures a more objective account of the family's functioning (ie. providing a "family" perception of family functioning). As already mentioned, in the current study the opportunity to use different informants was limited because fathers were often busy at the time of the research, and many of the epileptic children were too young to complete the FACES questionnaire. The findings of the current study were therefore limited to family perceptions of mothers, rather than the combined views of various individuals within the family and must therefore be interpreted in this light. As suggested by Woods and Lewis (1992) "The challenge of providing a holistic view of family phenomena can be met by considering multiple levels of family systems as sources of data, including individuals, dyads, total family and family networks" (p. 400). Future studies could include additional family members eg. fathers and siblings so that a more objective view of child and family functioning can be obtained (Austin, 1997; Olson et al., 1985).

Few studies in the area of childhood epilepsy have examined family cohesion and adaptability in relation to child psychological functioning and therefore direct comparison of the results of the current study with those of other studies is a difficult task. Other aspects of family functioning have been examined however. Austin (1988) for example found that children with epilepsy with higher levels of psychosocial adaptation had significantly lower levels of family resources and adaptation than children with lower level of psychosocial adaptation. Family adaptation was measured using the Family APGAR questionnaire which is a five item questionnaire that measures each family members satisfaction with five aspects of family function ie. adaptation, partnership, growth, affection, and resolve (Austin, 1988). Family resources were measured using the Family Inventory of Resources for Management (FIRM) to operationalize family

system resources and the Child Behaviour Checklist (Achenbach & Edelbrock, 1983) was used in order to measure level of behavioural problems.

The results of the current study were also similar to studies examining a range of other types of chronic illnesses which have also found that both family cohesion and adaptability play a significant role in child adjustment (Lavigne et al., 1988; Moise in Daniels et al., 1987). For example, higher family cohesion has been associated with better psychosocial adjustment among children with sickle cell anemia, as well as children with cancer and juvenile rheumatic disease. Steinhausen et al (in Wallander et al, 1988) found differences in the relationship between psychological family resources and child psychological adjustment in children with various disorders. In this study family resources appeared to play a stronger role in the development of psychological problems in children with less severe conditions (eg. asthma) when compared to children with more severe conditions (eg. cystic fibrosis).

One of the limitations of Wallander et al's (1989) model is that it specifically categorizes family variables as protective factors rather than depicting the family as having both risk and protective functions. The results of the current study, as well as previous research indicates that family factors can play both a protective as well as a risk function in the development of disorder in children with chronic illness (Austin, 1988; Lothman & Pianta, 1992; Hoare & Kerley, 1991; Richie, 1981). Further research is needed to determine the specific factors within the family (eg. parent-child relations etc) that may be associated with higher levels of adjustment in children with epilepsy.

The current study indicates that family variables alone only weakly predict psychological problems, but when combined with other variables contributes significantly to the Logistic Regression model. This suggests that other variables in combination with family variables play a role in the psychological functioning of the child with epilepsy. A systemic approach to understanding child psychological adjustment to childhood epilepsy appears to be useful in understanding the results of the current study where as suggested by Miller (1976) "living systems adapt to their environments, and in return mold it. The result is that after some period of interaction, each in a sense becomes a mirror of the other" (p. 306). It is evident that the family and the child with epilepsy appear to play an important role in each other's development, but since the current study used a cross-sectional design one cannot specify the direction of effects between variables (Turks & Kerns, 1985). Although the current study found that families with

high levels of adaptability and cohesion are associated with less risk of disorder in children with epilepsy one cannot necessarily determine however a) whether the family protects the child from functioning poorly, or b) if it is the behavioural and emotional problems of the child with epilepsy that impacts on family functioning in a negative manner (Daniels et al., 1987).

## 7.6 FAMILY COPING

The findings of the current study did not support the hypothesis that any of the specific family coping strategies (as perceived by the mother) were associated with either an increased or decreased risk of psychological problems in children with epilepsy. Although passive appraisal failed to be significantly associated with risk of disorder there appeared to be a trend in the results which indicated that higher scores of this sub-scale appeared to be associated with higher risk of disorder. The lack of significant results may have been due to the relatively small sample size and further studies based on larger samples are needed to reexamine this variable in relation to risk of disorder. Passive appraisal has been viewed as operating as more of an "avoidance response" to problems, and as suggested by Olson et al (1985) "tends to reflect a more pessimistic attitude toward resolving issues" (p. 145). In attempting to understand the relationship between family coping strategies and psychological adjustment in children with epilepsy, one has to be careful in assuming that one family coping strategy is "better" than another, as different coping responses may be more adaptive in different families depending on the developmental stage of the family (Olson et al., 1985).

Although none of the studies in the field of childhood epilepsy have specifically used the F-COPES to examine family coping in relation to child psychological adjustment in children with epilepsy, it is apparent that rigid decision making styles observed in families have been associated with disorder in children with epilepsy (Richie, 1981). Family resources have additionally been found to play a role in child adjustment where higher levels of resources have been associated with improved psychological adjustment in children with epilepsy (eg. social support from extended family, family esteem and communication between family members) (Richie, 1981). It is interesting that a variety of researchers in the area of childhood chronic illness have defined "family coping" differently. Some studies have viewed family coping in terms of family problem solving ability as well as the availability of maternal social supports. Higher levels of both these factors have been associated with a decrease in psychological problems in children with chronic illness (Hamlett et al, 1992; Holroyd & Guthrie, 1986; Johnson, 1985).

It is apparent from the literature that there is a lack of research investigating aspects of family coping, or family support structures in relation to psychological adjustment of children with epilepsy. Olson et al (1985) offer an explanation for the lack of studies specifically focused on family coping strategies and suggests that in "Shifting from the individual level to a family level of coping, coping becomes much more complex. This has been cautiously attempted by only a few due to the enormous number of theoretical and methodological problems involved. This explains why researchers have focused mainly on the individual level of coping" (Olson, 1985; 139). Some of these methodological difficulties became apparent in the current study firstly when attempting to operationalize this variable, and also while collecting data in relation to family coping for the study.

It was noted during the interviews that a number of the mothers appeared to have difficulty completing the F-COPES questionnaire. Many mothers commented that they were unsure as to whether questions were concerned with their own individual way of handling problems or were specifically aimed at determining how the family as a whole handled problems. Some mothers noted that their way of coping was completely different from that of their husband's or their children's way of coping and that there was no set way that the family as a whole coped with specific problems. In order to try to overcome this problem it was apparent that certain mothers attempted to answer certain questions with reference to their own particular way of coping with problems. This response by mothers raises some questions regarding 1) the usefulness of the F-COPES in measuring family coping strategies as well as 2) the notion of family coping as consisting of specific shared strategies that the family uses to cope with problems. It can further be suggested that the responses to the F-COPES in the current study may be far more related to the individual coping strategies seen as useful by the mother (the informant), rather than actually providing insight into family coping strategies used by the family as a whole. Additionally, in order to overcome the difficulties mentioned above, mothers may have completed the questionnaire randomly, or in such a manner as to create a favourable impression to the researcher which may in turn have increased the possibility of response bias.

Various authors have suggested that it can be dangerous to theoretically assume that groups have the same properties as individuals, and to lose sight of the fact that the family is made up of various individuals who respond and cope in unique ways to various stressors (Olson et al., 1985; Shapiro, 1983). As suggested by Olson et al (1985) in their study of family coping strategies used by family members over the lifecycle, it was found that husbands, wives and adolescents

assessed their family coping strategies in very different ways. Olson et al (1985) suggest however that "In addition to the fact that individuals have different "worlds," the data suggests that family coping involves the collection of various skills and abilities from family members. Integrated together, they produce the family's coping strategies, which change and develop as the family moves through the life cycle" (p. 153). On a practical level however, family coping can be considered a difficult concept to both measure and operationalize. The F-COPES appears to be limited in this regard as it 1) does not account for both individual and family coping strategies of family members 2) does not offer a way in which to combine different individual family members perceptions of family coping. This appears to be a problem with family assessment in general where "only in combining the unique perceptions of family members does the reality of the family emerge" (Deal, 1995; p. 1109). In light of the above discussion, it can be suggested that the findings in the current study in relation to family coping may therefore be strongly biased by methodological as well as conceptual difficulties.

## 7.7 ILLNESS VARIABLES

The results did not support the hypothesis that an increased length of illness would be associated with higher risk of psychological problems or the hypothesis that an increased frequency of seizures would be associated with a higher risk of disorder. Type of epilepsy was not found to be correlated with risk of disorder and yet it became a significant predictor in the logistic regression model. The hypothesis that type of medication (whether mono or poly-medication) would be significantly associated with risk of disorder was supported both in the correlational results and by the fact that type of medication became a significant predictor in the final logistic model. These findings will be discussed in more detail below:

The lack of support for the hypothesis that a higher *frequency of seizures* would increase the risk for disorder in the current study contrasts with findings of other studies that have found that children with a higher frequency of seizures have been found to have an increased risk of psychological problems (Austin, 1988; Hoare & Kerley, 1991). It is noted however, that the current study did not include more intractable forms of epilepsy (such as Lennox-Gastaut syndrome) which are often included in other research studies (Hoare & Kerley, 1991). More intractable forms of epilepsy are often associated with higher rates of seizures and may partly

explain why higher risk of disorder has been found to be associated with frequency of seizures in previous studies but not in the current study (Hoare & Kerley, 1991).

*Type of seizures* was not associated with risk of disorder as hypothesized, but subsequently became an important variable as part of the Logistic Regression Model. In addition, although not statistically significant, the frequency tables indicated that there were trends in the data where grand mal seizures tended to be associated with a higher risk of disorder than petit mal seizures. This trend is also supported by research in the area of childhood chronic illness which has found that illnesses with more obvious symptoms have been associated with higher levels of disorder (Lavigne et al., 1993; Perrin et al., 1993). As would be expected, grand mal epilepsy (with the more obvious symptoms of falling down, tremors, loss of consciousness etc.) tended to show trends of being associated with higher risk of disorder than petit mal epilepsy. Given that type of seizures became a significant predictor in the logistic model one can suggest that the limited number of subjects used in the analysis (particularly where type of seizures was reduced to 38 subjects in the analysis) may have lowered the power in the correlational results. One could also speculate that type of seizures may only become significant when in combination with other variables, while alone does not appear to be associated with risk of disorder.

The hypothesis that *poly-medication* would be associated with increased rates of disorder in the current sample was supported, although this relationship did not appear to be very strong. These results are in accordance with the results of other studies that have similarly found poly-medication to be associated with increased risk of disorder in children with epilepsy (Hoare & Kerley, 1991). Although it is not possible to determine cause and effect due to the cross-sectional nature of the study, one could suggest that the association between poly-medication and psychological problems could be related to the fact that children with more severe forms of epilepsy are on more medications. Another explanation could be that the side effects of a number of combined medications might have served to increase the risk of disorder in the epileptic children in this group. Future studies could examine specific types of medications in relation to psychological adjustment in children with epilepsy. This was not possible in the current study as there was a large range of prescribed medications for a relatively small sample size of children and there was a strong possibility that this would have resulted in a loss of statistical power in subsequent analyses.

## **7.8 RISK OF TYPE ONE AND TYPE TWO ERRORS IN CORRELATIONAL AND CHI-SQUARED TESTS**

Some of the variables in the analysis failed to be significantly associated with risk of disorder in either the chi-square tests or the correlations i.e. type of epilepsy, length of illness, gender. This lack of significance could be related to a number of factors. It could be the case that there was indeed no association between these variables and that the null hypotheses were in fact correct. One could suggest however, that the small frequencies in these tests concerning these variables may have lowered the power of the analysis thereby failing to reveal the significance of their association with risk of disorder. Given the relatively small sample size in the current study and the small expected frequencies this may place the study at risk of both Type I and Type II errors as the researcher "will have violated the assumption of normality for small expected frequencies." (p. 136). Howell (1987) suggests that "for a fixed number of subjects, power is maximized by setting  $N_1 = N_2$ " (p. 202). In the current study given the constraints related to time and finances it was extremely difficult to obtain a larger number of subjects to provide equal grouping of variables such as gender, socio-economic status and types of epilepsy. It is the researcher's view that it is important to be tentative when interpreting the seemingly nonsignificant results of some of the variables in the study such as gender, length of illness and type. When considering the risk of Type II errors in the statistical analyses, one could suggest that these results should be considered as inconclusive rather than providing evidence for the rejection of the alternative hypothesis (Howell, 1987). In addition, it may additionally be suggested that a certain amount of caution should also be made when interpreting the results from the current study, due to the additional risk of a type I error. A repeat of the study on a larger sample would help cross-validate the current results.

## **7.9 DISCUSSION OF THE LOGISTIC MODEL**

Although the technique of logistic regression does not directly address the relations among predictors, it should be emphasized that the results suggest that child, disease, demographic, family, and contextual factors in combination all appeared to interact and overlap to some extent in predicting child adjustment in children with epilepsy. The current study provided a model whereby type of epilepsy, level of socio-economic status, type of medication (whether poly or mono-medication) and total family type were found to be important predictors of risk of disorder. Multiple risk factors were thus found to act in combination and potentiate each other. The final

model indicated that there was a "good fit" of the combined illness variables, family variables and demographic variables with the predicted dependent variable risk of psychological problems. This suggests that the combination of these variables played an essential role in the development of risk of disorder in children with epilepsy in the current study.

In attempting to interpret the results further, the question arises as to whether or not it is possible to determine which of the variables can be considered more important than others in predicting risk of disorder. A rough indication of the relative contributions of the variables can be obtained through observation of the beta weights of each variable (Howell, 1987). Type of medication was found to have the largest beta weight (-8.09) with type of epilepsy as the second highest beta weight (-5.25). The size of the beta weights of SES (-2.57) and total family type (1.79) were relatively smaller. The beta weights appeared to be very unstable as they seemed to alter depending on the order in which they were entered into the logistic model and can therefore be seen to offer only a rough indication of the relative contribution of each of the predictors to the model. The instability of the beta weights could be considered to be related to the small sample size in the current study and the presented relative contributions of the beta weights in this study must be interpreted with caution. Another method that has been suggested to be useful in determining the contributions of the specific variables to the model has been through the calculation of the difference in the total value of the chi-square when entering individual variables to the model. Type of seizures and type of medication were again found to provide the largest contributions to the final model while SES and total family type contributed to the model significantly but to a lesser degree. It was apparent that the contribution of the individual variables differed depending on the order in which the variable was entered into the model, suggesting that again these values were very unstable and must therefore be regarded with high levels of caution.

As already noted although type of seizure was not found to be significant in either the chi-square tests or correlations with the dependent variable, it subsequently became significant when in combination with the other variables specified in final the Logistic Regression model. This suggests that it is only when this variable is combined with other risk factors that it becomes a significant predictor of risk. Various researchers (Rutter, 1979; Wallander et al., 1989) have additionally suggested that certain variables act in combination with other variables to predict risk of disorder. This alternative explanation may account for the significant contribution that type of epilepsy made to the final logistic regression model while not being found to be associated with

risk of disorder when alone. It was also interesting to note that while family cohesion and family adaptability both appear to be significantly associated with risk of disorder from the correlational results, neither of these variables could further contribute to the model once total family type was entered into the model. Howell (1987) has suggested that when variables are highly intercorrelated the beta weights become very unstable and the chi-square may actually change very little. Since the total family type classification was devised from both the family cohesion and family adaptability scales it was therefore not unexpected that neither family adaptability or family cohesion could significantly improve the model further. It was also noted that once family cohesion was added to the model that family adaptability no longer contributed to the model significantly. One can tentatively suggest that this may provide support for the assumption that family cohesion and family adaptability may measure similar factors related to positive family functioning. Relatively high correlations that were found between the cohesion and adaptability scales in the current study ( $r = .69$ ), as well as the fact that Olson et al (1992) has additionally indicated that the correlation between the scales of the FACES 11 could vary ( $r = .25 - .65$ ). This may suggest that in the current study there was some overlap between the two scales but also that families that have certain levels of cohesion (eg. strongly cohesive) appeared to have a strong tendency to show similar levels of adaptability (eg. be strongly adaptive).

Although one variable alone did not appear to play a large role in relation to psychological adjustment it was evident that when a number of risk factors were combined there appeared to be a rise in risk of psychological problems. These findings provide support for the synergistic interaction of variables by which the presence of one variable potentiates the effect of some other variable, so that the effect of the two is greater than the sum of the parts in isolation (Rutter, 1983). The proposed Logistic Model in the current study was only one possible model that was developed by the researcher to examine specific variables and additional models may be constructed containing different variables that have been entered in different ways. What is additionally needed to verify the significance of the proposed logistic model in the current sample is cross-validation of these results against an independent data set. An additional sample similar to the one in the study could be used to cross-validate the results, whereby a high correlation between the regression coefficients obtained in both samples would signify the validity of the model (Howell, 1987).

## 7.10 LIMITATIONS AND SUGGESTIONS FOR FUTURE RESEARCH

The type of research design chosen attempted as far as possible to increase both the validity and reliability of the results but despite these efforts it is evident that the study still has certain limitations which may influence the interpretations of the results. Although some of the limitations have been discussed within the body of the current thesis, further factors that may influence the interpretation of the findings of the current study are recognized below and suggestions for future studies are provided:

1- Firstly it is noted that the sample in the current study was not a random one as it involved a reliance upon samples of convenience which may subsequently have limited the study's external validity. By this it is meant that children were chosen by the researcher from specific sources such as schools and hospitals in order to obtain a large enough sample of children with epilepsy for statistical analysis in the current study. Attempts were made by the researcher in the current study to obtain epileptic children from both clinic and private populations as well as different socioeconomic groups. It is evident however, that a large number of the final sample of children included in the study were obtained from schools specifically catering for children with epilepsy who frequently have additional learning problems. These children can be seen to represent a distinct group of epileptic children who have specific resources available at the schools that they are attending (psychologists, occupational therapists, remedial teachers etc) as well as specific characteristics (eg. more severe forms of epilepsy). In addition, children obtained from hospitals and SANEL can also be seen to represent another distinct group of children who for example may have more severe forms of epilepsy or tend to come from low SES backgrounds. In addition, children were included in the study who met criteria specified by the researcher such as a specific age group, children with "active" epilepsy, and those children with no associated mental handicap (See p. 51). Lavigne and Faier-Routman (1992) suggest that to some degree it is reasonable that researchers obtain their sample from a particular site where they have access to patients in the particular locale where they work. However, these authors indicate that many of the researchers fail to provide information regarding the representativeness of their final sample (ie. rates of refusal, criteria for inclusion, percentage of patients sampled) and provide limited clarity on the possibilities of bias based upon peculiarities in the referral patterns to the centre (ie. geographical area, SES). A detailed description of the sample was provided in Chapter Five (Section 5.5; p. 52) and the generalization of the current results must be limited to similar populations.

2- Another factor that may have impacted on the results is that mother's perceptions of both family and their children's adjustment may have also been coloured by their own functioning levels. For example, if mothers were depressed they may have given a more negative overall impression of their child's psychological functioning, as well as on other measures of family functioning. Disagreement exists in the literature as to whether there are significant differences in different raters responses to perceptions of child psychological adjustment. Daniels et al (1987) examined cross correlations between parental perceptions of child functioning, and concluded that father reports were often related to mother's reports of child functioning. However, other researchers have found differences in ratings using different informants or raters of child psychological disorder (e.g parents, teachers, health professionals) (Lavigne & Faier-Routman, 1992; Perrin et al., 1993). It is noted however that severe symptom displays have been found to be observable in diverse environments independent of informant (Lewis et al., 1988). Given the mixed conclusions within the literature, one cannot ignore the possibility that different informants may have different experiences and perceptions of the child's functioning. In addition, child symptomatology may change or remain constant depending on the specific context in which the child is placed (Achenbach & Edelbrock, 1983; Combrinck-Graham, 1989). Although the current study was not able to include other informants due the unavailability of teachers and fathers at the time of the research, future studies may obtain more a more "systemic" understanding of child symptomatology by including multiple raters of child psychological functioning (eg. parent reports, teacher reports and psychiatric interviews with mental health professionals) (Daniels et al., 1987; Lavigne & Faier-Routman, 1992; Silver et al., 1996). Ideally accurate assessment of child psychological adjustment should take into account the situation (eg. home, clinic, school, neighbourhood) as well as the specific informants (eg. clinician, teacher, parent, peers). Longitudinal studies can be seen to have the potential to offer the most ecological valid data in this regard as they assess children across a number of settings (ie. school, family, peers) as well as over a long period of time.

3- In retrospect the current study could have additionally included the direct assessment of the child with epilepsy (eg. using projective drawings) as an additional indicator of child adjustment. As indicated by Lavigne and Faier-Routman (1992) the lack of children's self-reports of symptomatology "is a glaring omission in our understanding of the psychological problems of children with physical disorders" (p. 151). In addition, although the Rutter parent scale offers a useful overall measure of child risk of disorder which provided a quantifiable measure of overall psychological adjustment of the child with epilepsy, other aspects of child psychological

functioning could have been assessed in the current study eg. child self-esteem or competence. Additional questionnaires that measure specific aspects of child behaviour problems such as internalizing and externalizing symptoms (eg. the Child Behaviour Checklist, Achenbach & Edelbrock, 1983) were unavailable at the time of the study, but could be considered a potentially useful assessment tool in providing further information with regard to child psychological functioning. Observational techniques in addition to self-report scales may also provide additional information regarding child psychological adjustment and may be a useful approach for future studies.

4- Issues relevant to conducting research within a social or community context additionally emerged during the research. Due to the socioeconomic structure of South African society, many of the respondents were poorly educated or were from low socioeconomic groups which may have led to difficulty in comprehension of some of the questions in the self-report scales. Although all the mothers in the study spoke English, this was often their second language which may have led to the misinterpretation of specific questions.

5- Drotar (in Hamlett et al., 1992) argues that in interpreting differences on behaviour ratings of chronically ill and healthy children, the unique circumstances posed by the chronic illness should be considered. Higher scores on the Rutter may in fact have been influenced to some degree by the actual illness symptoms experienced by the child (ie. poor speech and headaches can be considered symptoms of epilepsy rather than being part of the diagnosis for poor psychological functioning). As far as possible it was attempted to question the mother as to whether the specified symptom on the Rutter parent scale was related to the child's condition of epilepsy. However, for mothers who were posted questionnaires it was not possible to determine whether illness factors were related to epileptic symptoms or child psychological symptoms. This may have elevated the level of psychological symptoms slightly in this group. It can be suggested that future research needs to take into account these factors and measuring instruments are needed that are sensitive to children with either disabilities or illnesses such as epilepsy.

6- The limitations of cross-sectional research are particularly evident when attempting to understand child symptomatology. Child development can be considered a fluid process, which is constantly under transition where certain child symptoms may change depending on the contexts in which the child is placed or may additionally disappear over time (Combrink-Graham, 1989). Cross-sectional research does not permit an understanding of the process by which

changing demands and modes of responding occur over time and can therefore be seen to be a limitation in the current study (Combrinck-Graham, 1989; Turk & Kerns, 1985). One mother in the current study for example suggested that her child with epilepsy would have scored very highly on the Rutter parent scale if she had been tested one year previously before she had placed her child in a school that was more understanding and accomodating of her child's needs. Again, as suggested earlier longitudinal studies are needed in order to understand the development of symptoms over time and within specific contexts (Magassun & Allen, 1983).

7- Various additional variables not measured in the current research have been found by past research to play an important role in child resilience to stress in children with a range of chronic illnesses, as well as in children with no chronic illness eg. individual factors such as intelligence, individual coping, temperament (Kyrios & Prior, 1990; Lavigne et al., 1988; Lewis, 1988). The coping style of the child for example may be related to overall psychological adjustment (Lavigne et al., 1988). Other contextual factors such as the school environment (eg. peer subculture) or life events may additionally play an important role in child psychological adjustment when a child has a chronic illness. Although it was only possible to examine a number of selected variables in the current study, one can suggest that future research needs to further examine additional variables in order to determine their association with child psychological functioning. However, as suggested by Magassun and Allen (1983) "Even though we conceptualize an individual's functioning during the course of development from the perspective of a total system, this does not mean that a particular research study can be expected to give attention to all the important components that comprise a system. For most investigators this would be an unrealistic condition" (p. 370). A multidimensional approach to understanding symptomatology of children with epilepsy is required where longitudinal studies with large samples are needed which examine a broad range of risk and protective factors within the context of the child's total life.

8- At present, very little data is available concerning interactive patterns among variables studied among children with physical disorders. Although it was not possible in the current study to further analyze interactions between variables (due to the small sample size in comparison to variables measured), closer examination of the way in which variables interact to affect the development of adjustment problems in children with epilepsy can be considered a fruitful area of additional research (Lavigne & Faier-Routman, 1993).

## 7.11 SUGGESTIONS FOR INTERVENTION

Given the broad range of factors that were found to be involved in child psychological functioning in children with epilepsy, one can suggest that intervention strategies should attempt to address the child's symptoms from as many "systems" as possible as well as from a biopsychosocial perspective. In this regard, children with epilepsy can be seen to require ongoing availability of medical services to assist with the medical care and control of seizures, as well as the provision of effective medications that have minimal risk of side effects that may impact on cognitive, social and psychological adjustment. Individual therapy can be considered important to enhance coping skills and develop self-esteem of the child with epilepsy. Given the significant relationship between family variables in combination with other variables, it appears appropriate that intervention strategies should include aspects of the family context through the provision of supportive structures and the strengthening of the family unit. As suggested by Combrinck-Graham (1989) "accessing and treating childhood problems in their family contexts permits interventions that support the competent functioning of both child and family in larger contexts. In this way the momentum of development may be restored" (p. 87).

While the researcher was collecting data for the current study a number of requests were made by parents for advice related to specific behavioural or emotional issues that parents were having difficulty dealing with. It was apparent that although the children attending specialize schools were offered individual therapy much less focus has been given to the role that the family can play in the development of child behavioural and emotional problems. Given these requests and the comparatively high rates of child symptomatology found in the current study, it can be suggested that parent support groups may be useful where parents could be taught specific coping skills (Hoare and Kerley, 1992; Cowen et al., 1990; Sholevar & Perkel, 1990). Teachers or parents for example may be trained to facilitate such groups and parents could provide support for one another. In addition, other systems that the child and family are in contact should be taken into account, such as the school system. More in-depth family therapy may be needed for some families where particular issues related to dealing with the illness may be addressed (eg. communication patterns, restructuring of boundaries/roles etc. ). The identification of both risk factors as well as protective factors can be seen to directly impact on intervention and treatment programs for children with epilepsy.

Macro-systems issues such as poverty (low SES) and inadequate services should additionally be addressed. It must be noted that many of the children and families in the current study rely on the provision of services from the specialized schools that they attend that cater for children with epilepsy. Recent government policies related to mainstreaming children with special needs may leave many of these children (and families) without the broad range of services and resources currently provided for by these schools. Research investigating the importance of other systems in the epileptic child's psychological development may be of extreme importance in this regard.

## 7.12 CONCLUSION

The current study focused on a number of specific risk factors in the family, demographic factors and illness factors with regard to their relationship with psychological problems in children with epilepsy. Overall the results indicated that the psychological adjustment of children with epilepsy involved the influence of family relationships, demographic factors, as well as illness factors which all appeared to overlap to some extent in predicting child adjustment. The factors in the current study that specifically played a role in adjustment included type of seizures, socioeconomic status, number of siblings, family relations (cohesion and adaptability, overall family type) and medication factors. This suggests that conceptually, the findings support an understanding of child adjustment from a socio-ecological perspective where transactions occur both within and between the child and the family as well as being related to macro-system factors (eg. SES). In addition, it was found that the Circumplex Model of marital and family systems (Olson et al., 1979) provided a useful model in which to understand the relationship between family cohesion and adaptability and child psychological problems where specific types of family structures appeared to be associated with risk of disorder or alternatively no risk of disorder.

It was evident that an array of methodological challenges faced the researcher in the current study and although many of these issues were addressed through the design of the study a number of limitations remain. The results of the current study should be viewed as tentative until future studies with larger sample sizes are able to address some of the methodological problems discussed earlier in this chapter and can replicate the findings of the current study. The variables examined in the current study can be seen to have only investigated only a small part of the larger question of why some children with epilepsy develop psychological problems while others do not appear to do so. The psychological adjustment of children with epilepsy can be seen as a complex process that involves multiple stressors or risk factors as well as various protective

factors. Closer examination of the way in which variables interact in relation to the development of adjustment problems and competencies among children with chronic illness can be considered an important area for future research (Garmezy et al., in Lavigne & Faier-Routman, 1993; Rutter, 1979; Wallander et al., 1989). As indicated by Masten (1990) a key challenge is to clarify how risk and protective factors "unfold and intertwine" to shape individual children's adaptation over time. In addition, "to understand and prevent maladaptation, we will do well to understand resilience in development; they are different parts of the same story" (in Cowen, 1990; p. 290).

In general, it is evident that our knowledge with regard to the factors that play a role in the psychological adjustment of children both within a specific disease group (eg. epilepsy) and across disease groups is quite limited (Lavigne et al, 1988). The identification of factors that either protect or increase the child's psychological adjustment is critical if early intervention efforts are to be initiated in situations where resources for psychological interventions are limited. Systems theory can be seen to provide an ecological as well as biopsychosocial perspective from which to understand the psychological adjustment of children with epilepsy. Further research is needed to provide a deeper as well as more holistic understanding of the factors and complex processes involved in the psychological adjustment of children with epilepsy.

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## APPENDICES

### Appendix A

#### Demographic Information Questionnaire

The following questions are concerned with your personal details. Please try to be as accurate as possible in your answers. All information will be treated with absolute confidentiality and names will be kept anonymous.

Thankyou for your help and cooperation. *Please either place a cross on the correct answer and/or respond to the question in your own words where needed.*

#### BACKGROUND INFORMATION ON YOUR CHILD WITH EPILEPSY

**Child's name? (optional)**

**Child's date of birth?**

**Child's Sex? (girl or boy)**

**Your relationship to your child with epilepsy?  
(eg. mother, father, aunt)**

#### **(a) Medical Factors**

1. What type (s) of epilepsy does your child have (if known)?
  
2. Approximately when did your child have his or her last seizure? *(eg. a month ago)*
  
3. How frequently does your child experience seizures per month?
  
4. Is your child on any forms of medication for epilepsy? **(YES) (NO)**  
Please specify names (if known)
  
5. How old was your child when she or he suffered the first seizure?
  
6. Does your child suffer from any illnesses other than epilepsy? **(YES) (NO)**  
If YES please specify:

**(b) Background Information**

1. Is your child a) Living at home b) living in a school hostel c) living with other family members  
d) other (please explain)

2. Does your child have any learning difficulties of which you are aware? **(YES) (NO)**  
If **YES** please specify:

3. Is your child in a special class at school? **(YES) (NO)**

4. Is your child mentally handicapped? **(YES) (NO)**

**INFORMATION ON YOUR FAMILY**

Please mark the correct box as it applies to you and answer the following questions:

1. Are you currently employed? **(YES) (NO)**  
If **YES** what is your current occupation?

2. Do you have any other children? If **YES**, please specify their names and ages:

-  
-  
-  
-  
-

3. Are you currently:

**a) married b) single c) living with your partner d) other (please specify)**

4. Do any other members of your family suffer (or have ever suffered) from epilepsy? **(YES) (NO)**  
If **YES** which family members? (eg. grandparent)

5. Have you or any other family member ever suffered from any major illness, disability or breakdown? (either medical or emotional) **(YES) (NO)**

If **YES** please specify from what you (or other family members) suffered from:

6. Is your partner currently employed? **(YES) (NO)**

If **YES** what is his current occupation?

7. a) What is your highest level of education? (eg. matric, std 6, primary, or tertiary education)

b) What is your partner's highest level of education?

8. Have you had any other major stressors in the last year which your family has had to deal with? (eg. death in family, moving house, change of job etc. ) **(YES) (NO)**

If **YES** please indicate type of stressor

## **Appendix B**

### **The Rutter Parent Scale**

#### **Section A (Health problems)**

Below is a list of minor health problems which most children have at some time. Please tell us how often each of these happens with your child (at the present moment) by marking the correct letter following the health problems described below:

**(a) Never in the last year (b) Less often than once per month (c) At least once per month (d) At least once per week**

1. Complains of headaches (a) (b) (c) (d)
2. Has stomach-ache or vomiting (a) (b) (c) (d)
3. Complains of biliousness (feeling like s/he wants to get sick) (a) (b) (c) (d)
4. Wets his/herself or loses control of bowels (cannot wait when wants to use toilet) (a) (b) (c) (d)
5. Has temper tantrums (that is, complete loss of temper with shouting, angry movements, etc.) (a) (b) (c) (d)
6. Had tears on arrival to school (a) (b) (c) (d)
7. Runs away from school (a) (b) (c) (d)

#### **Section B (Habits)**

Please indicate whether any of the following are true of your child. Choose from each option  
**(a) No (b) Yes-mildly (occasionally) (c) Yes-severely (frequently)**

1. Has s/he stutter or stammer (a) (b) (c)
2. Has he/she any problems with speech other than stammering or stuttering? (a) (b) (c)
3. Does he/she ever steal things? (a) (b) (c)
4. Does he/she have any eating difficulty i.e. eats too much, not enough or with difficulty (a) (b) (c)
5. Difficulties with getting to sleep, waking or other (a) (b) (c)

Section C below, provides a series of descriptions of behaviour often shown by children. After each statement are three columns: **(a) doesn't apply (b) applies somewhat and (c) certainly applies**

Make a cross by each statement which applies to your child:

1. Very restless. Often running about or jumping up and down. Hardly ever still. (a) (b) (c)
2. Squirmy, figety child (a) (b) (c)
3. Often damages own or others' belongings (a) (b) (c)
4. Frequently fights or is extremely quarrelsome with other children. (a) (b) (c)
5. Not much liked by other children (a) (b) (c)
6. Often worried, worries about many things (a) (b) (c)
7. Tends to do things on own rather than with others (a) (b) (c)
8. Irritable. Gets angry easily (a) (b) (c)
9. Often appears miserable, unhappy, tearful or distressed (a) (b) (c)
10. Has twitches, mannerisms or tics of the face or body (a) (b) (c)
11. Frequently sucks thumb or finger (a) (b) (c)
12. Frequently bites nails or finger (a) (b) (c)
13. Is often disobedient (a) (b) (c)
14. Cannot settle to anything for more than a few moments (a) (b) (c)
15. Tends to be fearful or afraid of new things or new situations (a) (b) (c)



## Appendix D

### The Family Crisis Orientated Evaluation Scale (F-COPES)

These questions look at problems solving attitudes and behaviours which families use to respond to problems or difficulties.

#### Directions:

1. Read the list of "Response Choices" one at a time.
2. Decide how well each statement describes your family's attitudes and behaviour in response to problems or difficulties. If the statement describes your response very well, then circle the number 5 indicating that you STRONGLY AGREE; if the statement does not describe your response at all, then circle number 1 indicating that you STRONGLY DISAGREE; if the statement describes your response to some degree, then select a number 2, 3, or 4 to indicate how much you agree or disagree with the statement about your response.

1  
(STRONGLY DISAGREE)

2  
(SOMEWHAT DISAGREE)

3  
(NEITHER AGREE OR DISAGREE)

4  
(SOMEWHAT AGREE)

5  
(STRONGLY AGREE)

1. Sharing our difficulties with relatives. 1 2 3 4 5
2. Seeking encouragement and support from friends. 1 2 3 4 5
3. Knowing we have the power to solve major problems. 1 2 3 4 5
4. Seeking information and advice from persons in other families who have faced the same or similar problems 1 2 3 4 5
5. Seeking advice from relatives (grandparents, etc.) 1 2 3 4 5
6. Seeking assistance from community agencies and programs designed to help families in our situation. 1 2 3 4 5
7. Knowing that we have the strength within our own family to solve our problems. 1 2 3 4 5
8. Receiving gifts and favours from neighbours (e.g. food, taking in mail etc) 1 2 3 4 5
9. Seeking information and advice from the family doctor. 1 2 3 4 5
10. Asking neighbours for favours and assistance. 1 2 3 4 5
11. Facing the problem "head-on" and trying to get a solution right away. 1 2 3 4 5
12. Watching television. 1 2 3 4 5
13. Showing that we are strong. 1 2 3 4 5
14. Attending church services. 1 2 3 4 5
15. Accepting stressful events as a fact of life. 1 2 3 4 5
16. Sharing concerns with close friends. 1 2 3 4 5
17. Knowing luck plays a big part in how well we are able to solve family problems. 1 2 3 4 5
18. Exercising with friends to stay fit and reduce tension. 1 2 3 4 5
19. Accepting that difficulties occur unexpectedly. 1 2 3 4 5
20. Doing things with relatives (get togethers, dinners, etc.) 1 2 3 4 5
21. Seeking professional counselling and help for family difficulties. 1 2 3 4 5
22. Believing we can handle our own problems. 1 2 3 4 5
23. Participating in church activities. 1 2 3 4 5
24. Defining the family problem in a more positive way so that we do not become too discouraged. 1 2 3 4 5
25. Asking relatives how they feel about problems we face. 1 2 3 4 5
26. Feeling that no matter what we do to prepare, we will have difficulty handling problems. 1 2 3 4 5
27. Seeking advice from a minister. 1 2 3 4 5
28. Believing if we wait long enough, the problem will go away. 1 2 3 4 5

29. Sharing problems with neighbours. 1 2 3 4 5  
 30. Having faith in God. 1 2 3 4 5

**Appendix E**

**Cronbach's Alpha for each of the F-COPES Subscales**

	Cronbach's Alpha			Test-Retest
	Sample 1 (N = 1338)	Sample 2 (N = 1244)	Combined Scales (N = 2582)	(N = 116)
Acquiring social support	.84	.83	.83	.78
Reframing	.82	.81	.82	.61
Seeking social support	.79	.81	.80	.95
Mobilizing family to seek help	.71	.70	.71	.78
Passive appraisal	.64	.62	.63	.75
Total scale	.86	.87	.86	.81

**Appendix F**

**Classification of Breadwinner's Education**

Type of Education	Score
Professional, executive, administrative and technical occupations	9
Professional, administrative and managerial workers	8
Independent commercial	7
Lower grade administrative, technical, and clerical with limited supervisory and administrative responsibility	6
Artisans and skilled workers with trade qualifications	5
Routine clerical and administrative workers, service and sales workers	4
Semi-skilled production and manual workers	3
Unskilled production and manual workers	2
Not economically active or productive	1
No response	0

## **Appendix G**

### **Classification of Educational Level**

<b>Educational level</b>	<b>Score</b>
University attendance	7
Post-matric training (not university)	6
Matric	5
Apprenticeship	4
Junior Certificate	3
Primary school	2
None at al	1
No response	0

## **Appendix H**

### **Classification of Socio-economic Status (SES)**

	<b>Lower</b>	<b>Middle</b>	<b>Upper</b>
White	2-10	11-13	14-16
Coloured	2-6	7-10	11-16
Black	2-5	6-10	11-16